VARIABLES AFFECTING QUALITY OF LIFE AND ADHERENCE IN ADULTS WITH TYPE 2 DIABETES

BY

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THESIS

Submitted as partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing Science in the Graduate College of the University of Illinois at Chicago, 2001

Chicago, Illinois
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be accepted in partial fulfillment of the requirements for the degree of
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[Members of Thesis or Dissertation Defense Committee]
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<td>ADA</td>
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<td>ADS</td>
<td>Appraisal of Diabetes Scale</td>
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<td>CIT</td>
<td>Chronic Illness Trajectory</td>
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<td>DCCT</td>
<td>Diabetes Control and Complications Test</td>
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<td>DCP</td>
<td>Diabetes Care Profile</td>
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<td>DOII</td>
<td>Demands Of Illness Inventory</td>
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<td>DQOL</td>
<td>Diabetes Quality of Life Measure</td>
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<td>DSCA</td>
<td>Diabetes Self-Care Activities Checklist</td>
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<td>DSES</td>
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<td>GHb</td>
<td>Glycohemoglobin</td>
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<td>HbA1c</td>
<td>Hemoglobin A1c</td>
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<td>HBM</td>
<td>Health Belief Model</td>
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<td>IMDSES</td>
<td>Insulin Management Diabetes Self-Efficacy Scale</td>
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<td>MOS</td>
<td>Medical Outcomes Study</td>
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<td>PAID</td>
<td>Problem Areas In Diabetes</td>
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<td>QLI</td>
<td>Quality of Life Index</td>
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<td>QLI-D</td>
<td>Quality of Life Index – Diabetes version</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<td>SF-36</td>
<td>Medical Outcomes Study Health Survey 36-item Short Form</td>
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<td>SLC</td>
<td>Social Learning Composite</td>
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<td>SWC</td>
<td>Satisfaction With Care Questionnaire</td>
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<td>UKPDS</td>
<td>United Kingdom Prospective Diabetes Study</td>
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SUMMARY

This two-phase, mixed methods study was designed to examine the influence of selected variables on quality of life (QOL) and adherence to diabetes regimen in a convenience sample of adults with Type 2 diabetes. All participants were clients of the same American Diabetes Association-recognized diabetes center and had previously received comprehensive diabetes education. Sixty-one percent of the participants reported education beyond the high school level; 41.5% reported annual family income of more than $50,000.

In Part 1 of the study, participants (n=94) completed a survey that included measures of self-efficacy, illness demand, family support, satisfaction with care, QOL, and adherence. Survey respondents were categorized as high, medium, or low adherence based on the total score for the adherence measure. In Part 2, selected respondents (n=23) whose adherence scores were in the upper or lower third participated in an interview that focused on the same variables. For both survey and interview data, comparisons were made between those in the high and low adherence groups with regard to self-efficacy, illness demand, family support, and satisfaction with care.

Persons in the low adherence group had significantly lower self-efficacy and higher illness demand than those in the high adherence group. Low adherers reported greater difficulty in adhering to diet and exercise recommendations and less difficulty with medications and glucose testing. Those with longer duration of diabetes were also found to have lower self-efficacy scores and higher illness demand scores. Individuals in both high and low adherence groups reported lower levels of self-efficacy for activities related to making adjustments in the diabetes self-care regimen.

A moderate correlation (r = 0.50, p <.001) was found between adherence and QOL. Data from the interviews indicated that, although many people believed that strict
adherence would lead to improved quality of life, there was a tendency of those in the low adherence group to believe that strict adherence would have a negative impact on quality of life. Self-efficacy was found to be a significant predictor of both adherence ($R^2 = 0.35, p < .001$) and QOL ($R^2 = 0.40, p < .001$). Illness demand and family support contributed to QOL, but did not significantly influence adherence for this sample. Findings from the survey were supported and augmented by the interview data.

The results suggest that diabetes educators should focus on efforts to improve self-efficacy and the individual's perception of QOL in order to enhance adherence to recommended diabetes self-care activities, and that ongoing attention to these aspects is needed in order to provide optimal support to those with longer disease duration.
I. PROBLEM AND SIGNIFICANCE

A. Background and Significance

Type 2 diabetes is a significant cause of morbidity and mortality in the U.S, and its incidence and prevalence are increasing steadily (CDC, 2001; Mokdad, Ford, Bowman, et al., 2001). Furthermore, health status and outcomes are less than optimal, even among those who are receiving diabetes care that meets accepted standards (Harris, 2000). Though much is known about how to treat and control Type 2 diabetes, the key dilemma centers on how to encourage, support, and improve the adherence of diagnosed persons to the recommended regimen. While the development of new hypoglycemic medications has improved the ability to achieve and maintain normoglycemia, it has added a new layer of complexity to the treatment. Persons with the disease are expected to negotiate a regimen that may include several medications, as well as specific diet and activity prescriptions and instructions to monitor blood glucose at regular intervals.

Many approaches have been investigated in an attempt to find effective means to assist individuals with Type 2 diabetes to learn and consistently follow their treatment program. Adherence, defined as "the degree to which a patient follows a predetermined set of behaviors or actions (established cooperatively by the patient and provider) to care for diabetes on a daily basis" (McNabb, 1997), is recognized as a desirable goal. Adherence to a regimen that is tailored to the needs of the individual provides the greatest likelihood of achieving and maintaining normoglycemia. Results of the UK Prospective Diabetes Study clearly established the benefits of lower blood glucose levels in delaying the onset of microvascular complications of diabetes (ADA, 2001a; UKPDS Group, 1998).

However, while health care professionals can provide the initial education and ongoing support, they cannot mandate or control the individual's adherence. Despite the variety of interventions and approaches that have been tested, adherence to diabetes management programs is much less than desired. One early study reported a 93% nonadherence rate to a
regimen that included insulin, diet, urine testing and foot care (Cerkoney & Hart, 1980).
Numerous studies have confirmed that patients tend to adhere selectively to certain aspects of
their regimen, while ignoring others (Anderson, Fitzgerald, & Oh, 1993; Ary, Toobert, Wilson, &
Glasgow, 1986; Orme & Binik, 1989; Ruggiero et al., 1997).

Reasons for patient nonadherence have been the subject of much research. In some
cases, lack of knowledge of recommended procedures or routines can be identified as a factor
contributing to nonadherence. Other studies, however, indicate that knowledge of the regimen
is not highly correlated with adherence to the regimen (Coates & Boore, 1996; McCaul,
Glasgow, & Schafer, 1987). For some people, environmental or socioeconomic factors are
barriers to adherence (Ruggiero et al., 1997). Yet even among those of average or above
average socioeconomic or educational level, lack of adherence to regimen remains problematic
(McCaul et al., 1987; Wilson, Ary, Biglan, Glasgow, Toobert, & Campbell, 1986).

Using many different theoretical frameworks, numerous psychosocial and
environmental factors have been investigated. Research findings indicate that the psychosocial
variables of self-efficacy (Crabtree, 1986; Kavanagh, Gooley, & Wilson, 1993; Kingery &
Glasgow, 1989) and perception of illness burden or demand (Callaghan & Williams, 1994;
Coates & Boore, 1995; Glasgow, Hampson, Strycker, & Ruggiero, 1997) are influential in the
individual's decisions regarding adherence. Furthermore, there is evidence that the supportive
behaviors of significant others (Crabtree, 1986; Schafer, McCaul, & Glasgow, 1986), as well as
the patient's satisfaction with relationships with health care providers (Callaghan & Williams,
1994; Hernandez, 1995; Price, 1989) play a significant role in adherence behavior.

Despite evidence which links certain factors, alone or in concert with others, to
adherence to diabetes regimen, no theoretical framework has satisfactorily explained the
reasons for nonadherence. Yet, an understanding of the variables that affect adherence is
critical if health care professionals hope to successfully influence patients (Kavanagh et al.,
1993). Perhaps a different approach—a holistic perspective—is called for in the study of this
question. The pattern of relationships inherent in complex human behaviors such as adherence cannot be understood by “separating the...variables and then calculating their independent contribution to a singular main effect” (Benner, 1985, p. 3). Though much research has focused on one or more variables that are significant components of adherence behavior, few studies have examined the problem from the viewpoint of the individual, the patient with Type 2 diabetes. An appreciation of the meanings and self-interpretation that the individual ascribes to the experience of having Type 2 diabetes will enrich the health care professional’s ability to describe and explain adherence behavior (Paterson, Thorne, & Dewis, 1998).

The meaning and interpretation that an individual gives to his/her situation is closely linked to the appraisal of quality of life, the individual’s “sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans & Powers, 1992, p. 29). Quality of life is a multidimensional, subjective, and dynamic construct (Cella, 1992). Although it has been included as a variable in a few studies of adherence to diabetes regimen (Glasgow, Ruggiero, Eakin, Dryfoos, & Chobanian, 1997; Glasgow, Toobert, Hampson, Brown, Lewinsohn, & Donnelly, 1992; Greenfield, Kaplan, Ware, Yano, & Frank, 1988), its operationalization has been limited to physical and functional aspects. Furthermore, though quality of life considerations are an integral aspect of an individual’s lifestyle decisions, this construct has only been examined as an outcome of behavior. The role of quality of life appraisal as an input factor in an individual’s decision to adhere to the recommended diabetes regimen needs to be considered as part of a holistic examination of the individual’s context (Weinberger, et al., 1994).

B. **Purpose of the Study**

The purpose of this study, therefore, was to investigate and compare variables that influenced adherence to recommended diabetes self-care behaviors among persons with varying degrees of adherence. Subjects were recruited from a population of persons with Type 2 diabetes who had received the recommended diabetes education. Quantitative methods were
used to describe the influence of four key variables on quality of life and adherence to regimen. Comparisons were made between subjects who self-reported as having high, moderate, and low levels of adherence. Using qualitative methods, "low-adherent" and "high-adherent" individuals were interviewed to obtain additional data to enhance the interpretation of the quantitative data.

C. **Conceptual Model**

The objectives of the study are derived from the conceptual model shown in Figure 1.

![Conceptual Model Diagram]

Figure 1. Conceptual model for the study

The conceptual model indicates that self-efficacy, illness demand, support from family members, and satisfaction with medical care are key variables that influence both quality of life appraisal and adherence to regimen. Quality of life and adherence to regimen are outcomes
that influence each other. Perceptions about quality of life influence the individual's decisions about adherence, and likewise, adherence behaviors influence the individual's perceptions about quality of life.

D. **Specific Aims**

This study had four specific aims:

1. To compare persons with varying levels of adherence in terms of the influence of:
   a. perception of self-efficacy
   b. appraisal of illness demand
   c. support from family members
   d. satisfaction with interactions with health care professionals

2. To describe factors identified by adults with Type 2 diabetes that positively or negatively influenced their decision to adhere to various aspects of the recommended regimen

3. To describe the effect of self-efficacy, appraisal of illness demand, support from family members, and satisfaction with interactions with health care professionals on the individual's appraisal of his/her quality of life

4. To examine the relationship between appraisal of quality of life and the individual's decision to adhere to some or all of the recommended regimen
II. REVIEW OF THE LITERATURE

A. Adherence

1. Definition and evolution from “compliance” to “adherence”

Research into adherence behavior, especially among persons with chronic illness, was stimulated by the development of the Health Belief Model (HBM), Theory of Reasoned Action, and Self-Efficacy Theory. Early on, the term “compliance” was favored in this research, but over time, that word was rejected as implying passive submission of the patient to the will of the health care professional (Lutfey & Wishner, 1999; Turk, Salovey, & Litt, 1986). Eventually, “adherence” became the preferred term, since it suggests free-will cooperation on the part of the patient (Johnson, 1992; Lutfey & Wishner, 1999). In more recent times, even that word has carried too much of a negative connotation; contemporary researchers favor “self-care” or “self-management” to indicate the activities implemented by an individual in order to manage his/her illness or condition (Anderson & Funnell, 2000; Kurtz, 1990). However, in this study, the term “adherence” will be used, as the objective of this study was to compare patients’ behaviors with a known standard, i.e., the physician’s regimen prescription. Thus, the focus of this study was not on the individual’s self-initiated actions, but rather on “the extent to which a person’s behavior (in terms of medications, diet, or life-style changes) coincides with medical or health advice” (Haynes, Taylor, & Sackett, 1979, p. 1), as adherence has been defined.

2. Adherence in diabetes

As noted earlier, the typical regimen for daily diabetes care is quite complex. Responsibility for implementation of all aspects of the regimen rests almost entirely on the patient, with help, perhaps, from significant others. Management of diabetes provides a prototype of other chronic illnesses, such as hypertension, where the patient is able, and indeed expected, to perform self-care. Thus, adherence to diabetes regimen has been the focus of much research. Early studies found low rates of adherence to regimen. One of the first studies found that more than half of patients made errors in insulin dosage, nearly two-thirds were
testing their glucose incorrectly, and about three-fourths were non-compliant in terms of dietary management (Watkins, Williams, Martin, Hogan, & Anderson, 1967). Cerkoney and Hart (1980) found that only 7% of subjects adhered completely to all aspects of the regimen.

A survey of a large sample (n=2,056) of persons with Type 1 (13.8%) and Type 2 (86.2%) diabetes mellitus (Ruggiero et al., 1997) confirmed the findings of these and other researchers regarding adherence to the multiple aspects of the recommended diabetes regimen. In this sample, which was representative of the national population in terms of several demographic characteristics, self-reported frequency of adherence was highest for medication recommendations (whether insulin or oral medication), and lowest for diet and exercise recommendations. Different patterns of self-management were reported for different aspects of the regimen, as well.

Furthermore, there was considerable variation in what subjects recalled having been advised to do in relation to their diabetes management. For example, in this study, nearly half of those with Type 2 diabetes who were not on insulin did not recall having been advised to test their blood glucose. Nearly 40% of those with Type 1 diabetes reported no recommendation regarding exercise (Ruggiero et al., 1997). While it could be argued that failure of the subject's memory, rather than failure of the health professional, was responsible for the perceived absence of the recommendation, nevertheless, this gap highlights the problem of different criteria for evaluating "adherence."

As noted above, studies of adherence to recommended diabetes regimen have consistently found highest rates of adherence to medication, and lowest rates of adherence to lifestyle changes such as diet or exercise (Anderson et al., 1993; Ary, et al., 1968; Glasgow, et al., 1989). Diet and exercise modifications may have the greatest impact on daily life and the individual's perception of overall quality of life. Diet and exercise recommendations for persons with diabetes are not much different from the general recommendations for healthy lifestyle, and the difficulty in adhering to these recommendations mirrors the difficulty that healthy individuals have in incorporating these activities into their daily lives.
It seems that persons with diabetes make decisions about whether or not to adhere to each aspect of the regimen individually. Adherence to one aspect of the regimen is not correlated with adherence to any other aspect of the regimen (Johnson, 1992). This finding has been confirmed in studies of adults with both Type 1 (Glasgow, McCaul, & Schafer, 1987) and Type 2 diabetes (Ary, et al., 1986; Glasgow, et al., 1989).

For example, in a study of 227 persons with diabetes, adherence to weight control recommendations, glucose testing, medication, symptom reporting recommendations, and safety recommendations were reported by the patient and by a physician or nurse familiar with the patient (Orme & Binik, 1989). Adherence to medication prescription was reported at such a high level (77% of subjects reported "perfect" adherence) that this variable was dropped from subsequent analyses. For the remaining four dependent variables, when adherence was determined by the physician, none of the correlations was statistically significant (mean weighted correlation = 0.08). For patient report of adherence to the four behaviors, the mean weighted correlation was 0.12, with two correlations (weight control with safety, $r = 0.24$, $n = 39$, and glucose testing with symptom reporting, $r = 0.25$, $n = 45$) being statistically significant ($p < .05$). However, in both cases, level of adherence to one behavior explained less than 10% of the variance in level of adherence to the other behavior. Similar findings of lack of correlation between glucose testing, diet, and insulin adherence were reported by Schafer et al. (1986).

The implication of these findings is that conclusions about adherence to an aspect of the regimen cannot be extrapolated from measurement of adherence to a different part of the regimen (Kurtz, 1990). Aggregate scores on a global measure of adherence will probably not be useful to explain or predict future adherence to a specific behavior. Furthermore, the notion of a single underlying personality trait, belief, or attitude that consistently influences an individual's adherence decisions is not supported by research (Johnson, 1992). Again, the reasonable conclusion seems to be that decisions about adherence are affected by multiple factors, each of which has varying significance for each individual patient.
3. **Assumptions about adherence behavior**

Health professionals believe that faithful adherence to the recommended treatment regimen will benefit the patient by ensuring the success of the treatment and by preventing complications (Weir, Nathan, & Singer, 1994). Furthermore, health professionals believe that adherence is a necessary requirement in order to evaluate the effectiveness of recommended treatment (Roberson, 1992). Thus, for health professionals, adherence to recommendations is a top priority.

Examination of these beliefs reveals assumptions that may be questioned. First is the assumption that medical advice is "good for" the patient, i.e., that the health professional knows what is "right" for the patient's situation. However, the health professional is often unaware of the role of diabetes in the full context of the patient's life. Patients must learn to incorporate their diabetes regimen as but one aspect of their life (Coates & Boore, 1995; Day, 1995; Roberson, 1992). Concerns such as maintaining family obligations and social interactions, preserving financial stability, or maximizing one's comfort may take precedence over the health professional's recommended activities (Roberson, 1992; Strauss & Glaser, 1975). Sometimes, the treatment regimen may be perceived as being more burdensome, or causing greater discomfort, than the illness itself (Roberson, 1992). Without a full understanding of the patient's perspective of the illness and how it fits in with other aspects of his/her life, the health professional may be confounded by the patient's lack of adherence.

A second questionable assumption is that strict adherence to recommended regimen will improve health outcomes and prevent complications. Although DCCT and UKPDS results provide evidence that adherence to a strict regimen delays the onset of some diabetes complications, many patients can cite anecdotal evidence of friends or relatives who developed severe complications or whose diabetes continued on a downward trajectory, despite following "doctor's orders." Likewise, many people know of someone whose health outcomes were quite positive, despite purposeful disobedience (Becker, 1985). In their own experience, patients may find that acute complications caused by the treatment regimen, such as hypoglycemic episodes,
provide a compelling reason for "rational" non-adherence (Kurtz, 1990). On the other hand, the
rewards of adherence, such as prevention of long-term, chronic complications, are so far in the
future as to lack relevance to many individuals. Indeed, while chronic complications of diabetes
due to microvascular disease may be postponed in persons who faithfully adhere to their
regimen, they appear to be inevitable as the individual reaches old age.

The findings of several scientific studies also appear to challenge the belief that
adherence to regimen carries the greatest assurance of favorable health outcomes (Glasgow et
al., 1987; Mazze, Pasmantier, Murphy, & Shamoon, 1985; Wilson et al., 1986). In the Medical
Outcomes Study (MOS), only 11 of 132 comparisons showed statistically significant positive
effects of adherence on health outcomes (Hays et al., 1994). In this four-year study of over
2,000 adults with four different chronic conditions (hypertension, diabetes, recent myocardial
infarction, and congestive heart failure), a self-report assessment instrument was used to
measure adherence. Health outcomes were measured using the SF-36—an instrument which
measures "quality of life" in terms of physical functioning—and, for persons with diabetes,
glycosylated hemoglobin. Despite the overall poor correlations between adherence and health
outcomes, which could be viewed as evidence that strict adherence is useless, the strongest
associations were found for glycemic control among insulin-using persons with diabetes (Kravitz
et al., 1993). Unfortunately, persons with diabetes may be aware of the overall conclusions of
the study, without realizing that, in diabetes, adherence did seem to improve control.

A third assumption of health professionals is that they are the patient’s sole, or at least
most important, source of health-related advice. Believing this, many health professionals are
unaware that their advice must compete against the counsel of others, i.e., trusted family
members, friends, co-workers, or neighbors (Roberson, 1992). Furthermore, in many cultures,
reliance upon folk remedies may outweigh professional medical advice (Roberson, 1992). Some
people express belief that their health outcomes are "in God's hands," thus diminishing the
value of any human intervention.
The belief that adherence to regimen is a static, "all-or-none" behavior is a fourth assumption that must be questioned. McNabb (1997) describes a typical diabetes regimen as "a series of 'if-then' statements," (p. 215) rather than a standardized protocol. Research indicates that few patients consistently perform all activities, but rather, make choices that include full or partial adherence to some or all of the recommendations. Furthermore, patients may carefully follow a recommended regimen for a period of time, and then "take a holiday" when life circumstances interfere (Maclean, 1991; Paterson & Sloan, 1994). Studies indicate that adherence rates are high just after the diagnosis of diabetes is made, but then decline within a few months. Motivation to adhere increases again following hospitalization for complications. Adherence thus seems to be very much a dynamic behavior, involving day-to-day consideration of the pros and cons of carrying out recommended activities, and daily decision-making about each aspect of the regimen.

4. **Problems in measuring adherence**

This dynamic quality of adherence is but one of the difficulties that interfere with precise definition and measurement of the construct. Another is the "illusiveness of medical or health advice" (Johnson, 1992, p. 1660), that is, the tendency of health professionals to use vague or nonspecific language when providing information about daily care. The patient thus has no clear criteria of what constitutes adherence in the health professional's view. Furthermore, diabetes care instructions are frequently not documented. Thus, follow-up to evaluate the extent to which the patient adheres to recommendations is difficult, if not impossible. There is also a tendency for health professionals to ask global questions of patients on follow-up (e.g., "Are you following your diet?"), rather than questioning more deeply and specifically to determine whether the patient accurately understands and is carrying out recommended regimen components. In this way, patients' misconceptions persist and the health professional remains unaware of potential gaps in the patient's understanding.
a. **Differing definitions between health professional and patient**

The result is that the definition of adherence, and the indicators of adherence, are often not consistent between health professional and patient. Patients frequently misunderstand their regimen prescription, or do not hear the professional’s advice when given, or subsequently forget portions of that advice. Thus, while the patient may believe he/she is being faithful to the professional’s recommendations, the professional may be frustrated to learn that certain aspects of the regimen have been overlooked (Orme & Binik, 1989). An important implication is that, when measuring adherence, the question of whether to use the patient’s criteria or the health professional’s criteria is crucial. If the patient’s and professional’s criteria do not match, the patient may self-report as being highly adherent, while being considered non-adherent by the professional.

Patients often do not share the same goals as health professionals in regard to what are considered desired outcomes of care (Day, 1995). For patients, successful care may be defined in terms of increased feeling of well-being or relief of troublesome symptoms; health professionals, on the other hand, tend to rely more on physiological parameters as evidence of success (Wikblad, 1991). Thus, while a patient may believe that partial adherence is sufficient in order to attain desired outcomes, the health professional might not feel that success has been achieved. Again, day-to-day diabetes management strategies must be incorporated into the patient’s everyday life-style, must be consistent with the patient’s beliefs, and must fit well with the patient’s priorities. Patients who feel that they have successfully adapted the regimen to their lifestyle may perceive themselves as managing their diabetes quite effectively (Price, 1993), while health professionals label the patient as “non-adherent” (Roberson, 1992).

b. **“Adherence” vs “control”**

There is a tendency for health professionals to equate “adherence” with “metabolic control” in evaluating outcomes of their patients with diabetes. For example, health professionals may regard glycosylated hemoglobin level (HbA1c), which is a reliable indicator of average blood glucose over the preceding three months, as a surrogate for adherence to diet,
medication, and exercise aspects of the regimen. The patient with an above average HbA$_{1C}$ may be presumed to have been non-adherent over the past several weeks. Yet, closer examination of the situation may reveal another reason for the abnormally high lab value, such as the influence of other disease conditions or medications, hormonal changes, or even an inappropriate regimen prescription (Johnson, 1992). Although adherence and metabolic control should be measured concomitantly, they should be measured independently, and conclusions about one should not be drawn from measures of the other.

c. **Self-report vs objective measures**

Aside from conceptual problems associated with measurement of adherence, there are also numerous methodological issues. Several methods have been used to measure adherence, including health-provider ratings, direct observation, patient self-report, and, as already discussed, physiological indices. Each method has associated problems; no method by itself has emerged as a "gold standard." Ratings by health providers tend to be global in nature and are often affected by the provider's knowledge of the patient's current level of metabolic control (Johnson, 1992; McNabb, 1997). Thus, health-provider ratings tend to lack validity. Direct observation can be useful, particularly to assess skill in technical aspects such as insulin injection; however, direct observation is time-consuming, labor-intensive, and difficult to implement for aspects such as adherence to diet or activity prescription. Reactivity may also be a problem, as patients may alter their usual behavior while they are being observed (Johnson, 1992).

Patient self-report is the most widely-used method to measure adherence. Though relatively simple to carry out, self-report often has suspect reliability (McNabb, 1997). It is usually presumed that patients who report excellent adherence are not being entirely truthful. The tendency of people to want to be regarded in a positive way by their health provider provides a strong impetus for shading or distorting "true" behavior (Kurtz, 1990). On the other hand, patient reports of non-adherence are generally regarded as being more valid, the
assumption being that few people would deliberately want to appear negligent about following instructions (Johnson, 1992).

The quality of data obtained from patient self-report is highly influenced by the questions patients are asked. When patients are asked to report about very specific behaviors related to each aspect of the regimen over a specific time interval, more useful data are obtained (Johnson, 1992). This may be done in the form of a questionnaire, interview, or by a log or journal which the patient keeps over a series of days. In some cases, subscale scores for adherence to each aspect of the regimen are aggregated into a single composite adherence score.

It may be useful to calculate a single adherence score, although caution must be used in using composite scores as an indicator of changes in adherence over time. A single adherence score is not sensitive to the complexities of diabetes regimen activities (McNabb, 1997). For example, improved adherence to one activity might be balanced by declining adherence to another activity, with the total composite score showing little, if any, change.

5. **Recommendations regarding measuring adherence in diabetes**

"Adherence, in the context of diabetes, is a global concept that must be operationally defined in terms of the many specific behaviors it subsumes" (Kurtz, 1990, p. 55). Recognizing that adherence is a multivariate construct, several researchers have recommended that it be measured using a combination of methods (Becker, 1985; Johnson, 1992; Kurtz, 1990). For example, subjective self-report measures, observations by the clinician of the patient’s verbal and nonverbal behavior, and objective measures of physiological status and laboratory data could be used together as a “multicomponent measurement strategy” (Johnson, 1992, p. 1661).

**Fundamental to the task of measuring adherence is a clear understanding, on the part of patient and health professional, of the standard against which the patient’s behavior will be measured. Furthermore, assessment strategies should be selected based upon the reliability and validity of the instrument, rather than its brevity and ease of use. Finally, the professional**
should re-evaluate adherence at regular intervals, recognizing that adherence behavior is dynamic and subject to change.

Some experts recommend that global “adherence scores” be avoided. Because it is a mathematical “average” of behavior, i.e., a simple mean, a global score does not provide useful information about the level of adherence to each aspect of the regimen. Self-report measures should include all the behaviors associated with the recommended regimen, “with no assumption of adherence or nonadherence to one regimen task based on data from any other task” (Kurtz, 1990, p. 54).

McNabb (1997) asserted that researchers interested in measuring adherence to diabetes regimens should give up trying to find a “gold standard” for adherence. He noted that the individual variability of regimens complicates the task of distinguishing between variances in subject behavior versus errors in measurement. Furthermore, the multiple factors, aside from adherence, that contribute to the variance in metabolic control challenge the expectation that highly adherent patients will attain better glycemic control than less-adherent or non-adherent patients. McNabb advocates developing “definitions of diabetes self-care that include both behavior and context” (McNabb, 1997, p. 217). Rather than focusing on measuring adherence in order to draw conclusions about groups of people, our objective should be to achieve better understanding of the relationships between the patient’s self-care activities, metabolic control, and perceived quality of life. To that end, Kurtz (1990) recommends including qualitative, as well as quantitative, data in the evaluation of an individual’s adherence to regimen.

B. **Illness Demand**

1. **Conceptualization of illness demand**

   Illness demand can be defined in terms of all the activities undertaken by the individual with Type 2 diabetes that are included in the prescribed medical regimen, as well as activities that focus on symptom management and measures to prevent crises associated with the illness. This conceptualization is derived from the notion of “illness-related work,” one of three “lines of work” described in Corbin and Strauss’ (1988) Chronic Illness Trajectory. Aside
from illness-related work, the individual must attend to everyday life work and biographical work, according to this model. Each line of work consists of characteristic clusters of tasks. Everyday life work includes routine tasks of household management, child care, and occupational work. Biographical work consists of developmental tasks that focus on maintenance of one's identity and self-concept.

The Chronic Illness Trajectory (CIT) emphasizes the reciprocal nature of the three lines of work. That is, increases in the demands of one line of work will necessitate adjustment in the other two lines of work in order to maintain balance. Thus, incorporating illness-related work into the routines of daily life is one strategy that enables the chronically ill individual to cope. This requires a dynamic balance, since change is always occurring in one or another aspect of the individual's life (Corbin & Strauss, 1988).

2. **Operationalization of illness demand**

Corbin and Strauss' grounded theory was derived inductively from interviews with couples, one or both of who had a chronic illness. Each couple had unique definitions of the specific tasks in each of the three lines of work. Thus, the concept of "work" as it relates to the CIT framework has not been operationalized or measured quantitatively. Some studies of adherence to regimen among persons with diabetes have included illness-related aspects of work as a variable, and provide evidence that adherence is increased when regimen complexity is reduced (Sanson-Fisher, Campbell, Redman, & Hennrikus, 1989). However, review of several studies reveals that the concept has not been operationalized consistently or fully. Some examples will be described.

A quantitative study of 208 outpatients with Type 2 diabetes examined the relative importance of several psychosocial variables for predicting the self-care behaviors of taking medication, following diet, exercising, and testing blood glucose (Wilson et al., 1986). In this study, the demands of diabetes management were operationalized as "life-style interference" and were measured with seven items on a true-false self-report subscale of an instrument that also measured subjects' beliefs regarding discomfort caused by performance of regimen tasks.
and effectiveness of each task in controlling diabetes. Together, these health beliefs were the
most predictive of adherence to self-care behaviors: health beliefs were correlated with
adherence to dietary self-care behaviors at 0.45 (n = 156); with adherence to exercise self-care
behaviors at 0.40; and with adherence to glucose testing at 0.48 (p<.001 for all three
correlations). However, the use of a composite score, of which life-style interference was but
one portion, precludes any conclusions about the specific contribution of the life-style variable to
adherence.

The notion of illness demand as the negative impact of the diabetes regimen on the
individual's life was developed further by Glasgow and associates. The Barriers to Adherence
Questionnaire (Glasgow, McCaul, & Schafer, 1986) assessed factors that interfere with
adherence to the specific regimen behaviors of insulin injection, glucose testing, diet and
exercise. While “barriers,” a concept derived from the Health Belief Model, cannot be equated
with illness demand, there is overlap in that both concepts focus on the patient’s perception of
negative or problematic aspects of the management regimen. In other words, an individual’s
appraisal that a regimen involves too many demands can also be interpreted as having too
many barriers to adherence. On the other hand, where an individual perceives barriers to
adherence, it is likely that the regimen will also be perceived as too “demanding” (Glasgow et
al., 1997).

In a study of 65 persons with Type 1 diabetes (27 males, 38 females, mean age = 32
years), subjects participated in two series of home interviews, separated by a 6-month interval
(Glasgow et al., 1986). Subjects also completed several psychosocial measures, including the
Barriers to Adherence Questionnaire, and self-reported adherence to four aspects of the
diabetes regimen, using several adherence measures. Statistically significant correlations (n =
65 for all correlations) were obtained at the 6-month follow-up between frequency of reported
barriers and self-report of adherence to four regimen areas. The correlation between the
glucose barriers subscore and adherence to glucose testing was 0.44 (p<.001); between the
exercise barriers subscore and adherence to exercise recommendations, 0.30 (p<.05); between
the diet barriers subscore and adherence to dietary recommendations, 0.39 ($p<.005$); and between the insulin barriers subscore and adherence to insulin prescription, 0.44 ($p<.001$). Correlations obtained during the initial round of assessment were in the predicted direction, but only two were statistically significant at $p<.05$. It is possible that subjects' responses to the barriers scale and adherence measures at the 6-month follow-up were influenced by their familiarity with the instruments and study procedures, thus resulting in higher correlations. Nevertheless, the measurement of patients' perceptions of barriers seems to be helpful in understanding their adherence behaviors.

The Barriers to Adherence Questionnaire was also used in a study of 127 persons (66.9% female, mean age 60.8 years) with Type 2 diabetes (Glasgow et al., 1989). The prevalence of barriers to adherence in each of the four regimen-specific behaviors was included with measures of family support and satisfaction with medical care in an assessment of “environmental support.” Perceived barriers to adherence were greatest for diet ($M=2.89$, $SD=1.18$, range = 1 to 7) and exercise ($M=2.54$, $SD=1.23$, range = 1 to 7).

Glasgow and associates later expanded the measure of barriers to adherence to a scale of 31 items (Glasgow, 1994) and re-named it the “Barriers to Self-Care Scale,” reflecting their later preference for the term “self-care” over “adherence.” The revised instrument, consisting of 31 items assessing challenges to glucose testing, exercise, diet, and diabetes medication (7 items per area) and four items assessing general barriers, was used in a study of 2,056 persons with both Type 1 (14%) and Type 2 (86%) diabetes (Glasgow et al., 1997). Findings once again included higher frequency of barriers to diet and exercise.

A more direct evaluation of illness demand is provided by the Demands of Illness Inventory (DOII), a 125-item instrument which was developed for a research program that focused on the impact of a mother's breast cancer, diabetes, or fibrocystic breast changes on the health, coping, and functioning of the family (Haberman, Woods, & Packard, 1990). Women with diabetes ($n=15$) reported a significantly higher number of treatment-issue demands
than women with breast cancer or fibrocystic breast changes. However, analysis of all data derived from the psychometric study of the DQII indicated that as women adapted to their diabetes, "the distinction between the demands of daily living and the demands of illness became fuzzy" (Haberman, Woods, & Packard, 1990, p. 33). This is congruent with Corbin and Strauss’ notion of the interplay between everyday life work and illness-related work.

3. Emotional impact of illness demand

In the evolution of diabetes researchers' understanding of the complexity of the diabetes regimen, and the implications of the regimen for the patient's life-style, the construct of illness demand has been extended to include affective and cognitive factors as well as social and environmental influences. Researchers stress the necessity of assessing the impact of the regimen from the patient's perspective (Glasgow, 1994; Pollock, 1993), and assessing it holistically, including not only concrete variables such as cost or time, but also emotional responses such as irritability, depression, or loss of self-esteem.

Qualitative studies have been helpful to clarify the personal impact of regimen demands upon the individual. Qualitative data from interviews of a subsample of 20 young adults with Type 1 diabetes (total n=275 for the quantitative portion of the study) indicated that barriers to adherence relate predominantly to life-style and perceived disruption of daily life (Coates & Boore, 1995). In some cases, respondents revealed that daily life took precedence over diabetes management, even if that was detrimental to maintaining metabolic control. Others purposefully made adjustments in their treatment regimen in order to better suit their life-style (Price, 1993).

In another qualitative study, of adults (n=11) with Type 1 diabetes, the impact of diabetes on daily life was characterized in terms of loss of spontaneity and uncertainty (Callaghan & Williams, 1994). Loss of spontaneity affected several aspects of daily life, particularly dietary intake, work-related activities, and social activities. The threat of long-term complications of diabetes gave rise to a sense of uncertainty about life, and the fear that
disability due to long-term complications would eventually erode their independence. These affective responses clearly influenced the individual's perception of the demands of having diabetes.

Similar results were reported by Handron and Leggett-Frazier (1994), who did a content analysis of in-depth interviews of six persons with Type 2 diabetes. Psychosocial themes that emerged from the interviews, indicating problem areas for these respondents, included a sense of isolation from other family members, due to the need for strict attention to meal and medication schedules, as well as other aspects of the regimen. A sense of loss—of physical capabilities, well-being, and freedom—was also identified as a theme.

Emotional aspects of adjustment to diabetes are measured by the Problem Areas in Diabetes Survey (PAID), a 20-item Likert-type instrument in which each item corresponds to a unique area of diabetes-related psychosocial distress (Polonsky et al., 1995). Examples of distressful reactions include feeling angry about having diabetes, feeling that friends and family are not supportive, and being frustrated with aspects of the diabetes regimen. In psychometric assessment of the PAID on a sample of 451 insulin-requiring females with Type 1 or Type 2 diabetes, hierarchical multiple regression analysis indicated that diabetes-related emotional distress was associated with adherence to blood glucose testing, insulin usage, and meal planning, even after adjustment for age, duration of diabetes, and general emotional distress. In this study, PAID scores were also associated with glycemic control. The study results suggest that diabetes-related emotional distress is different from general emotional distress, and furthermore, it is an independent contributor to regimen adherence. Further research using the PAID with samples of males as well as females is needed.

4. **Direction for future research**

In summary, the construct of illness demand as related to diabetes management regimens has taken many forms in the research done on adherence. It has been conceptualized as "illness-related work" and operationalized as life-style interference, barriers, and emotional
distress. In all cases, perception of greater demands, barriers, or distress has been associated with decreased level of adherence to at least some aspects of the regimen.

The definition of illness demand at the beginning of this section is clearly inadequate, in light of the evolution of research in this area. A satisfactory definition must include both the thoughts (emotional responses) and events (regimen tasks, symptom monitoring and management) that the individual experiences in the process of managing diabetes. Likewise, assessment of illness demand must also be holistic, that is, include the impact of the recommended regimen on life-style, social relationships, and emotional state, in order to provide a comprehensive picture of the individual's perception of the personal impact of diabetes. The best strategy would appear to be one that acquires quantitative data from a combination of instruments along with qualitative data from interviews with persons with diabetes.

C. Self-Efficacy and Outcome Expectation

1. Derivation from Social Cognitive Theory

Self-efficacy and outcome expectation are constructs developed by Bandura within the context of social cognitive theory. Bandura (1977) defined self-efficacy as the belief that one can successfully implement a specific behavior. It is separate from the skills that an individual possesses; rather, self-efficacy is the individual's judgment or appraisal of what he/she can do with those skills. Bandura described self-efficacy as a central mechanism of human agency (Bandura, 1986). It is different from outcome expectation, which is described as the person's appraisal of the consequences of a given behavior.

Bandura believed that self-efficacy and outcome expectation are intertwined and that both must be considered in evaluating the likelihood of a person performing a certain behavior. Although an individual may hold an expectation of a positive outcome from a behavior, a lack of confidence in one's capabilities to perform the behavior may forestall its enactment. On the other hand, lack of confidence in the outcome of a behavior may also prevent its performance, even in the individual who believes he/she possesses the ability to perform the behavior (Bandura, 1986). This hypothesis has clear implications for behavior of individuals with chronic
illness, such as diabetes. Failure to adhere to an aspect of the regimen, for example following the recommended diet, may be due either to negative outcome expectations or to low self-efficacy. Whether the individual judges that the consequences of the behavior are not desirable, or judges that he/she is lacking the capabilities to perform the behavior, the result is the same: the behavior is not carried out.

Although Bandura posited distinctive contributions to behavior from self-efficacy and outcome expectation, he asserted that self-efficacy is nevertheless the more powerful predictor of behavior. Early research of behavior related to phobias, smoking cessation, and pain tolerance (among others) indicated that perceived self-efficacy predicted performance of a behavior much better than outcome expectation (Bandura, 1986). Later research on people with Type 2 diabetes (Kingery & Glasgow, 1989) found that outcome expectation scores added little if anything to self-efficacy scores in predicting adherence to dietary and glucose testing recommendations. However, for this sample (n=127, 67% female), outcome expectations for exercise were more important than self-efficacy beliefs in predicting exercise behaviors among the males.

On the other hand, Bandura (1990) asserted that controlling for the person's judgment of self-efficacy accounts for much of the variance in expected outcomes. This seems to happen because, in many everyday activities, "variations in performance produce concurrent changes in outcomes" (Bandura, 1986, p. 393). The individual learns that the outcome of a behavior is largely determined by his/her performance. As skill in a behavior increases, the outcome tends to improve, and thus there is reinforcement to continue performing the behavior. This illustrates the role of "enactive attainment" in the formation of self-efficacy beliefs.

This assertion was supported in a study of women with Type 2 diabetes (Skelly et al., 1995), where a strong correlation (r=+0.775, p<.001, n = 118) existed between self-efficacy and confidence in outcomes at the first measurement. Interestingly, the strength of the correlation was lower, though still statistically significant (r=+0.247, p<.05, n = 82), four months later. This
finding supports the belief that, for adherence decisions over time, self-efficacy is a more important factor than outcome expectation.

Another important finding of the early research is that self-efficacy beliefs can be enhanced by intervention, thus increasing the likelihood that a behavior will be performed. However, the focus of early research was on proscriptive actions, that is, avoiding behaviors such as smoking or various phobias. The ability of an intervention to increase self-efficacy and thus the performance of a prescriptive activity, such as exercise or medication, has not been so consistently supported by research (Hurley & Shea, 1992).

In accordance with principles of social cognitive theory, Bandura recommended a "microanalytic methodology" in the assessment of self-efficacy (Bandura, 1986). In other words, individual judgements of self-efficacy must be made for each of the behaviors under scrutiny. People do not possess a single, global judgment of self-efficacy; rather, their self-evaluation varies with the task at hand. Support for this proposition is found in study results cited earlier which indicate differential levels of adherence to various regimen behaviors. As applied to a multi-task chronic illness regimen, such as diabetes, the individual may possess a high degree of self-efficacy in regard to following the medication prescription, yet low degree of self-efficacy with regard to dietary recommendations.

Bandura identified four sources of information that individuals use in forming self-efficacy judgments. These are, in order of importance: 1) enactive attainment, i.e., previous performance of a behavior; 2) vicarious experience, i.e., observing others successfully perform a behavior; 3) verbal persuasion, i.e., attempts by others to convince an individual that he/she is able to perform a behavior; and 4) physiological state, i.e., awareness of somatic indicators of stress or anxiety, which usually interfere with the performance of a behavior. Each of these sources of information is filtered through cognitive processes which ultimately determine the relative influence of each type of information on the appraisal of self-efficacy in regard to a specific behavior (Bandura, 1990).
2. **Self-efficacy and the Health Belief Model**

Self-efficacy has been widely recognized as an important cognitive influence on a person's behavior (Golin, DiMatteo, & Gelberg, 1996). Rosenstock, one of the authors of the Health Belief Model (HBM), recommended that self-efficacy be added as a fifth element (Rosenstock, 1985). Thus, according to the HBM, adherence behavior is posited as being dependent upon the individual's motivation to be healthy, combined with the individual's beliefs about his/her susceptibility to an illness or its consequences, the seriousness of the illness or its consequences, the benefits of performing the recommended behavior, his/her judgment of self-efficacy relative to the behavior, and the overall judgment of risk-benefit ratio. Judgments about the benefits or risks of recommended behavior can be viewed as outcome expectations. The point is that both self-efficacy and outcome expectation fit comfortably within the framework of the HBM. Subsequent research on adherence behavior among people with diabetes has often included self-efficacy or outcome expectation in combination with each other or with one or more of the original HBM variables.

3. **Influence of self-efficacy and outcome expectation on adherence to diabetes regimen**

Studies of the roles of self-efficacy and outcome expectation in adherence to diabetes regimens have provided descriptive data about the relative level of each variable in regard to specific regimen behaviors. However, in terms of predicting adherence behavior or examining correlations between various factors and adherence, self-efficacy and outcome expectation have usually been combined with each other or with other psychosocial variables into a composite score. Thus, it is difficult to draw conclusions about the singular influence of either self-efficacy or outcome expectation on diabetes regimen adherence.

Measurement of self-efficacy in relation to regimen-specific behaviors among people with diabetes has generally shown higher perceptions of self-efficacy for medication-taking and glucose-testing, and lower levels for dietary and exercise behaviors (Glasgow et al., 1989; Kavanagh et al., 1993; Skelly et al., 1995). On the other hand, beliefs about outcome
expectation tend to be more positive for exercise or medication, and less optimistic for glucose-
testing (Glasgow et al., 1989; Kingery & Glasgow, 1989). People with diabetes appear to be
confident both in their ability to follow their medication prescription and in the beneficial effects
of following that prescription. The combination of belief in both self-efficacy and positive
outcome expectation for medication-taking may help to explain the observed high rate of
adherence to medication recommendations.

Adherence to exercise recommendations, which tends to be much lower, might be
explained by the conflict between high outcome expectation and low self-efficacy beliefs. In
other words, although people with diabetes recognize the importance of exercise and believe it
is a beneficial part of their regimen, they lack confidence in their ability to faithfully implement an
exercise regimen. Adherence rates are therefore lower; and this is consistent with Bandura’s
assertion that self-efficacy beliefs are more predictive of behavior than outcome expectations.

Closer examination of the association between self-efficacy and adherence behavior
reveals inconsistent research findings. One study of African-American women with Type 2
diabetes (Skelly et al., 1995) found that the effects of self-efficacy beliefs were unstable over
time in relation to the size of the effect and the regimen behavior affected. The authors
concluded that self-efficacy is but one variable that influences adherence decisions; under some
circumstances, it may be an important consideration, and in other situations, it is overshadowed
by other factors. In another study (Glasgow et al., 1992), the hypothesized increase in self-
efficacy score in response to an intervention designed to improve problem-solving and self-
efficacy among persons over age 60 with Type 2 diabetes did not occur, despite the finding of
improved adherence to dietary and exercise recommendations.

In other studies, a demonstrable association between self-efficacy and adherence was
observed. Crabtree (1986) found that self-efficacy beliefs were better than selected
demographic variables, disease-related variables, and perceived social support as predictors of
diet, exercise, and general self-care. Using a modification of Crabtree’s self-efficacy measure,
Hurley and Shea (1992) found positive associations between self-efficacy and general
management, diet, and insulin behaviors. The Hurley and Shea study is notable because self-care behaviors were measured one month after self-efficacy beliefs, suggesting a prospective influence of self-efficacy upon adherence. Similar results were found in another study where self-efficacy and adherence were measured on two occasions, separated by a two-month interval (Kavanagh et al., 1993). Self-efficacy was a significant predictor of adherence to diet, exercise, and glucose-testing behaviors even after past levels of adherence were taken into account.

There have been few studies which examined the singular effect of self-efficacy or outcome expectation upon adherence behavior. More commonly, self-efficacy or outcome expectation scores have been combined with scores on measures of other psychosocial variables to form a composite score. For example, beliefs about treatment effectiveness were combined with beliefs about treatment discomfort and life-style interference to form a composite “health belief” score (Wilson et al., 1986). Outcome expectation has also been combined with beliefs about the importance of a regimen activity to form a composite “effectiveness score” (Glasgow et al., 1997). Self-efficacy and outcome expectancy together have been added to a score on a measure of negative self-thought to yield an “expectancy score” (McCaul et al., 1987). And a “social learning composite” score was obtained from the addition of scores on measures of self-efficacy, outcome expectation, environmental support, skills, and knowledge (Glasgow et al., 1989). In each case, the score that included self-efficacy or outcome expectation beliefs significantly contributed to the prediction of adherence to one or more regimen-specific behaviors, more so than knowledge, skill, or demographic variables.

The strategy of combining scores from multiple psychosocial measures tends to yield stronger correlations between the composite beliefs and adherence. It is consistent with the conceptualization of multiple psychosocial factors exerting differential levels of influence on adherence behavior under different circumstances. The implication seems to be that each individual patient must be assessed for the unique combination of factors, psychosocial and otherwise, that influence decisions to adhere. Furthermore, one cannot assume that the relative
influence of these factors will remain stable for that individual over time and under different circumstances (Paterson et al., 1998). Rather, as situations change, new variables will come forward to exert an influence. However, for educators and practitioners it may be difficult to devise research-based strategies to foster desirable beliefs, since it appears that many different types of beliefs are influential over time.

It should be noted that problems in measurement of the constructs of self-efficacy and outcome expectation may be at least partially responsible for the inconsistent results of studies of the association between these variables and adherence behavior. Instruments that purport to measure self-efficacy or outcome expectation must be examined for consistency with the accepted conceptualization of the construct. Furthermore, ceiling effects may influence findings if subjects report fairly high levels of self-efficacy (Glasgow et al., 1992).

D. Social Support

“Social support” is a multi-dimensional construct that can be defined many different ways, depending on one’s theoretical perspective. A definition that is useful in the context of health care of persons with chronic illness is provided by Stewart (1993): “interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance. These communications improve coping, moderate the impact of stressors, and promote health” (p. 7). The definition makes clear that social support can be derived from several sources; can be provided in several different ways; and can serve a variety of purposes for the individual. An examination of social support in its full complexity is beyond the scope of this paper. Rather, the focus will be on the influence of the behaviors of family and significant others upon the adherence of the person with diabetes to recommended diabetes regimen activities. In a later section of this review of literature, the influence of the individual’s satisfaction with interactions with health professionals will be examined separately.

1. Social support and social network

It is important to distinguish between social network and social support, although the two terms are sometimes used interchangeably in the literature (Stewart, 1993). Social
network is usually used as a quantitative term to indicate the number of persons with whom an individual maintains social relationships (Kaplan & Hartwell, 1987). It has been depicted as a “convoy” that surrounds a person, with decreasing levels of intimacy and contact as one moves from closer to more distant relationships (Kahn & Antonucci, 1980). Though the social network may serve functions which are perceived by the individual as having a positive influence on his/her life, the network may also perform inhibitory or negative functions, as well (Becker & Maiman, 1980). Not all of the relationships within one's social network are voluntary, and so size of the network is not by itself indicative of the magnitude of benefit perceived by the individual (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). Indeed, persons with a complex social network may experience stress and even a decline in their physical and emotional health as they attempt to meet their social obligations and maintain a large number of relationships.

Thus, “support” should not be confused with “involvement” (Turk et al., 1986). Simply having people, even close family members, available does not mean that the individual will perceive these people as being supportive. Even well-intentioned family members may unknowingly behave in ways that undermine the confidence or motivation of the individual who is attempting to carry out a disease-related regimen (Bailey & Kahn, 1993; Cameron, 1996). And sometimes, family members deliberately act to subterfuge the efforts of the individual to carry out prescribed activities (Lorenz et al., 1996; Maclean, 1991). Thus, the nature of the support is far more significant than its mere presence.

2. **Social support and adherence to regimen**

Social support is recognized as an important factor in long-term treatment plans, such as for weight control or management of chronic illness (Becker, 1985; Rosenstock, 1985). And yet, as will be seen in the discussion of research on social support as it relates to individuals with diabetes, the exact nature of the relationship between support and adherence to regimen is not clear. While it might be anticipated that high levels of perceived support would be associated with improved adherence, this has not always been found (Schafer et al., 1986). Reviewers have commented on the potentially deleterious effects of family members on the
individual’s adherence (Becker, 1985; Fisher et al., 1998), as in when, for example, a woman who has primary responsibility for cooking family meals refuses to follow the recommended meal plan for her spouse with diabetes (Handron & Leggett-Frazier, 1994).

Goodall & Halford (1991) noted that research has not clarified which aspects of social support are necessary for effective self-management of chronic illness. Furthermore, the question remains as to whether it is more important to the individual to have continuous access to support, or to be confident that supportive resources can be mobilized when needed. In an extensive review of the literature on family support in chronic disease, Fisher et al. (1998) concluded that families provide the context in which patient characteristics, healthcare factors, and stress interact over time to influence disease management. Chronic illness of one family member affects the health and well-being of the entire family. The ability to respond to and successfully manage a family member’s chronic illness depends on the characteristics of the chronic illness, the family’s developmental stage, and the family’s culture and belief system. Clearly, closer examination is needed of the interaction between support from family members and other variables which have been identified as being important in adherence behavior (Becker, 1985).

3. **The role of family support in the management of diabetes**

Support from family members appears to play an important role in adherence for persons with diabetes, perhaps even more than for persons with other chronic illnesses. The influence of social support as one of several possible antecedents to regimen adherence was investigated in a subset of subjects from the Medical Outcomes Study (Sherbourne et al., 1992). The number of supportive relationships and perceived quality of support were measured for persons with hypertension, coronary heart disease, and diabetes (n = 1198). Social support was found to be positively related to adherence only for those subjects with diabetes. This finding may be attributed in part to the complexity of the diabetes regimen, and to the close involvement that family members have in assisting the person with diabetes to adopt recommended behaviors (Fisher et al., 1998). At times, family members may even be
personally affected by regimen activities, such as dietary changes. Of note is the finding in this study that the number of close relatives and friends within the individual's social network was not predictive of adherence. It was the quality of supportive relationships, rather than quantity, that was the significant aspect of support.

Much of the research into the role of social support in regimen adherence in diabetes has focused on the influence of the family on children and adolescents with Type 1 diabetes (Fisher et al., 1998; Glasgow, 1994). These studies generally found that the perception of family support, combined with a sense of family cohesion, were associated with better adherence (Bobrow, Avruskin, & Siller, 1985) or control (Anderson & Auslander, 1980; Anderson, Miller, Auslander, & Santiago, 1981). However, the relationship between a parent and a child with diabetes is quite different from the dynamic that occurs when an adult member of the family has the illness. Furthermore, the differential influence of positive and negative family behaviors must be considered (Glasgow, 1994).

Findings of studies of adults with Type 1 or Type 2 diabetes have failed to yield consistent results regarding the influence of family support. These inconsistencies may reflect problems in measurement of the construct, such as equating social network with social support, or failing to consider the deleterious effect of negative family behaviors. For example, a statistically significant linear relationship was found between adherence and the supportive behaviors of family members and friends in a study of 30 adults with Type 1 diabetes (Schlenk & Hart, 1984). However, all but one of the items used to measure social support were worded positively; thus, the influence of negative behaviors was not seriously considered. Furthermore, this sample was quite homogeneous in their self-reports of adherence: every one of the subjects was compliant with at least 70% of the regimen behaviors that were assessed.

In contrast, in another study, support from family members did not predict adherence to exercise, medications, or general self-care in adults with Type 1 or Type 2 diabetes (n = 143) (Crabtree, 1986). In this study, self-efficacy was found to be the best predictor of adherence to regimen behaviors. Using an instrument designed to assess both supportive and nonsupportive
family behaviors towards persons with Type 1 diabetes (total n = 72; adult subjects = 54), other researchers found that the relationship between positive family behaviors and adherence was not statistically significant. Interestingly, in this sample, the perception of negative family reaction was associated with decreased adherence for the adults subjects (Schafer et al., 1986).

It appears that "family support" is a complex behavior, which, like self-efficacy, does not lend itself to measurement using a single global score. Indeed, the degree of support extended by significant others appears to vary, depending on the specific regimen behavior. For example, Wilson et al. (1986) found that persons with Type 2 diabetes (n = 184) perceived highest levels of support for taking medication, and lowest levels of support for exercise. Glasgow and Toobert (1988) found that measures of family support that were specific to regimen components were better predictors of adherence than the summary score of family support. Furthermore, intercorrelations among the regimen-specific family support scores were low, leading these investigators to conclude that family support of adherence to one regimen behavior does not connote support of other regimen behaviors.

Perhaps because it is difficult to make broad generalizations about the degree of influence of family support relative to other variables that affect adherence behaviors, some researchers have combined measures of family support with other variables. In a study of persons with Type 1 diabetes (total n = 107; adult subjects = 84), McCaul et al. (1987) incorporated family support with several other variables into a measure of "environmental support," and found that this factor, along with expectancies, was a better predictor of adherence than either knowledge or skill. Glasgow et al. (1989) used a similar technique with subjects with Type 2 diabetes (n = 127), combining family support with other variables as a "social learning composite" (SLC). These investigators found that the combined social learning variables increased the prediction of adherence over and above demographic variables; however, they were not able to draw conclusions about the distinct contribution of each component of the SLC. What they did find was that each variable contributed differently to
adherence to each regimen behavior, in one case being very important, and in another case, of little importance. They caution that their findings "underline the complexity of behavioral factors in diabetes" (Glasgow et al., 1989, p. 300) and note that other factors not included in their study are also influential.

One of those other factors, quality of life, was included in a recent study of 150 insulin-requiring subjects (Trief, Grant, Elbert, & Weinstock, 1998), which investigated the influence of family environment upon metabolic control and psychosocial adaptation. While family behaviors were not found to be related to metabolic control, both positive and negative family behaviors were predictive of the satisfaction score on a quality of life measure. The results of this study indicate that affirmation and aid from family members contributes to the overall sense of life satisfaction perceived by persons with diabetes. But, what is the nature of the relationship among the individual's perception of quality of life, perception of family support, and adherence to diabetes regimen? The interaction among these variables is an area that requires closer examination.

E. Satisfaction With Medical Care

The relationship between patient and health care provider has long been viewed as an important modifying factor of adherence (Becker & Maiman, 1975). More to the point, research indicates that patient satisfaction with medical care is positively associated with adherence to medical recommendations (Francis, Korsch, & Morris, 1969; Rosenstock, 1985; Sherbourne et al., 1992). Very few quantitative studies were found that examined the relationship between satisfaction with care and adherence to diabetes regimen. In three studies reported by Glasgow and associates, satisfaction with medical care was incorporated with other variables (family support, perceived barriers, perceived stress) into a measure of "environmental support." For subjects with either Type 1 (McCaul et al., 1987) or Type 2 diabetes (Glasgow & Toobert, 1988; Glasgow et al., 1989), the composite support variable significantly improved the ability to predict adherence to diabetes regimen. However, this does not provide sufficient information to draw conclusions about the singular effect of satisfaction with care.
1. **Theoretical foundations of “satisfaction”**

Much of the research into satisfaction with medical care has been based on either fulfillment theory or discrepancy theory. The theories are similar in that they view satisfaction as the difference between what the individual expects or desires and what the individual perceives as having occurred. The distinction between the two theories is that discrepancy theory factors in the amount desired or expected in the first place by dividing the simple difference of expectation/desire and occurrence by the amount expected/desired:

\[
\text{Satisfaction} = \frac{\text{Expectation or Desire} - \text{Occurrence}}{\text{Expectation or Desire}}
\]

Fulfillment theory, on the other hand, uses only the simple difference between expectation/desire and occurrence to calculate satisfaction (Linder-Pelz, 1982a):

\[
\text{Expectation or Desire} - \text{Occurrence} = \text{Satisfaction}
\]

Many studies of satisfaction with health care have used, either implicitly or explicitly, the definition of satisfaction which is suggested by fulfillment theory, i.e., “the difference between rewards desired and those received” (Linder-Pelz, 1982a, p. 579). Thus, the overall relationship that has been posited is that fulfillment of the patient's positive expectations about medical care leads to a sense of satisfaction with care, which in turn increases the likelihood of adherence (Becker & Maiman, 1975; Becker & Maiman, 1980). Much of the early research on satisfaction with care therefore focused on the patient’s expectations about medical care and the provider-patient relationship.

The construct of expectations is drawn from Social Learning Theory, in which Bandura described expectations as antecedent determinants of behavior. Expectations are generally learned, from previous experience in similar situations, by observing others' experiences.
vicariously, or by hearing about similar situations from other people (Bandura, 1986). Thus, in the context of the relationship between a patient with diabetes and the provider, the patient comes to the relationship with expectations about the provider's role and behaviors, as well as expectations about the anticipated treatment plan, and expectations about what his/her role and behaviors should be.

When positive expectations are fulfilled, the patient is likely to describe feeling satisfied with the care received from the provider and is also more likely to adhere to the provider's recommendations (Becker, 1985). However, if positive expectations are not met, or if the patient comes to the interaction with negative expectations which are fulfilled, the patient describes a sense of dissatisfaction with care (Golin et al., 1996). These theory-driven hypotheses received empirical support in research by Linder-Pelz (1982b), where satisfaction was found to be highest among patients who had both favorable expectations and favorable occurrences and lowest in those patients with both negative expectations and negative occurrences.

2. Patients' expectations about provider behaviors

These conceptual formulations place the onus for patient satisfaction on the provider of medical care. It would appear that if providers exhibited behaviors that patients react to in a positive way, then satisfaction would increase. For this reason, early investigations of satisfaction with medical care focused on the patient's expectations of the relationship with the provider.

Comprehensive literature reviews (Becker, 1985; Becker & Maiman, 1975; Becker & Maiman, 1980) summarized specific provider behaviors which have been shown to be regarded positively by patients. These included asking about the patient's concerns, being responsive to the patient's need for information about his/her medical condition, and showing sincere concern and sympathy (Becker, 1985; Golin et al., 1996). Agreement by patient and provider about the specifics of the treatment regimen was also associated with higher degree of patient satisfaction.
with care (Becker & Maiman, 1980), as was continuity of contact with a single physician (Becker & Maiman, 1975).

Recent research has supported similar conclusions. In a study of adult patients (n=416) receiving hemodialysis treatment, the opportunity to ask questions of health care providers and receive relevant explanations were identified as important determinants of satisfaction with care (Ferrans, Powers, & Kasch, 1987). Among adults with insulin-requiring diabetes (n=34), subjects valued physicians who were willing to listen to their complaints about the required diet, and who were nonjudgmental about dietary lapses, demonstrating an understanding of the need for a balanced approach to diabetes treatment (Maclean, 1991). In another study of adults with insulin-requiring diabetes (n=26), communication with providers that is "individualized, readily accessible, nonjudgmental and interactive" was identified by subjects as a critical resource (Armstrong, 1990).

The landmark Diabetes Control and Complications Trial (DCCT) provided evidence that continuity of the relationship between patient and health care providers fosters a sense of satisfaction with care (Lorenz et al., 1996). Contact is especially important during the early phase of diabetes treatment; a minimum of once per week is recommended. DCCT investigators found that even brief telephone contact provided the sort of verbal feedback that was reassuring to patients and supportive of their efforts to incorporate new lifestyle behaviors (DCCT, 1993).

On the other hand, several provider behaviors have been identified which negatively affect the patient's feeling of satisfaction with the relationship. These include perception of impersonal behavior by the physician (Coe & Wessen, 1965), or lack of communication, where the patient perceives the physician to be formal, rejecting, or controlling (Davis, 1968). Other behaviors which are viewed negatively by the patient center on the failure of the physician to provide feedback or adequate explanations about diagnosis and treatment (Francis et al., 1969).
There is preliminary evidence that the physician’s attitudes about diabetes and the efficacy of treatment may influence the patient’s degree of success in self-management (Cameron, 1996). In a small (n=7) qualitative study (Dietrich, 1996), the physician’s reaction and attitude, as perceived by the patient at the time the diagnosis of diabetes was communicated, were crucial in influencing patients’ perceptions of the severity of the disease, and consequently, their intent to adhere to treatment recommendations.

What is troubling, however, is that at least some health care providers’ beliefs about diabetes are negative. Larme and Pugh (1998) found that primary care providers (physicians, family nurse practitioners, and physician assistants) rated diabetes as being harder to treat than other chronic diseases, such as hypertension or angina. Diabetes treatment was described as being “labor intensive,” requiring frequent adjustments in regimen and close monitoring of the patient. Subjects in this study believed that current diagnostic and treatment protocols are not clear, and that a good outcome is not assured, even with the best of care. Both providers and patients spoke of the lack of a sense of being in control, leading to many frustrations in treatment.

It is not clear, however, how the physician’s attitude about diabetes and its treatment affects the patient’s feeling of satisfaction with medical care. Perhaps, if the physician’s attitude mirrors the patient’s expectations, then satisfaction will be high. For example, the patient may have expectations that diabetes is difficult to treat, and that treatment has little effect on eventual outcome. If the physician exhibits that attitude as well, the patient may feel satisfied, and may even have a ready-made rationale for non-adherence. On the other hand, if the physician’s negative attitudes are in conflict with the patient’s expectations about treatment and prognosis—or vice versa, where the physician expresses positive attitudes, but the patient has negative expectations—then the patient may describe a feeling of dissatisfaction with the care.

3. **Patients’ expectations about their own role**

   It seems clear that provider behaviors that inform, support, reassure, and motivate the patient are likely to contribute to satisfaction with care. But what role and behavior
do patients expect of themselves in the relationship? Some research has indicated that patients favor an "active orientation," that is, their preference is to actively participate in the management of their care. For example, persons with hypertension who perceived themselves as actively involved in therapeutic planning and self-care activities had better blood pressure control, better adherence to prescribed regimen, better understanding of their treatment, and even, fewer side effects from medications (Schulman, 1979). Rost (1989) analyzed audiotapes of the conversations between chronically ill men (n=45) and their physicians and found that those with greater participation in the interaction had better compliance with prescribed medications. In this same study, patients who interrupted the physician more frequently reported higher levels of satisfaction with their relationship with the provider.

Based on findings such as these, some investigators concluded that active participation in the interaction would be beneficial for all patients. Turk et al. (1986) advocated a collaborative framework in which the provider presents the relevant information and treatment options to the patient, and the patient decides what goals to work toward and what self-care behaviors to perform. However, their method advocates a paternalistic approach to ensure that the patient accepts the provider's goals as his or her own. "Ideally, the health care provider should attempt to orchestrate interactions so that the goals and behaviors suggested by the patient coincide with those that are most appropriate given the medical condition or health problem" (Turk et al., 1986, p. 53). True patient involvement is not what is valued in this approach; rather, it is only important that the patient "comes to believe that he or she has contributed equally to the health care regimen" (p. 53).

Less controlling is the contractual approach favored by Rosenstock (1985), in which patient and provider together decide upon treatment goals, which are written down along with a time limit for achievement. Rosenstock describes this as a "true partnership" (p. 614) because, while both patient and provider participate in selecting goals, the patient must believe that the goals are realistic within the given time frame. However, others may view the method as
unnecessarily formal and legalistic, with its requirement that all expectations, including rewards for goal achievement, are written down and signed by both parties to the contract.

4. **Qualitative research on patient-provider relationship**

Even among health care providers who strive to exhibit empathy and concern in their interactions with patients, little effort is made to solicit a description of how the patient experiences diabetes management (Price, 1989). The emic (insider) perspective of the person's experience often reveals findings which challenge accepted beliefs (Thorne & Paterson, 1998). Thus, recent studies of persons with chronic illness, such as diabetes, have used qualitative methods to explore more deeply the individual's experience of illness and expectations about the patient-provider relationship.

Participants (n=17) in a qualitative study of women with Type 2 diabetes who were identified as exemplars of self-management described a "shared relationship" with health care providers (Ellison & Rayman, 1998). They consulted with providers only after they were unable to solve a diabetes management problem on their own. Providers were thus regarded as a "safety net." These women had, over time, moved beyond regarding diabetes management as a set of rules to be followed or as a set of onerous tasks. They had fully incorporated disease management into the context of their life. They viewed themselves as experts who could teach health care providers—a sort of role reversal. What they expected from providers was an "organizational culture" that values a caring attitude, being available when needed for assistance, and working collaboratively to solve management problems (Rayman & Ellison, 1998).

The women cited above had reached the highest level of self-management. However, it is not justifiable to conclude that all persons with diabetes aspire to this degree of independence. Indeed, some patients do not wish to become experts in self-management, perhaps because they have other priorities that demand their time and energy (Thorne & Paterson, 1998). Based on meta-analysis of 43 qualitative research reports of persons with diabetes (Paterson et al., 1998), it was concluded that patients' decisions about how much
control to assume in self-management are dynamic. As changes occur in their life context, or even in the disease process, the individual's desire for independence falls on a continuum ranging from full control to shared control to complete dependence.

Similar conclusions were deduced from the comprehensive meta-analysis of individuals' experience with chronic illness (Thome & Paterson, 1998), of which the analysis cited above was a part. Thome and Paterson cautioned against ignoring the desire of many chronically ill people for expert help. "Clearly, a static interpretation of partnerships in health care relationships is not realistic" (p. 176). It is important for providers to always appreciate the complexity of human experience, and to be able to provide the varying degrees of support that patients expect at different times in their lives.

Other researchers note the importance of recognizing that patients and providers may not always share the same goals for treatment (Lorenz et al., 1996). For example, while professionals place high value on "controlling" the disease, patients seem to place greater priority on finding ways to "balance" the demands of the disease with other life demands (Toombs, 1995). Thus, true collaboration requires willingness on the part of the professional to "discover the patient's priorities and place them at the top of the agenda" (Lorenz et al., 1996, p. 650).

5. **Areas for further study**

In conclusion, research on patient satisfaction with medical care indicates that satisfaction is maximized when the patient-provider relationship meets the patient's expectations. These expectations incorporate the roles and behaviors of both participants in the relationship, patient and provider. While there is research support for a set of provider behaviors which are consistently viewed positively by patients, there is inconsistency in the findings regarding patients' expectations about roles. Patients who have reached a high degree of expertise in self-management tend to desire a more active role, and regard their relationship with the provider as a collaboration that incorporates shared decision-making. However, there is evidence that other patients desire less control, and indeed, look to the provider as the expert
who will provide direction. Little research is available on this latter group of patients. It would seem useful to investigate persons who are less adherent or non-adherent in order to determine their expectations about role and behavior of providers, as well as themselves. In addition, further research is needed to explore the relationships between patients’ expectations, degree of satisfaction with care, and likelihood of adherence to the recommended regimen.

F. Quality of Life

1. Definition and characteristics of quality of life

Quality of life (QOL) is a construct which has assumed prominence as an outcome measure in a wide range of studies (Leplege & Hunt, 1997). Indeed, the term is used, sometimes loosely or even incorrectly, to describe a desirable effect of a multitude of new products, services, or programs. For example, the National Cancer Institutes require inclusion of QOL as an outcome for funding of all clinical trials. The draft of Healthy People 2010 includes QOL in Goal #1: “to increase length and quality of life.” The problem is that there has never been consensus on a definition of QOL (Leplege & Hunt, 1997), which, like pain, sometimes appears to be “whatever the individual says it is.” Because it is a characteristic so fundamental to personal well-being, everyone knows what they mean by QOL.

Nevertheless, assessment of the individual’s perception of QOL is essential to the understanding of the effect of a disease and its treatment on the full context of the individual’s life. It also enables the researcher to compare different interventions as to their acceptability to patients and likelihood of being implemented by them (Greenfield, et al., 1994).

Despite the lack of agreement on a standard definition of QOL, it is generally accepted that subjectivity and multidimensionality are two of its fundamental attributes (Cella, 1992). Furthermore, the individual’s appraisal of his/her QOL is recognized as being dynamic and changeable. In this study, the definition of QOL proposed by Ferrans and Powers (1992) will be used: “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (p. 29). This definition acknowledges the subjective nature of QOL and is based on a conceptual framework of QOL that includes four domains:
health and functioning, social and economic, psychological and spiritual, and family. These dimensions are similar to those identified by others who have studied QOL (Cella, 1992).

2. **Problems in measuring quality of life**

Problems in measuring QOL are both conceptual and methodological. Conceptual difficulties have been alluded to, but can become even more problematic when designing research that seeks objective and quantifiable data. Much of the research that has included QOL as a variable suffers from a lack of theoretical description of the construct (Hunt, 1997). Few researchers describe their conceptual framework for QOL; their definition and measurement of it are driven by the convenience or efficiency of available instruments. Gill and Feinstein (1994) randomly selected 75 reports of research studies in which QOL had been measured. They found that investigators had conceptually defined QOL in only 15% of the articles, had identified targeted domains in less than half, and had stated a rationale for their choice of instrument in only 36%.

Methodological problems abound, as well. If QOL is accepted as being subjective in nature, then self-report would seem to be the logical way to measure it. However, self-report ratings can be affected by mood of the day or by the desire for social acceptance (Hanestad, 1990). Moreover, cultural or linguistic differences may affect the individual’s interpretation of items on an instrument. Finally, the expectations of a person with a chronic illness may have been adjusted in such a way that an ill individual expresses a higher degree of satisfaction with life than does a healthy individual. Thus, differences between individuals or groups might be more difficult to discriminate (Hanestad, 1990).

a. **Health-related measures vs comprehensive measures**

Perhaps the most widespread problem in quality of life assessment in medical research is the tendency to equate QOL with functional status or physical health (Gill & Feinstein, 1994; Guyatt & Cook, 1994). Not only does this limit QOL measurement to but one of its domains, it also fosters the assignment of value to different levels of functional ability. For example, the assumption is made that a state of full physical health equates with the highest
level of QOL, while severe functional limitation connotes a much lower level. Yet, it is clear that health status cannot be equated with QOL; for some, it plays a minor role in comparison with other aspects of life (Hunt, 1997). By using health status indicators as a proxy for QOL, "we thus infer QOL from a variety of indicators, many of which tell us something about life, but nothing about quality" (Leplege & Hunt, 1997, p. 47).

Some have suggested that the term "health-related quality of life" should be used in order to make clear that only the domain of physical health and functioning is being examined (Guyatt & Cook, 1994). However, Gill & Feinstein (1994) argued convincingly that "overall QOL includes not only health-related factors, such as physical, functional, emotional, and mental well-being, but also non-health-related elements, such as jobs, family, friends, and other life circumstances" (p. 619). Gill and Feinstein asserted that the individual should be asked not only to rate their satisfaction in each domain, but also to evaluate the personal importance of each area being rated. Soliciting patients' preferences acknowledges the individual's unique values and provides a more valid measure of QOL perception. This same viewpoint is modeled in the Ferrans' and Powers' definition of QOL and is manifested in their Quality of Life Index (Ferrans & Powers, 1992).

Comprehensive assessment of QOL, rather than just evaluation of physical health and function, is of value in the study of persons with chronic illness, because it provides insight into the role of illness within the full context of the individual's life. Consider that chronic illness, such as diabetes, affects the individual's family and social relationships, economic status, and ability to work (Toombs, 1995). By focusing only on evaluation of physical aspects, the investigator misses much of the richness and complexity inherent in interactions between the disease and the individual's life (Kohen, Burgess, Catalan, & Lant, 1998).

Among those investigators who espouse comprehensive assessment of QOL, there is disagreement as to whether QOL is more accurately assessed via quantitative or qualitative methods. While Benner (1985) advocated interpretive research strategies in the study of QOL in order to "capture relational and configurational patterns" (p. 5), other investigators are
comfortable with quantitative instruments that measure QOL comprehensively. Still others assert that the best approach is one which combines both qualitative and quantitative data.

b. **Global vs disease-specific measures**

A final consideration in decisions about QOL evaluation is whether to use an instrument which is “global,” i.e., applicable to all persons, or one that is “disease-specific.” Comparisons of global and diabetes-specific QOL measures suggest that both types of instruments are useful and capture complementary data. When QOL was measured using the Diabetes Quality of Life Measure (DQOL) and the Medical Outcomes Study Health Survey 36-Item Short Form (SF-36) (Jacobson, deGroot, & Samson, 1994), both instruments were found to be sensitive to clinical characteristics such as frequency and severity of complications. However, the DQOL was more sensitive to lifestyle issues, such as the perceived burden of dietary management or insulin treatment. Similarly, in a comparison of the Diabetes Care Profile (DCP) to the SF-36 (Anderson, Fitzgerald, Wisdom, Davis, & Hiss, 1997), some overlap was found in the domains that were measured. However, the DCP was judged to be more appropriate for capturing the impact of regimen demand and acute complications. Meanwhile, the SF-36 was useful for making comparisons between persons with diabetes and persons with other chronic illnesses. It should be noted, however, that while the SF-36 can be considered “global” in the sense of its applicability to people of all levels of health states, it is by no means global in terms of comprehensively assessing all domains of QOL.

3. **Quality of life in persons with diabetes**

There are indications that the perceived QOL of persons with diabetes is lower overall than that of healthy persons. In the Medical Outcomes Study (MOS), 844 patients with diabetes were part of a sample of over 9,000 persons with a variety of chronic conditions, whose QOL was compared with that of persons without chronic illness. The Short-Form General Health Survey (SF-20) was used as the measure of QOL. This instrument, from which the SF-36 was developed, assesses the dimensions of physical, social, and role functioning, physical and emotional well-being, and current perceptions of health. Overall, subjects with diabetes
reported significantly lower QOL scores in all dimensions than subjects without chronic
conditions, though the QOL scores of persons with other diseases such as congestive heart
failure, arthritis, or chronic lung problems were even lower (Stewart et al., 1989).

Using only the physical functioning, social functioning, and mental health subscales of
the SF-20 with a large (n=2,056), national sample of adults with Type 1 or Type 2 diabetes,
Glasgow et al. (1997) reported even lower QOL scores than had been obtained for subjects with
diabetes in the MOS. These investigators further found that the three dimensions of QOL that
were examined were lower among those with less education, lower income, and those with no
health insurance or government insurance only, suggesting the need to include and control for
these factors in future research.

The same three QOL dimensions of physical, social, and mental functioning were also
investigated, albeit with a different QOL instrument, in a biethnic sample (n=976) of Hispanics
(42.6%) and non-Hispanic whites, 22.8% with Type 2 diabetes and 77.2% without diabetes
(Caldwell, Baxter, Mitchell, Shetterly, & Hamman, 1998). The subjects with diabetes reported
significantly lower (p<.05) QOL scores (mean=770, max=1000) than those without diabetes
(mean=821). Though Hispanics overall rated their perceived QOL higher than non-Hispanic
whites, an interaction term between diabetes status and ethnicity was not significant when
entered into the multiple regression model, indicating no difference in impact of diabetes
between the two ethnic groups. In this sample, unlike the findings reported by Glasgow et al.
(1997), education, income, and socioeconomic index were not significantly associated with QOL
score.

In the studies just described (Glasgow et al., 1997 and Caldwell et al., 1998), increased
severity of diabetes, presence of diabetes complications, or the presence of other comorbidity
were all associated with lower QOL scores. Similar findings were reported for a sample of 175
persons with Type 1 diabetes (Lloyd, Matthews, Wing, & Orchard, 1992), in whom the presence
of macrovascular disease or nephropathy was associated with significantly lower QOL than in
those who had no diabetes complications. Boyer and Earp (1997) also found the poorest QOL
among those persons with diabetes who had the greatest number of comorbid conditions, as well as an association between increased severity of diabetes and decreased rating of QOL.

It is important to keep in mind, however, that in these studies, the measures of QOL which were used focus on health and physical functioning, or assess the impact of health status on social or mental functioning. Thus, it is not surprising that those with more severe diabetes, diabetes complications, or other comorbidity were found to have lower levels of QOL. None of the instruments used in these studies can be said to measure QOL comprehensively in all of its domains. Furthermore, none of these instruments allows the subject to rate the personal importance of each measured area. Therefore, one can only draw inferences about the impact of diabetes and reduced physical functioning on health-related QOL; no conclusions can be made about their impact on an individual's overall QOL.

a. **Metabolic control and quality of life**

This assertion is reinforced when we examine the findings of research into the association between metabolic control in persons with diabetes and perception of QOL or well-being. Though it might be expected that improved metabolic control, as indicated by change in glycohemoglobin (GHb) level, should be associated with improved rating of QOL, results have been inconsistent. Weinberger et al. (1994 and 1995) reported on a subset (n=275) of adults with Type 2 diabetes, whose GHb levels and health-related QOL, measured with the SF-36, were evaluated at baseline and one year later. Two hundred-four of the 275 subjects were randomly assigned to a nurse-coordinated intervention which consisted of telephone calls, at least once per month, to monitor patients' health status, provide ongoing education and support, and facilitate resolution of problems (Weinberger et al., 1995). Though subjects in the intervention group had significantly lower fasting blood sugar and GHb than the control subjects, statistically significant differences were not found for the SF-36 scores. Weinberger et al. (1995) concluded that patients may perceive no immediate benefit from small gains in metabolic control.
Van der Does et al. (1996) reported a positive association between GHb and well-being as measured by mood and diabetes symptoms; however, the correlations were not strong—most were <0.20. Furthermore, a statistically significant correlation between GHb and scores on the Affect Balance Scale, a general measure of well-being, was not obtained.

However, in a randomized, controlled, double-blind trial comparing dietary treatment of Type 2 diabetes with treatment using a combination of diet and an oral hypoglycemic medication, subjects in the intervention group were found to have improved GHb levels as well as better physical and emotional health, higher cognitive function, and fewer missed work days (Testa & Simonson, 1998). These investigators used five visual analog scales (perceived health; mental and emotional health; self-reported cognitive function; general health perception; and symptom distress) as their measure of QOL. The favorable QOL outcomes in the intervention group were largely due to a decrease in symptom distress associated with symptoms of hyperglycemia. Once again, the QOL measure largely evaluated physical health and function, and thus it is not surprising that improvement in objective indicators of health was associated with increases in subjective indicators.

b. **Regimen intensity and quality of life**

Physicians who treat persons with diabetes are sometimes hesitant to impose a more demanding self-care regimen on the patient, fearing that the demands of the regimen will negatively impact well-being, and thus decrease likelihood of adherence. However, the few studies which have examined this relationship have failed to show a decrease in well-being or QOL with increased regimen demand. Most notably, DCCT investigators found no difference in QOL between patients in the conventional and intensive treatment groups (DCCT, 1996). Likewise, a descriptive prospective cohort study of persons with Type 2 diabetes in The Netherlands (n=272), showed no change in physical symptoms, mood states, general well-being, or treatment satisfaction when insulin was added to the regimen (deSonnaville et al., 1998).
An important consideration in evaluating the results of these two studies is that, in both cases, subjects in the intervention group had close and frequent contact with health care professionals. The benefits gained from these long-term therapeutic relationships may have offset the negative impact of the more intensive or demanding regimen.

Indeed, another study (Hanestad, 1992) indicates that the person's perception of the "impact" of the regimen on daily life may be a more important influence than the objective requirements of the regimen. Subjects were categorized into two groups—greater impact of diabetes on daily life and lower impact of diabetes on daily life—on the basis of their score on one item from a comprehensive QOL measure. Although there were no significant differences between the two groups regarding treatment regimen, metabolic control, or duration of diabetes, the group reporting greater impact of diabetes on daily life had significantly lower scores in all but one of the domains of QOL. A notable demographic difference between the high- and low-impact groups was that those who lived alone reported greater perceived impact of the disease. This finding lends support to indications of the salutary effect of family support.

4. **Depression and quality of life perception**

The relationship between a person's overall perspective on life and their perception of QOL is further demonstrated by studies of the association between depression and QOL. Lloyd et al. (1992) found associations between the presence of depressive symptomatology, lower QOL perception, and number of diabetes complications. Because their measures were administered only one time, no inferences can be made regarding causation. In other words, it is possible that diabetes complications cause a person to become depressed, and this in turn caused a decrease in the perceived QOL. On the other hand, the presence of depression may be a factor in the development of certain complications, particularly if depression causes the individual to be less adherent to their recommended diabetes self-care activities.

Differences in physical health and age were controlled in a study of the relationships between anxiety, depression, and QOL perception in adults with Type 1 or Type 2 diabetes.
(Kohen et al., 1998). The investigators found significantly lower QOL scores in the group that had been categorized as depressed, even after statistically controlling for the severity of physical impairment. A note of caution, however, is that physical impairment was rated by physicians, rather than by the subjects, using the Kamofsky Performance Index (KPI). One cannot assume that physicians' ratings of functional status would be identical to the individuals' self-ratings.

While the results of these studies are not strong enough to warrant firm conclusions about the association between depression and QOL, they do at least indicate that depressed mood and QOL perception are linked in some way. It has been suggested that QOL perception may be a stable personality trait (Hanestad & Albrektsen, 1992). Perhaps QOL perception provides a perspective through which the individual interprets life experiences and physical symptomatology. Those who have an overall negative orientation toward their perceived QOL may be at greater risk for development of physical or psychological complications. The nature of the relationship between perceived QOL and overall psychological orientation has yet to be researched in a meaningful way.

5. **Quality of life and adherence to regimen**

Likewise, the nature of the relationship between perceived QOL and adherence to diabetes regimen has not been carefully investigated. To date, studies which have included QOL have generally viewed it as an outcome variable. In only one study (Hanestad & Albrektsen, 1991) was QOL hypothesized as an input into decisions regarding adherence. The investigators interpreted their findings of statistically significant association between QOL domains and perceived difficulties in adherence to indicate that persons who have higher levels of life satisfaction will perceive fewer problems in adhering to diabetes regimen. However, because this study provided correlations only, the direction of causation cannot be inferred. Nevertheless, it is intriguing to consider the notion that an individual’s perception of their QOL is somehow a factor in decisions regarding adherence to diabetes regimen, rather than being solely an outcome of adherence behavior.
Qualitative data provide insight into the perceptions of health and well-being that are held by persons with chronic illness such as diabetes and the influence that these perceptions have on decisions about adherence (Maclean, 1991; McWilliam, Stewart, Brown, Desai, & Coderre, 1996). People who are chronically ill distinguish between physical health and overall well-being, and describe their self-care management activities as elements of a "balancing act" between health and well-being. While people with chronic illness desire a degree of health which is as close as possible to normal, they generally are reluctant to sacrifice well-being, as they define it for themselves, in order to achieve greater physical health. Thus, when health conflicts with well-being, people may be inclined to take liberties with their recommended regimen in order to preserve well-being, even if it is at the expense of reduced physical health (Maclean, 1991). The individual may re-frame their expectations of life in order to maintain the aspects of well-being which are of greatest personal importance. If the individual does not perceive a benefit to well-being from adherence to aspects of the diabetes regimen, they may be less likely to perform the recommended self-care activities (Weinberger et al., 1994). This may help to explain the high rates of non-adherence that are observed in persons with diabetes, especially with regards to diet and physical activity, two aspects that are often perceived as having a major influence on well-being.

6. Directions for future research

Reflecting on the literature regarding QOL as it relates to persons with diabetes, it is clear that most of the QOL measures which have been used do not adequately measure all aspects (domains) of QOL, but rather, concentrate on health status or physical function (Haas, 1999). Since Type 2 diabetes affects the individual's life in all aspects, it seems reasonable to examine QOL comprehensively, both through a measure of QOL which assesses all domains and through qualitative methods which provide an emic perspective of living with diabetes. Furthermore, the relationship between QOL and decisions to adhere to each aspect of the self-care regimen requires further investigation. Again, qualitative methods would seem more likely
to provide information that accurately depicts the perspective of individuals who are making these decisions on a daily basis.
III. METHOD

A. Research Design

This study combined qualitative and quantitative techniques in order to address the research objectives. The quantitative component employed a non-experimental, descriptive design and utilized several self-report instruments to measure the independent variables, self-efficacy, illness demand, support from family members, and satisfaction with interactions with health care professionals, as well as the dependent variables, adherence to regimen and quality of life. For the qualitative component of the study semi-structured interviews were used as the means for data collection.

The technique of combining qualitative and quantitative methods in the study of a research problem is called triangulation, and serves both to reveal the full context of the phenomenon and to validate the data obtained by different methods. These are referred to as the completeness and confirmation purposes of triangulation (Breitmayer, Ayres, & Knafli, 1993). For this study, the purpose of the quantitative analysis was to examine the associations between the four independent variables and the two dependent variables. Analysis of the qualitative data enhanced the interpretation and understanding of quantitative data. Each type of data was needed in order to attain a fuller understanding of adherence or nonadherence to regimen among persons with Type 2 diabetes.

B. Description of Sample

1. Total sample

A total of 389 surveys were mailed to clients of an outpatient diabetes center that served approximately 800 clients and that adhered to standards of the American Diabetes Association (ADA) for patient education (ADA, 2000). The Center was located in a middle-class, blue-collar suburban area adjacent to the community hospital that sponsors it. In 1998 (the most recent
information available), approximately 19% of the Center’s clients were diagnosed with Type 1 diabetes; 35% were diagnosed with Type 2 diabetes and were treated with insulin; 33% were Type 2, not on insulin; and 13% were diagnosed with gestational diabetes.

Surveys were mailed to clients who met the following inclusion criteria: age 35 or older, diagnosed with Type 2 diabetes for a minimum of six months, treated with oral hypoglycemic medication, and able to speak and read English. In addition, in order to control for the effect of knowledge as a factor that influences adherence, all subjects had previously received education about their diabetes and its management. Persons who were being treated with insulin only or who were identified by the clinic’s diabetes specialists as having complications that interfered with self-care, whether related to diabetes or other comorbidity, were excluded. Ninety-four surveys were returned, a response rate of 24%.

A sample size of 100 was desired to ensure approximately 25 subjects per variable in order to obtain a reliable regression equation (Pedhazur, 1997). In this study, four independent variables—self-efficacy, illness demand, support from family members, and satisfaction with medical care—were measured and examined for their influence on quality of life and adherence to recommended regimen by persons with Type 2 diabetes. Twenty-six subjects each in the high and low adherence groups was calculated as necessary to produce a 0.80 probability of detecting a 2-point difference (delta) in adherence score at an alpha of 0.05 (sigma = 2.5). Thirty subjects in each group would produce a 0.80 probability of detecting a 3-point difference in quality of life score at alpha of 0.05 (sigma = 4.5).

The sample group had distinct socioeconomic and educational advantages, as evidenced by 60.7% reporting education beyond high school, and 41.5% reporting annual family income of more than $50,000. Subjects' ages ranged from 33 – 86 years, with a mean of 60.88 years (sd=12.1); the number of years since diagnosis of diabetes ranged from 1 – 35 years, with a mean of 8.55 years (sd=8.5).
2. **Assignment to adherence groups**

After determining that the total scores for the Diabetes Self-Care Activities Checklist (DSCA) were normally distributed (Kolmogorov-Smirnov statistic = 0.085, df = 87, sig. = 0.169), subjects in the total sample were divided into three adherence level groups, n = 29 for each group. The "low adherence" group included subjects whose DSCA total score was 1.52 or less. The "middle adherence" group included subjects whose total DSCA score was between 1.53 and 4.28, while the "high adherence" group included subjects whose score was 4.40 or greater.

3. **Interview Subset**

The names of all survey respondents who had complete data for the DSCA (n = 87) were listed, and this list—without DSCA data—was submitted for review by staff members of the diabetes center. One Registered Nurse and one Registered Dietician reviewed the list and ranked each subject as high, medium, or low adherence, based upon their experience with the individual and their professional judgment of the individual's adherence behavior. Staff members were able to provide ratings for 48 of the 87 subjects. In 23 of the 48 cases (48%), there was agreement in adherence level as determined both by DSCA score and by staff rating. In 13 cases (27%), there was discrepancy in the adherence ratings assigned by the two staff members. Where discrepancy occurred, assignment to adherence group was based on DSCA score.

3. **Interview subset**

Survey respondents were mailed a letter inviting them to participate in an interview if they met either or both of the following criteria: 1) DSCA score in the upper or lower third; or 2) rated by both staff members as having high or low adherence. This purposive sampling of "maximum variation cases" (Patton, 1980) was employed in order to have representation of persons who were at opposite ends of the continuum in regards to perceived
adherence, thus facilitating the identification of factors that promote or prevent adherence. Of the 40 who were asked, 23 (57%) agreed to be interviewed. For five of the 23 interview participants (22%), there was agreement in adherence level based on both DSCA score and staff member rating. For seven of the interviewees (30%), staff members were unable to provide a rating, so assignment to adherence group was based on DSCA score. In 11 cases (48%), there was discrepancy between the adherence level as based on DSCA score and that assigned by staff members; once again, assignment to adherence group was based on the DSCA score. However, in four of those cases, the subject was placed in the "medium" adherence group based on DSCA score, but was rated as "high" adherence by both staff members; these four subjects were assigned to the "high adherence" group based on the staff member ratings.

Among the interview subset, 65.1% reported education beyond high school, and 65.2% reported annual family income of more than $50,000. The ages of interview participants ranged from 41-78 years, with a mean of 58.8 years and the number of years since diagnosis of diabetes ranged from 1 -35 years, with a mean of 11.5 years.

Demographic characteristics of the sample and interview subset are listed in Table I, along with characteristics of the population of clients who received services from the diabetes center during 1998. The sample had significantly more females (62%) than the population of clients of the diabetes center (49%), $\chi^2 (1) = 6.65, p < .01$ and was significantly older, $\chi^2 (2) = 25.82, p < .001$. However, the sample did not differ significantly from the population in terms of racial-ethnic makeup, $\chi^2 (3) = 3.82, p = .28$. The interview subset was similar to the total sample in terms of gender ($\chi^2 (1) = .073, p = .79$), racial-ethnic makeup ($\chi^2 (3) = 6.27, p = .10$), and percentage with college education ($\chi^2 (1) = 2.03, p = .16$). However, the interview subset differed significantly from the total sample in age, with the subset having proportionately fewer persons in the young adult range (19-40 years) and more in the middle adult range (41-65 years).
years) than the sample ($\chi^2(2) = 168.23, p < .001$). There was also a significant difference in marital status, with a higher percentage of the interview participants being married and fewer widowed ($\chi^2(3) = 1528.30, p < .001$). Interview participants also tended to have higher income level than the full sample ($\chi^2 (6) = 306.91, p < .001$).
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<td></td>
</tr>
<tr>
<td>• Graduated from high school</td>
<td>28 (29.8)</td>
<td>6 (26.1)</td>
<td></td>
</tr>
<tr>
<td>• Some college</td>
<td>31 (33)</td>
<td>7 (30.4)</td>
<td></td>
</tr>
<tr>
<td>• Graduated from college</td>
<td>11 (11.7)</td>
<td>1 (4.3)</td>
<td></td>
</tr>
<tr>
<td>• Graduate education after college</td>
<td>15 (16)</td>
<td>7 (30.4)</td>
<td></td>
</tr>
<tr>
<td>Total Family Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Less than $10,000</td>
<td>5 (5.3)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>• $11,000-$20,000</td>
<td>8 (8.5)</td>
<td>1 (4.3)</td>
<td></td>
</tr>
<tr>
<td>• $21,000-$30,000</td>
<td>9 (9.6)</td>
<td>1 (4.3)</td>
<td></td>
</tr>
<tr>
<td>• $31,000-$40,000</td>
<td>12 (12.8)</td>
<td>2 (8.7)</td>
<td></td>
</tr>
<tr>
<td>• $41,000-$50,000</td>
<td>8 (8.5)</td>
<td>3 (13)</td>
<td></td>
</tr>
<tr>
<td>• $51,000-$60,000</td>
<td>9 (9.6)</td>
<td>3 (13)</td>
<td></td>
</tr>
<tr>
<td>• $61,000 or more</td>
<td>30 (31.9)</td>
<td>12 (52.2)</td>
<td></td>
</tr>
</tbody>
</table>

*May not total 100% due to missing responses*
C. **Instruments**

Each of the independent variables was measured quantitatively using one or more self-report instruments which had previously been used in research on persons with diabetes and which had demonstrated satisfactory psychometric properties (See Appendix A).

1. **Diabetes Self-Efficacy Scale (DSES)**

Subjects' appraisal of self-efficacy was assessed using a modification of the Insulin Management Diabetes Self-Efficacy Scale (Hurley, 1990). A 27-item scale, the IMDSES is based upon Bandura's conceptual model of self-efficacy. Items are structured to assess the individual's appraisal of self-efficacy in regards to seven diabetes self-care behaviors: diet (6 items), exercise (2 items), foot care (2 items), glucose testing (3 items), medications (4 items), recognizing and managing problems (4 items), and general aspects (6 items).

Responses are graded on a Likert scale from 1 ("strongly agree") to 6 ("strongly disagree"); a "not applicable" category is also provided. Items that are positively worded are reverse-scored; thus, higher scores indicate a higher degree of self-efficacy. Score means can be calculated for the total scale or for three subscales: general, diet, and insulin. The range of possible score means for total or subscale scores is 1 to 6.

Psychometric testing of the IMDSES indicated satisfactory internal consistency for a combined group of 38 outpatients and 89 inpatients (Cronbach's alpha of 0.82 for total scale, 0.68 for the general subscale, 0.78 for the diet subscale, and 0.62 for the insulin subscale). Test-retest stability (mean duration of 22 days between test and retest) was 0.58. Content validity of the instrument was evaluated by diabetes content experts and self-efficacy construct experts. Furthermore, evidence to support convergent validity was provided by moderate correlation ($r = 0.376, p < .001, n = 122$) between the IMDSES and a diabetes self-care scale (IMDSCS). A weak positive correlation ($r = 0.169, p = .032, n = 121$) between the IMDSES and a
measure of expectation of well-controlled diabetes in the future provided further evidence of construct validity.

In this study, the four items of the IMDSES that specify behaviors related to insulin were modified to indicate "diabetes medication," e.g., "I can take my diabetes medication using the recommended procedure." For this sample, internal consistency reliability for the modified Diabetes Self-Efficacy Scale (DSES) was supported with Cronbach's alphas of 0.89 for the total scale, 0.84 for the general subscale, 0.85 for the diet subscale, and 0.80 for the medication subscale.

2. **Appraisal of Diabetes Scale (ADS)**

Illness demand was measured using the Appraisal of Diabetes Scale. This Likert-type scale consists of 7 items that assess the individual's cognitive and affective appraisal of his or her diabetes (Carey et al., 1991), thus providing an indication of the individual's perception of illness demand. The items measure the individual's emotional response to having diabetes, with items that relate to the degree of upset and uncertainty caused by diabetes, the individual's perception of the likelihood of their diabetes condition worsening, and the individual's sense of control and effectiveness in coping with diabetes. Higher scores on the ADS indicate perception of greater illness demand. Two items require reverse-scoring.

In a study of 200 adult males with diabetes, the scale had a coefficient alpha of 0.73, demonstrating satisfactory internal consistency, and Pearson product-moment correlations of 0.89 for 1-hr retest and 0.85 for 1-week retest, demonstrating stability of the measure. Validity was manifested by correlational analyses which indicated that higher levels of negative appraisal of diabetes were associated with higher levels of anxiety (r = 0.55), anger (r = 0.39), depression (r = 0.58), perceived stress (r = 0.49), and diabetes-related hassles (r = 0.59). Although additional research with different patient groups is needed, the ADS appears to be useful as a brief screening instrument to identify persons with diabetes who are experiencing, or
are at risk for, problems with adherence to regimen (Carey et al., 1991). For the present study, Cronbach’s alpha for the ADS was 0.84.

3. **Diabetes Family Behavior Checklist (DFBC-II)**

Support from family members was measured using the Diabetes Family Behavior Checklist (DFBC), a 16-item instrument derived from principles of social learning theory which assesses the frequency of supportive and nonsupportive behaviors that may influence the individual’s adherence to recommended regimen (Schafer et al., 1986). The DFBC includes 9 items that measure the individual’s perception of positive, or supportive, behaviors by family members and 7 items that measure negative, or non-supportive, behaviors. Respondents rate the frequency with which a close family member exhibits the designated behavior, with a rating of 1 indicating that the behavior is “never” exhibited, and a rating of 5 indicating that the behavior is demonstrated “at least once a day.” The instrument yields separate scores for positive (supportive) and negative (nonsupportive) behaviors.

In a study of 127 outpatients with Type 2 diabetes (Glasgow & Toobert, 1988), Cronbach’s alphas of 0.71 for the positive score and 0.64 for the negative score were obtained, indicating marginally acceptable internal consistency. The authors note that family behaviors related to diverse aspects of diabetes self-care may account for the relatively low alpha coefficients. Over a 6-month test-retest interval, Pearson product-moment correlations for adults ranged from 0.55-0.70, indicating adequate stability. It should be noted that these correlations may be reflective of actual change in family support over the six month interval, as well as test-retest stability of the instrument. Evidence of convergent validity was provided by moderate correlations between subjects’ scores and family members’ scores ($r= 0.53$ for positive scores and 0.56 for negative scores, both $p < .001$). In the present study, Cronbach's alpha for the DFBC positive scale was acceptable at 0.82. For the DFBC negative scale, Cronbach's alpha was marginally acceptable at 0.63.
4. **Satisfaction With Care Questionnaire (SWC)**

Satisfaction with medical care was measured using a modification of the Satisfaction With Care Questionnaire (SCQ) developed by Ferrans et al. (1987). The original instrument consisted of 27 items with responses indicated on a 6-point Likert-type scale. Three subscales emerged from factor analysis of the items—physician, nursing care/dialysis treatment, and financial/transportation. In a study of 416 patients who were receiving hemodialysis, this instrument had a coefficient alpha of 0.94 for the entire instrument. Internal consistency reliability of each of the subscales was supported by coefficient alphas of 0.90 (physician subscale), 0.93 (nursing care/dialysis treatment subscale), and 0.73 (financial/transportation subscale). Evidence of criterion-related validity was provided by a correlation of 0.78 between total SCQ score and the score on a single item measuring satisfaction with care in general.

The SCQ was modified for this study by deleting six items that relate specifically to hemodialysis procedures and by re-wording other items to reflect management of diabetes. The modified Satisfaction With Care scale (SWC) thus consisted of 21 items. Diabetes content experts and persons with Type 2 diabetes reviewed the modified instrument for content validity. The new instrument was pilot-tested on a small sample of persons with Type 2 diabetes (n = 10) to assess clarity and ease of administration. The pilot group included 6 males and 4 females, nine of whom were diagnosed with Type 2 diabetes and one with Type 1 diabetes. Mean age of the pilot group was 66 years (SD = 11.99) and mean duration of treatment for diabetes was 5.65 years (SD = 7.14). Minor revisions in the wording of some items were made based on recommendations from the pilot group subjects. For the full sample (n = 91), Cronbach’s alpha coefficient was 0.92 for the entire modified SWC instrument. The bivariate correlation between the total SWC score and the item measuring satisfaction with care in general was 0.46 (p < .01).
5. **Quality of Life Index - Diabetes version**

The construct of quality of life was assessed with the diabetes version of the Quality of Life Index (Ferrans & Powers, 1992). The QLI is a two-part instrument, with 32 items which measure satisfaction with various aspects of life, and 32 corresponding items which ask the subject to rate the importance of each of those aspects. Items sample four domains of quality of life—health and functioning, social and economic, psychological and spiritual, and family—with each domain yielding a subscale score. Subscale scores and total scores reflect the weighting of satisfaction responses by importance responses, with higher scores indicating perception of better quality of life. In a field test of the QLI with 349 patients on hemodialysis, the measure demonstrated satisfactory internal consistency reliability, with alpha coefficients of 0.93 for the entire instrument, 0.87 for the health and functioning subscale, 0.82 for the socioeconomic subscale, 0.90 for the psychological/spiritual subscale, and 0.77 for the family subscale. Construct validity of the instrument was assessed and supported by factor analysis, as well as a contrasted groups approach. A correlation of 0.77 between the overall QLI score and a single-item life satisfaction assessment provided support for convergent validity (Ferrans & Powers, 1992).

The diabetes version of the QLI (QLI-D) includes two additional items related to satisfaction with aspects of life that are affected by diabetes and two additional corresponding items related to importance of those aspects to the individual. Psychometric properties of the QLI-D were assessed in a pilot study (Quinn, Poradzisz, & Ferrans, 1999) of a multi-ethnic sample (n = 61) of persons with Type 1 and Type 2 diabetes. Internal consistency reliability of the QLI-D was supported by acceptable Cronbach’s alpha for the total scale (0.94) and for all subscales (health/functioning = 0.90; social/economic = 0.82; psychological/spiritual = 0.87; and family = 0.68). For a subset of the sample with lower extremity arterial disease (n = 25), moderate correlations between total QLI-D and subscale scores with scores on the Perceived Stress Scale provided support for construct validity of the QLI-D. For the sample in the current
study, the following Cronbach's alpha coefficients were obtained: total scale = 0.95; health/functioning subscale = 0.90; social/economic subscale = 0.76; psychological/spiritual subscale = 0.88; and family subscale = 0.83.

6. **Diabetes Self-Care Activities Scale**

Adherence to regimen was assessed using the Diabetes Self-Care Activities Scale (DSCA) (Wilson et al., 1986). On this instrument, subjects are asked to compare their level of self-care behaviors in four areas against what they recall having been instructed to do. Some items ask subjects to indicate the number of days in the past week that they performed the behavior as instructed. Other items ask for the percentage of time they follow recommendations by selecting one of five response options—0, 25, 50, 75, or 100%. The four aspects of self-care behavior that are assessed are medication, glucose testing, physical activity, and diet. For this sample, internal consistency reliability of the DSCA was supported by Cronbach's alphas of 0.80 for the total scale, 0.81 for the diet subscale, 0.91 for the exercise subscale, and 0.76 for the glucose testing subscale.

D. **Interview Questions**

A schedule of questions for the semi-structured interview was developed as the tool for collection of qualitative data (Appendix B). The choice of questions was guided by the conceptual framework, with the addition of open-ended questions designed to solicit additional factors that affect adherence. The approach was one of "working down" from the conceptual framework, exploring and building on hunches and ideas it suggests (Richards & Richards, 1994).

E. **Data Collection**

Procedures for data collection and protection of human subjects' rights were approved by the Institutional Review Boards of University of Illinois at Chicago and the parent organization of the diabetes center. In order to avoid potential selection bias on the part of the researcher, a packet including all the self-report instruments described above was mailed to all patients of the
participating diabetes center who met the inclusion criteria (n = 389). Included in the packet was a letter, signed by the researcher, faculty advisor, and the director of the center, describing the purpose and procedure of the study, and soliciting their participation. Each packet of self-report instruments was marked with an identification number that corresponded to a list of names accessible only to the researcher. Confidentiality of participants' responses was maintained throughout the study. Completed instruments were returned directly to the researcher by mail. Those persons who did not respond to the first mailing were sent a second packet of instruments, along with another letter requesting their participation.

Participants were asked to provide demographic data, including age, marital status, length of time since being diagnosed with Type 2 diabetes, highest level of education, income level, and medication prescribed for diabetes. A separate question asked participants to give consent for review of their medical information on file at the diabetes center. The charts of those who consented were reviewed for the three most recent glycohemoglobin levels, presence of complications of diabetes, and other comorbidity.

Subjects who met the criteria for interview were sent a letter requesting their participation. Those who agreed to be interviewed returned a signed consent with their name and contact information directly to the investigator, who subsequently contacted them by phone to arrange an appointment. Interviews were conducted in a mutually agreeable location, with all but three interviews conducted at the diabetes center. Three participants requested that the interview be conducted at a university that was more conveniently located for them. All interviews were conducted in a private conference room by the investigator and were audiotaped. The duration of interviews ranged from 40 minutes to 70 minutes. Interview participants were given information to contact the investigator by phone or email with any additional information that they wanted to share after the interview. One participant contacted the investigator with an email addendum to her interview comments. Participants were also asked for permission to be contacted by telephone at a later date to confirm or clarify information as needed.
IV. RESULTS: SURVEY DATA

A. Method of Statistical Analysis

SPSS 10.0 computer software was used for all statistical analyses. The first step in the analysis of the survey results was the determination of descriptives and measures of central tendency for the results of all six of the survey instruments. These will be reported for each instrument separately in subsequent sections. The distribution of total scores for each instrument was examined for normality, using the Kolmogorov-Smirnov statistic. Measures of skewness and kurtosis for each variable were also obtained. These results are presented in Table II below. Scores for the ADS, DFBC(+), DFBC(-), SWC, and QLI-D were not normally distributed, and this must be taken into consideration in the interpretation of results.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Kolmogorov-Smirnov statistic</th>
<th>df</th>
<th>Sig.</th>
<th>Skewness</th>
<th>Std. error</th>
<th>Kurtosis</th>
<th>Std. error</th>
</tr>
</thead>
<tbody>
<tr>
<td>OSES</td>
<td>.091</td>
<td>91</td>
<td>.059</td>
<td>-.565</td>
<td>.253</td>
<td>.050</td>
<td>.500</td>
</tr>
<tr>
<td>ADS</td>
<td>.154</td>
<td>94</td>
<td>.000</td>
<td>.637</td>
<td>.249</td>
<td>-.036</td>
<td>.493</td>
</tr>
<tr>
<td>DFBC (+)</td>
<td>.117</td>
<td>86</td>
<td>.006</td>
<td>1.364</td>
<td>.260</td>
<td>3.208</td>
<td>.514</td>
</tr>
<tr>
<td>DFBC (-)</td>
<td>.095</td>
<td>86</td>
<td>.055</td>
<td>.868</td>
<td>.260</td>
<td>1.776</td>
<td>.514</td>
</tr>
<tr>
<td>SWC</td>
<td>.211</td>
<td>91</td>
<td>.000</td>
<td>-1.829</td>
<td>.253</td>
<td>3.775</td>
<td>.500</td>
</tr>
<tr>
<td>QLI-D</td>
<td>.130</td>
<td>87</td>
<td>.001</td>
<td>-.949</td>
<td>.258</td>
<td>1.391</td>
<td>.511</td>
</tr>
<tr>
<td>DSCA</td>
<td>.085</td>
<td>87</td>
<td>.169</td>
<td>-.211</td>
<td>.258</td>
<td>-.520</td>
<td>.511</td>
</tr>
</tbody>
</table>

For purposes of comparisons, subjects in the total sample were categorized by gender (males = 35; females = 58); education (with college education = 57; without college education = 36); diabetes duration (short duration = 29; long duration = 32); and adherence (high adherence = 29; low adherence = 29).
Assignment to diabetes duration group was made by dividing the sample into tertiles based on number of years since diagnosis. The lower third, designated as the "short duration" group, included persons whose disease duration was 2.5 years or less (n = 29). The upper third, or "long duration" group, included subjects who had been diagnosed with diabetes 10 or more years ago (n = 32).

Assignment to adherence group was made by dividing the sample into three groups (n = 29 for each group) based on total score for the Diabetes Self-Care Activities Checklist (DSCA). The "low adherence" group included subjects whose DSCA total score was 1.52 or less. The "middle adherence" group included subjects whose total DSCA score was between 1.53 and 4.28, while the "high adherence" group included subjects whose score was 4.40 or greater.

For each instrument, comparisons were made between total and, where applicable, subscale scores. Student's t-test was used for comparisons of total scores on each instrument, as this is the appropriate statistical test to make comparisons between two independent groups. For instruments with subscale scores, i.e., DSES, QLI-D, and DSCA, one-way repeated measures ANOVA was used to test for difference between one or more of the subscale scores. Using this test, the subscale scores were treated as one within-subjects factor with the number of levels corresponding to the number of subscales. Where a significant difference was found among subscale scores, post hoc pairwise contrasts were done to determine which scores were significantly different. Two-way repeated measures ANOVA tests were done on the three instruments with subscales in order to detect an interaction effect between subscale scores and the factors of gender, education, disease duration, and adherence. Because this was a descriptive study, with preliminary analysis of data, a correction for multiple comparisons, e.g., Bonferroni correction, was not used.

A non-parametric test, the Mann-Whitney U test, was used to compare DSES item means for high and low adherers. This statistical test was chosen because it can evaluate the difference in means for each item, when ranked for high and low adherence groups. Normally
distributed data are not required for the Mann-Whitney U test, although the distributions must be continuous and the scores on the test variable, i.e., item means, must be independent of each other (Green, Salkind, & Akey, 2000).

The next step in the analysis of survey results was the determination of bivariate correlations between: 1) the criterion variables and QLI-D scores; 2) the criterion variables and DSCA scores; and 3) QLI-D and DSCA total and subscale scores. In order to generalize beyond the sample statistic, and make inferences about the population, the relationships between variables must be linear and the sample must be representative of the population. Furthermore, the assumptions of normality and homoscedasticity must be met (Munro, 2001). The non-normal distributions of some of the variables may have masked the effects of these variables on the criterion variables.

The last step in the analysis of survey results was multiple regression analysis to test the effects of the linear combination of the criterion variables on 1) QLI-D scores and 2) DSCA scores. Multiple regression is the appropriate statistical procedure to determine whether there is a measurable multiple correlation between a group of predictor variables and one criterion variable (Munro, 2001). Multiple regression analysis provides information not only about the percent of variance explained by the model ($R^2$), but also about the relative contribution of each of the predictor variables to the variance in the criterion variable.

B. Diabetes Self-Efficacy

The mean total score for the Diabetes Self-Efficacy Scale (DSES) for this sample ($n = 91$) was 4.42 (SD = 0.79), with a range of 2.15 to 5.93 (maximum = 6, indicating highest self-efficacy). The mean subscale score for general self-efficacy (6 items) was 4.81 (SD = 1.04), with a range of 1.33 to 6.00. For diet self-efficacy (6 items), the mean score was 3.80 (SD = 1.10), with a range of 1.00 to 6.00. For medication self-efficacy (11 items), the mean score was 4.49 (SD = 0.87), with a range of 2.18 to 6.00.
A repeated measures ANOVA was performed to compare scores on the three subscales for the overall sample. Results indicated significant difference between one or more of the subscale scores (Wilks' $\Lambda = 0.36$, $F (2, 89) = 78.73$, $p < .001$). Pairwise contrasts between the subscales demonstrated that the diet subscale scores were significantly lower ($p < .001$) than the scores on the general and medication subscales.

Responses to individual items were examined in order to understand the significant findings of the ANOVA. It was interesting to note that the majority of respondents were confident about their ability to carry out most of their diabetes self-care activities, with 82.2% rating this item at 5 or 6 (6 = "strongly agree"). However, self-efficacy ratings were not consistently high across all self-care activities. Item scores were especially high for specific, concrete activities such as foot care, blood glucose testing, and taking medications on schedule. On the other hand, items that referred to the ability to make adjustments in self-care activities tended to receive lower ratings. For example, when asked about the ability to follow the diabetes plan when changes occurred in daily routine, only 63.8% rated the item at 5 or 6. Only 30.6% of respondents reported high level of ability to follow their diet plan at parties; 41.9% reported high level of ability to adjust diabetes self-treatment during illness; and 42.2% reported high level of ability to adjust medication dose based on blood glucose results.

As described above, the sample was divided into thirds, based on the total score for the Diabetes Self-Care Activities scale, in order to make comparisons between high and low adherers. Table III presents total and subscale scores for the three adherence groups.
### TABLE III

DIABETES SELF-EFFICACY TOTAL AND SUBSCALE SCORES FOR ADHERENCE GROUPS

<table>
<thead>
<tr>
<th></th>
<th>High Adherence Group (n = 27)</th>
<th>Middle Adherence Group (n = 29)</th>
<th>Low Adherence Group (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>General subscale</td>
<td>5.15 (0.86)</td>
<td>4.92 (0.90)</td>
<td>4.28 (1.20)</td>
</tr>
<tr>
<td>Diet subscale</td>
<td>4.18 (1.18)</td>
<td>4.08 (0.76)</td>
<td>3.07 (1.04)</td>
</tr>
<tr>
<td>Medication subscale</td>
<td>4.89 (0.97)</td>
<td>4.65 (0.78)</td>
<td>4.14 (0.82)</td>
</tr>
<tr>
<td>Total score</td>
<td>4.76 (0.75)</td>
<td>4.59 (0.58)</td>
<td>3.87 (0.80)</td>
</tr>
</tbody>
</table>

Comparison of mean total self-efficacy scores using t-test indicated significantly lower scores ($t = -4.23$, df 54, $p < .001$) for the low adherence group. Two-way repeated measures ANOVA was not significant when comparisons were made on the self-efficacy subscale scores for the high and low adherence groups ($\text{Wilks'} \Lambda = 0.916$, $F (4, 162) = 1.83$, $p = 0.13$).

In order to compare responses of the high and low adherence groups on the DSES, the items were ranked by item mean for the overall sample, with comparative rankings for high and low adherence groups (Table IV).

Examination of the differential means for DSES items revealed notable divergence between high and low adherers on two items in particular. For those in the high adherence group, the ability to fit diabetes self-care activities into the usual life style had the fifth highest ranking, with a mean item score of 5.48 (SD = 0.71). However, for those in the low adherence group, this item was ranked fourteenth, with a mean score for the item of 4.03 (SD = 1.72). Likewise, those in the high adherence group gave high ratings to the item that asked about ability to exercise several times a week, with an item mean of 5.34 (SD = 0.99), and a ranking of seventh. For those in the low adherence group this item ranked 21, with an item mean of 2.94 (SD = 1.61).
<table>
<thead>
<tr>
<th>ITEM</th>
<th>OVERALL (n = 85)</th>
<th>HIGH ADHERERS (n = 27)</th>
<th>LOW ADHERERS (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can take my medication according to the recommended schedule</td>
<td>1 (5.55, 0.84)</td>
<td>1.5 (5.70, 0.54)</td>
<td>1 (5.30, 1.16)</td>
</tr>
<tr>
<td>I can test my blood when I am away from home</td>
<td>2 (5.30, 1.40)</td>
<td>1.5 (5.70, 0.87)</td>
<td>2 (5.03, 1.74)</td>
</tr>
<tr>
<td>I can carry out practically all of the self-care activities in my daily diabetes routine</td>
<td>3 (5.22, 1.18)</td>
<td>3 (5.64, 0.68)*</td>
<td>4 (4.83, 1.54)*</td>
</tr>
<tr>
<td>I can take my medication when away from home</td>
<td>4 (5.10, 1.35)</td>
<td>6 (5.41, 1.12)</td>
<td>7.5 (4.59, 1.70)</td>
</tr>
<tr>
<td>I can routinely apply the recommended lotion to my feet</td>
<td>5 (5.07, 1.16)</td>
<td>8 (5.20, 1.21)</td>
<td>3 (4.92, 1.35)</td>
</tr>
<tr>
<td>I can figure out when to call my doctor about problems with my feet</td>
<td>6 (5.04, 1.44)</td>
<td>4 (5.60, 0.84)**</td>
<td>9 (4.24, 2.05)**</td>
</tr>
<tr>
<td>When I feel sick, I can test my blood more than I routinely do</td>
<td>7 (4.84, 1.48)</td>
<td>11 (4.99, 1.39)</td>
<td>7.5 (4.59, 1.84)</td>
</tr>
<tr>
<td>I feel sure about having to use what I know about diabetes self-treatment every day</td>
<td>8 (4.82, 1.55)</td>
<td>13 (4.82, 1.57)</td>
<td>5 (4.68, 1.63)</td>
</tr>
<tr>
<td>I can fit my diabetes self-treatment routine into my usual life style</td>
<td>9 (4.77, 1.40)</td>
<td>5 (5.48, 0.71)</td>
<td>14 (4.03, 1.72)**</td>
</tr>
<tr>
<td>I am confident in my ability to manage my diabetes</td>
<td>10 (4.72, 1.45)</td>
<td>9 (5.19, 1.33)**</td>
<td>10 (4.17, 1.54)**</td>
</tr>
<tr>
<td>I can recognize when my blood sugar is too high</td>
<td>11 (4.62, 1.55)</td>
<td>19 (4.33, 1.75)</td>
<td>6 (4.62, 1.45)</td>
</tr>
<tr>
<td>I think I'll be able to follow my diabetes plan even when my daily routine changes</td>
<td>12 (4.57, 1.31)</td>
<td>10 (5.07, 0.87)**</td>
<td>15 (3.86, 1.58)**</td>
</tr>
</tbody>
</table>
TABLE IV (continued)

RANK ORDER OF DIABETES SELF-EFFICACY ITEMS
BY ITEM MEAN FOR OVERALL GROUP

<table>
<thead>
<tr>
<th>ITEM</th>
<th>OVERALL (n = 85)</th>
<th>HIGH ADHERERS (n = 27)</th>
<th>LOW ADHERERS (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can follow my diabetes routines every single day</td>
<td>13 (4.54, 1.71)</td>
<td>15 (4.73, 1.65)</td>
<td>12.5 (4.09, 1.93)</td>
</tr>
<tr>
<td>I’ll be able to stay on my diabetic diet when the people around me don’t know that I have diabetes</td>
<td>16 (4.39, 1.62)</td>
<td>12 (4.83, 1.35)</td>
<td>12.5 (4.09, 1.83)</td>
</tr>
<tr>
<td>I can exercise several times a week</td>
<td>17 (4.15, 1.70)</td>
<td>7 (5.34, .99)**</td>
<td>21 (2.94, 1.61)**</td>
</tr>
<tr>
<td>I can figure out what to do about my medication dose when changes occur in my usual routine</td>
<td>18 (4.11, 1.72)</td>
<td>22 (4.14, 1.89)</td>
<td>17 (3.81, 1.78)</td>
</tr>
<tr>
<td>I can figure out what self-treatment to administer when my blood sugar gets higher than it should be</td>
<td>19 (3.99, 1.92)</td>
<td>16.5 (4.66, 1.78)**</td>
<td>19 (3.14, 1.96)**</td>
</tr>
<tr>
<td>I can exercise even if I don’t feel like exercising</td>
<td>20 (3.89, 1.58)</td>
<td>16.5 (4.66, 1.39)**</td>
<td>22 (2.92, 1.60)**</td>
</tr>
<tr>
<td>I can stay on my diabetic diet when I eat in familiar places away from home (such as at a friend’s house)</td>
<td>21 (3.84, 1.47)</td>
<td>20 (4.30, 1.41)**</td>
<td>25.5 (2.83, 1.37)**</td>
</tr>
<tr>
<td>I’ll be able to follow my diabetic diet every day</td>
<td>22 (3.73, 1.68)</td>
<td>25 (3.95, 1.87)</td>
<td>20 (3.13, 1.57)</td>
</tr>
<tr>
<td>I can adjust my diabetes self-treatments if I get a cold or the flu</td>
<td>23 (3.68, 1.86)</td>
<td>24 (4.02, 1.77)</td>
<td>18 (3.57, 1.99)</td>
</tr>
<tr>
<td>When I go to parties, I can follow my diet plan</td>
<td>24 (3.62, 1.46)</td>
<td>26 (3.73, 1.43)</td>
<td>23.5 (2.88, 1.44)</td>
</tr>
<tr>
<td>I can stay on my diabetic diet when I eat in unfamiliar places</td>
<td>25 (3.61, 1.44)</td>
<td>23 (4.04, 1.51)**</td>
<td>25.5 (2.83, 1.20)**</td>
</tr>
<tr>
<td>I can eat my meals at the same time every day</td>
<td>26 (3.41, 1.55)</td>
<td>21 (4.22, 1.45)**</td>
<td>27 (2.67, 1.52)**</td>
</tr>
<tr>
<td>I can adjust my medication dose based on the results of my blood tests</td>
<td>27 (3.25, 1.88)</td>
<td>27 (3.39, 2.03)</td>
<td>23.5 (2.89, 1.78)</td>
</tr>
</tbody>
</table>

* difference in item mean between high and low adherers is significant at p < .05;
** difference in item mean between high and low adherers is significant at p < .01
Examination of items that had lower means overall indicated that respondents had lower levels of self-efficacy with regard to making adjustments in diet, medication, or other self-care activities during unusual circumstances, e.g., when at a party or when sick. Considerable disparity between the two groups was present on the item that asked about ability to recognize when blood sugar is too high. Although the absolute difference in item means was not large, the difference in rankings for the item was striking. For the low adherence group this item ranked sixth, with a mean of 4.62 (SD = 1.45), while for the high adherence group, this item ranked much lower, at nineteenth, with a mean of 4.33 (SD = 1.75). This was the only item for which the low adherence group’s mean score was higher than the high adherence group.

A non-parametric procedure (Mann-Whitney U) was used to determine if there were significant differences between item means for the high and low adherence groups. Ten items had differences in item means that were significant at \( p < .01 \), and for one other item the difference in mean between high and low adherers was significant at \( p < .05 \). Low adherers assigned lower scores to items related to overall confidence in managing diabetes and carrying out recommended self-care activities, confidence in the ability to exercise on a regular basis, ability to maintain consistency in mealtimes and to follow diet even when away from home, and ability to make adjustments in self-care when blood glucose levels are higher than usual.

Finally, total self-efficacy scores were examined for differences in the sample related to duration of diabetes diagnosis, gender, and education. A significant difference (\( t = 2.51, \text{df} = 57, p < .05 \)) was found in the total self-efficacy score between those individuals who had been diagnosed between one to 2.5 years (\( n = 28; \text{mean score} = 4.80; \text{SD} = 0.53 \)) and those who had lived 10 or more years (\( n = 31; \text{mean score} = 4.34; \text{SD} = 0.82 \)) with the diagnosis of diabetes. Those who had been living with diabetes for a longer time had lower total scores than those who had been diagnosed more recently. However, two-way repeated measures ANOVA failed to demonstrate significant differences on the self-efficacy subscale scores based on disease duration. Likewise, the differences in mean total and subscale scores between males and
females was not significant. Finally, comparison of scores for those with and without college education did not demonstrate significant difference.

C. Appraisal of Illness Demand

The minimum possible score on the Appraisal of Diabetes Scale (ADS) is 7.00 and the maximum possible score is 35.00. Higher scores indicate perception of greater illness demand, i.e. burden due to diabetes. The mean ADS score for this sample was 17.84 (SD = 5.05), with a range of 9.00-33.00. Item means ranged from a high of 2.91 (maximum score = 5.0) to a low of 2.13.

The mean total ADS score for those in the low adherence group was 20.93 (SD = 5.08), while the mean for the high adherence group was 15.79 (SD = 3.22). Student's t-test comparison of mean total ADS scores demonstrated a significantly higher (t = 4.60, df 56, p < .001) score, indicating greater illness demand, for those in the low adherence group.

Comparisons of mean total ADS scores using t-test showed no significant difference between males (mean = 16.89, SD = 4.86, n = 35) and females (mean = 18.50, SD = 5.13, n = 58); neither was a difference demonstrated for those with college (mean = 17.72, SD = 5.01, n = 57) as opposed to those without college education (mean = 18.17, SD = 5.21, n = 36). However, those who had the longest duration since diabetes diagnosis (10 years or more) had a significantly higher ADS total score (mean = 18.69, SD = 5.28, n = 32), indicating greater perception of illness burden, than those who were diagnosed within the past 2.5 years (mean = 15.25, SD = 3.15, n = 29) (t = -3.05, df 59, p < .01).

D. Family Support

The Diabetes Family Behavior Checklist (DFBC) measures family behaviors that are both supportive (DFBC+) and non-supportive (DFBC-) to the person with diabetes. Positive and negative behavior items were analyzed separately in order to yield two scores. Nine respondents did not complete the DFBC, as they lived alone and were not in close contact with any family members.
It should be noted that mean total scores for both the positive and negative scales of the DFBC fell in the lower half of the possible range of scores. Examination of both scales showed that respondents gave a score of "1", indicating that the behavior "never" occurred, for the majority of items in both scales. This was a surprising finding, which indicated that overall this sample did not receive, and possibly did not expect, a great deal of involvement of family members in their diabetes self-care management.

1. **Supportive family behaviors**

   The nine positive items, indicating supportive family behaviors, included the following:
   
   - "praise you for following your diet;"
   - "suggest things to help you take your medication on time;"
   - "help you decide if changes should be made based on glucose testing results;"
   - "encourage you to participate in sports activities;"
   - "plan family activities so that they will fit in with your diabetes self-care schedule;"
   - "congratulate you for sticking to your diabetes self-care schedule;"
   - "eat at the same time you do;"
   - "exercise with you;" and
   - "buy you things containing sugar to carry in case of an insulin reaction."

   Scores for this sample on the DFBC+ scale ranged from a low of 9.00 to a high of 45.00. The mean score was 17.57 (SD = 6.75), which fell in the lower half of the possible range for scores, indicating less frequency of supportive family behaviors.

   Six of the nine items had median scores of 1.00, corresponding to "never" on the Likert scale. The items that asked how often a family member gives praise for following the diet and how often a family member provides congratulations for adhering to the diabetes self-care regimen had median scores of 2.00, which correspond to the behavior being exhibited "twice a
month." The item with the highest mean (item mean = 3.72, SD = 1.48) asked respondents to indicate how frequently the family member eats at the same time. The median for this item, 4.00, indicates that on average, the family member eats at the same time as the respondent "several times a week."

When mean total scores on the positive family behavior scale were compared for high and low adherers, the difference was not statistically significant. Likewise, comparisons for males versus females; for shorter versus longer duration since diabetes diagnosis; and for individuals with and without college education demonstrated no significant differences.

2. **Non-supportive family behaviors**

The seven negative, i.e., non-supportive, items included the following:

- "nag you about testing your glucose level;"
- "criticize you for not exercising regularly;"
- "nag you about following your diet;"
- "argue with you about your diabetes self-care activities;"
- "criticize you for not recording the results of glucose tests;"
- "let you sleep late rather than getting up to take your medication;"
- "eat foods that are not part of your diabetic diet."

Scores for this sample on the non-supportive behaviors ranged from 7.00 to 31.00 (maximum score = 35.00), with a mean of 13.36 (SD = 4.44). Again, the mean score for non-supportive (negative) behavior items was in the lower half of the possible range.

As with the positive behavior scale, the majority of non-supportive family behaviors—five out of seven items—had median scores of 1.00, corresponding to "never." The negative item with the highest median score, 4.00 (mean = 3.37, SD = 1.44) related to the family member eating foods that are not on the diabetic diet. The median score indicated that on average, the negative behavior occurred several times a week.
Comparisons based on level of adherence, gender, education, and diabetes duration demonstrated no significant differences between the various groups for the non-supportive behavior items.

E. Satisfaction With Care

The mean total score on the Satisfaction With Care Scale (SWC) was 5.51 (SD = 0.60), with a range of 2.94 to 6.00. Nearly 86% of respondents had a mean total score of 5.00 or greater, indicating a very high level of satisfaction with their medical care. This sample was deliberately drawn from a comprehensive center where clients received care that corresponded to the highest standards for diabetes care. The high mean total SWC score confirmed that most participants perceived that their care was excellent.

Student's t-test comparisons for persons in the high and low adherence groups showed no significant difference between the two groups in mean total score. Likewise, differences in mean total scores for males and females and for those with and without college education were not statistically significant. Furthermore, there was no difference found for those with shorter versus those with longer duration of time since diagnosis.

F. Quality of Life

Total QLI-D scores for this sample ranged from 8.59 to 29.00, with a mean total score of 21.10 (SD = 4.38). The maximum total score possible on the QLI-D is 30.00, with higher scores indicating better quality of life. Means for total and subscale scores for the total sample, high and low adherence groups, and college/no college groups are presented in Table V.
A one-way repeated measures ANOVA was conducted to compare QLI-D subscale scores for the sample. Results indicated a significant difference between the subscales, Wilks' $\Lambda = 0.55, F (3, 84) = 23.17, p < .001$. Post hoc pairwise contrasts among the means of the four subscales were conducted. The health and functioning subscale score was found to be significantly lower ($p < .001$) than the scores on the social/economic, psychological/spiritual, and family subscales.

Student's t-test comparisons for high and low adherers indicated that those in the low adherence group had significantly lower total QLI-D scores than the high adherers ($t = -3.60, df = 51, p < .01$). Two-way repeated measures ANOVA demonstrated significant difference in QLI-D subscale scores between low and high adherers (Wilks' $\Lambda = 0.811, F (6, 154) = 2.828, p < .05$). Post hoc pairwise contrasts demonstrated significant difference ($p < .001$) between the scores on the health/functioning and social/economic subscales. It should be noted that the mean total score for individuals in the high adherence group was 4.42 points.
higher than the mean total score for those in the low adherence group. A two or three-point difference in scores is considered a clinically significant difference in perception of quality of life.

Those without college education had significantly lower scores for the total QLI-D than did those with college education ($t = -2.19$, $df = 84$, $p < .05$). However, two-way repeated measures ANOVA failed to demonstrate significant difference in QLI-D subscale scores based on education. No significant differences on total QLI scores or any of the subscale scores were found for gender or length of time since diagnosis.

G. **Diabetes Self-Care Activities Scale**

The Diabetes Self-Care Activities Scale (DSCA) was used as the measure of adherence to self-care regimen. Because some DSCA items are rated on a scale of 0-100% and others are rated on a scale of 0-7 days, all item scores were standardized by converting to z scores. Means of the z scores for items pertaining to each of the three subscales—diet, exercise, and blood glucose testing—were obtained, and then summed for the total adherence score. Five items pertained to diet self-care activities; three to exercise self-care activities; and two to glucose testing. One item asked the respondent to rate their adherence to recommended insulin injections and one item rated adherence to recommended number of pills of diabetes medications. The medication items were not included in the total adherence score due to very high level of adherence to medication recommendations, with 98% of the sample indicating they took all their injections or pills as recommended. Scores for the total scale and each of the subscales are shown in Table VI.
TABLE VI

TOTAL AND SUBSCALE SCORES FOR DIABETES SELF-CARE ACTIVITIES SCALE

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet subscale</td>
<td>-7.10E-04</td>
<td>0.75</td>
<td>-2.32</td>
<td>1.45</td>
</tr>
<tr>
<td>Exercise subscale</td>
<td>2.76</td>
<td>1.92</td>
<td>0.33</td>
<td>6.33</td>
</tr>
<tr>
<td>Glucose testing</td>
<td>1.13E-15</td>
<td>0.90</td>
<td>-2.27</td>
<td>0.68</td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td>2.76</td>
<td>2.63</td>
<td>-4.26</td>
<td>8.21</td>
</tr>
</tbody>
</table>

One-way repeated measures ANOVA revealed significant difference among the three subscale scores of the DSCA (Wilks’ $\Lambda = 0.30, F(2, 85) = 98.58, p < .001$). Post hoc pairwise comparisons between subscales indicated that there was a significant difference ($p < .001$) between the exercise subscale scores and scores on the diet and glucose testing subscales.

1. **Diet**

The diet subscale score was computed as the mean of the z scores for the five diet items. Diet subscale scores are reported in Table VI. A two-way repeated measures ANOVA to evaluate the effect of adherence level on diet subscale scores indicated that scores for diet were significantly lower than the exercise scores ($p < .001$), but not significantly different from glucose testing scores. Subscale scores for males and females and for those with and without college education were not significantly different, nor was there a difference noted in diet subscale scores for those who were diagnosed 2.5 years or less compared with those who were diagnosed more than 10 years ago. The diet adherence subscale score was moderately correlated with the diet subscale score from the DSES ($r = 0.63, p < .001, n = 87$).

2. **Exercise**

The exercise subscale score was computed as the mean of the z scores for the three exercise items. Subscale scores are reported in Table VI. There were no significant differences found in exercise subscale scores when comparisons were made for gender,
education level, and diabetes duration. As noted above, however, exercise subscale scores were significantly higher than diet scores, when adherence levels were compared using two-way repeated measures ANOVA.

3. **Blood glucose testing**

The glucose testing subscale score was the mean of the z scores for the two items related to blood glucose testing. Subscale scores are reported in Table VI. There were no significant differences in glucose testing scores between males and females, between those with and without college education, between those with shorter and longer duration of disease, or between those with higher or lower levels of adherence.

4. **Overall adherence**

The total adherence score was computed as the sum of the three subscale scores. Total scores for the sample ranged from -4.26 to 8.21. The mean was 2.76, with standard deviation 2.63. There were no significant differences in mean total scores when comparisons were made for gender, education level, and disease duration. The total adherence score was moderately correlated with the general care subscale of the DSES (r = 0.44, p < .001).

Total scores on the DSCA were significantly different (t = -18.79, df = 56, p < .001) for those in the high adherence group (mean = 5.69, SD = 0.92) in comparison with the low adherence group (mean = -0.15, SD = 1.40). Post hoc comparisons using Scheffe's test demonstrated significant differences (p < .001) among all three levels of adherence groups for the total adherence score.

H. **Relationships Among the Variables**

1. **Bivariate correlations**

Bivariate correlations were computed between each of the criterion variables—quality of life and adherence—and each of the predictor variables—self-efficacy, illness demand, supportive family behaviors, non-supportive family behaviors, and satisfaction with care.
Correlations between each criterion variable and the set of predictor variables will be described separately.

a. Quality of life

Correlations among the four QLI-D subscales are presented in Table VII. All subscale scores were significantly correlated with each other at \( p < .01 \). Coefficient \( r \) ranged from a high of 0.85 for the correlation between the health/functioning and psychological/spiritual subscales to a low of 0.54 for the correlation between the psychological/spiritual and family subscales.

**TABLE VII**

CORRELATIONS AMONG QLI-D TOTAL AND SUBSCALE SCORES\(^{a,b}\)

<table>
<thead>
<tr>
<th></th>
<th>Total QLI-D score</th>
<th>Health/functioning subscale</th>
<th>Social/economic subscale</th>
<th>Psychological/spiritual subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health/functioning</td>
<td>.96</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social/economic</td>
<td>.80</td>
<td>.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>.89</td>
<td>.85</td>
<td>.65</td>
<td></td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>.78</td>
<td>.68</td>
<td>.58</td>
<td>.54</td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^{a}\) \( n = 87 \)

\(^{b}\) All \( r \)'s significant at \( p < .01 \)

Table VIII shows correlations among QLI-D total and subscale scores and the total scores on the measures of the predictor variables. Relationships among all variables were statistically significant, with the exception of correlations between QLI-D scores and scores for non-supportive family behaviors.
The moderate correlations between QLI-D total and subscale scores and the self-efficacy score indicated an association between perception of better QOL in all of its domains and increased level of self-efficacy. The negative correlation between QLI-D score and the total score on the ADS, the measure of illness demand, was also in the moderate range, indicating decline in QOL perception as perception of illness demand increased. Likewise, all QLI-D subscales except for the social/economic subscale had correlations with the total ADS score that were in the moderate range. QLI-D total and subscale scores had weak correlations with satisfaction with care score and supportive family behaviors. However, the relationships between QLI-D scores and the score for non-supportive family behaviors were not significant.

**TABLE VIII**

<table>
<thead>
<tr>
<th>QLI-D Score (n = 87)</th>
<th>Self-Efficacy Score (n = 84)</th>
<th>Illness Demand Score (n = 87)</th>
<th>Supportive Family Behavior Score (n = 81)</th>
<th>Non-Supportive Family Behavior Score (n = 81)</th>
<th>Satisfaction With Care Score (n = 84)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score</td>
<td>.60**</td>
<td>- .55**</td>
<td>.29**</td>
<td>-.13</td>
<td>.33**</td>
</tr>
<tr>
<td>Health/Functioning</td>
<td>.63**</td>
<td>- .60**</td>
<td>.22*</td>
<td>-.14</td>
<td>.32**</td>
</tr>
<tr>
<td>Social/economic</td>
<td>.37**</td>
<td>- .27**</td>
<td>.31**</td>
<td>-.15</td>
<td>.26*</td>
</tr>
<tr>
<td>Psychological/Spiritual</td>
<td>.57**</td>
<td>- .45**</td>
<td>.26*</td>
<td>-.16</td>
<td>.28**</td>
</tr>
<tr>
<td>Family</td>
<td>.37**</td>
<td>- .43**</td>
<td>.26*</td>
<td>-.16</td>
<td>.28**</td>
</tr>
</tbody>
</table>

** correlation is significant at p <0.01 (2-tailed); * correlation is significant at p <0.05 (2-tailed)

c. Adherence

Correlations among the total and subscale scores for the DSCA are presented in Table IX.
TABLE IX
CORRELATIONS AMONG DSCA TOTAL AND SUBSCALE SCORES *

<table>
<thead>
<tr>
<th></th>
<th>Diet</th>
<th>Exercise</th>
<th>Glucose Testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise subscale</td>
<td>.31**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glucose testing</td>
<td>.35**</td>
<td>.14</td>
<td></td>
</tr>
<tr>
<td>Total adherence</td>
<td>.64**</td>
<td>.87**</td>
<td>.54**</td>
</tr>
</tbody>
</table>

*Correlation is significant at p < .01 (2-tailed)

a n = 87

Examination of the bivariate correlations between the total adherence score and the three adherence subscales demonstrated a strong correlation between the total adherence score and the exercise subscale score; marginally strong correlation between the total adherence score and the diet subscale score; and moderate correlation between total adherence score and the glucose testing subscale. The dietary score had weak but statistically significant correlations with the exercise score and the glucose testing score. However, the correlation between the exercise score and the glucose testing score was not significant.

Table X shows correlations among total adherence score, adherence subscale scores, and scores on the measures of the predictor variables.
### TABLE X
CORRELATIONS AMONG DSCA SCORES AND PREDICTOR VARIABLES

<table>
<thead>
<tr>
<th></th>
<th>Self-Efficacy Score (n = 91)</th>
<th>Illness Demand Score (n = 91)</th>
<th>Supportive Family Behavior Score (n = 83)</th>
<th>Non-Supportive Family Behavior Score (n = 83)</th>
<th>Satisfaction With Care Score (n = 89)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Adherence Score</td>
<td>.60**</td>
<td>-.46**</td>
<td>.21</td>
<td>-.11</td>
<td>.31**</td>
</tr>
<tr>
<td>Diet Subscale</td>
<td>.59**</td>
<td>-.42**</td>
<td>.08</td>
<td>-.10</td>
<td>.23*</td>
</tr>
<tr>
<td>Exercise Subscale</td>
<td>.28**</td>
<td>-.27**</td>
<td>.10</td>
<td>-.12</td>
<td>.14</td>
</tr>
<tr>
<td>Glucose Testing Subscale</td>
<td>.30 **</td>
<td>-.13</td>
<td>.28**</td>
<td>.02</td>
<td>.29**</td>
</tr>
</tbody>
</table>

**Correlation is significant at $p < 0.01$ (2-tailed); * Correlation is significant at $p < 0.05$ (2-tailed)

*a n = 85 for total and subscale adherence scores

Scores on the measure of adherence correlated at 0.01 level of significance with scores on all of the measures of the predictor variables, with the exception of supportive and non-supportive family behaviors. The moderate negative correlation ($r = -0.46$) between adherence and illness demand suggests that decreased level of adherence to regimen is associated with increased perception of illness demand. Self-efficacy had correlations in the moderate range with total adherence score and the diet subscale, and weak correlations with the exercise and glucose testing subscale scores. The relationships between illness demand score and all three adherence subscale scores were in the expected negative direction; correlations reached significance for diet and exercise, but not for glucose testing. Neither supportive nor non-supportive family behaviors correlated significantly with adherence behaviors, except for a weak correlation between supportive behaviors and the glucose testing subscale.
c. Relationships between quality of life and adherence

Correlations among total and subscale QLI-D scores and scores on the DSCA are presented in Table XI.

<table>
<thead>
<tr>
<th></th>
<th>Total adherence score</th>
<th>Diet subscale</th>
<th>Exercise subscale</th>
<th>Glucose test subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total QLI-D score</td>
<td>.47***</td>
<td>.36**</td>
<td>.33**</td>
<td>.36**</td>
</tr>
<tr>
<td>Health/functioning</td>
<td>.50**</td>
<td>.35**</td>
<td>.37**</td>
<td>.38**</td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social/economic</td>
<td>.25*</td>
<td>.23*</td>
<td>.14</td>
<td>.23*</td>
</tr>
<tr>
<td>subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological/spiritual subscale</td>
<td>.48**</td>
<td>.36**</td>
<td>.36**</td>
<td>.34**</td>
</tr>
<tr>
<td>Family subscale</td>
<td>.25*</td>
<td>.24*</td>
<td>.14</td>
<td>.21</td>
</tr>
</tbody>
</table>

**Correlation is significant at p < .001 (2-tailed); *Correlation is significant at p < .05 (2-tailed)

a n = 82 for QLI-D total and subscale scores

b n = 87 for adherence total and subscale scores

The overall correlation between total QLI-D score and total adherence score was moderate. The total QLI-D score demonstrated significant (p < .01) correlations in the moderate range with the dietary, exercise, and glucose testing subscales, indicating that adherence to self-care behaviors was associated with perception of better QOL. Likewise, the total adherence score had significant (p < .01) correlations with all subscales of the QLI-D. Weak correlations were demonstrated between the social/economic and family subscales and the total DSCA score, while correlations between the health/functioning and psychological/spiritual subscales and the total DSCA score were in the moderate range.
2. Regression analyses

a. Adherence to regimen

Multiple regression analysis was conducted to evaluate how well self-efficacy, perception of illness demand, supportive or non-supportive family behaviors, and satisfaction with care predicted adherence to diabetes self-care regimen. The linear combination of predictor variables was significantly related to adherence, $F (5, 71) = 8.13, p = .001$. The sample multiple correlation coefficient was 0.60, and the $R^2$ was 0.36, indicating that approximately 36% of the variance in adherence to regimen in the sample can be accounted for by the linear combination of the predictor variables.

Table XII presents standardized coefficients (Betas), zero-order (bivariate) and partial correlations to indicate the relative strength of each of the predictors.

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized Coefficients (Betas)</th>
<th>Bivariate correlation between each predictor and adherence to regimen</th>
<th>Partial correlation between each predictor and adherence controlling for all other predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>.46**</td>
<td>.59</td>
<td>.37</td>
</tr>
<tr>
<td>Illness demand</td>
<td>-.13</td>
<td>-.46</td>
<td>-.12</td>
</tr>
<tr>
<td>Supportive family behaviors</td>
<td>.10</td>
<td>.21</td>
<td>.10</td>
</tr>
<tr>
<td>Non-supportive family behaviors</td>
<td>-.09</td>
<td>-.10</td>
<td>-.10</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>.02</td>
<td>.25</td>
<td>.02</td>
</tr>
</tbody>
</table>

**$p < .01$**
The model summary for regression of adherence on the five predictor variables is shown in Table XIII. The regression analysis indicated that self-efficacy was a strong predictor of adherence to diabetes self-care regimen for this group ($R^2 = 0.35$), accounting for 35% of the variance in adherence. The other four variables contributed only 1% additional.

**Table XIII**

<table>
<thead>
<tr>
<th>Model</th>
<th>$R$</th>
<th>$R^2$</th>
<th>$R^2$ Change</th>
<th>$F$ Change</th>
<th>Sig. $F$ Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE</td>
<td>.589</td>
<td>.348</td>
<td>.348</td>
<td>39.944</td>
<td>.000</td>
</tr>
<tr>
<td>SE + ADS</td>
<td>.596</td>
<td>.355</td>
<td>.007</td>
<td>.844</td>
<td>.361</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+)</td>
<td>.598</td>
<td>.358</td>
<td>.003</td>
<td>.303</td>
<td>.583</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+) + DFBC (-)</td>
<td>.603</td>
<td>.364</td>
<td>.006</td>
<td>.711</td>
<td>.402</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+) + DFBC (-) + SWC</td>
<td>.603</td>
<td>.364</td>
<td>.000</td>
<td>.020</td>
<td>.889</td>
</tr>
</tbody>
</table>

b. **Quality of life**

A second multiple regression analysis was conducted to evaluate how well the five predictor variables predicted QOL. The linear combination of predictor variables was significantly related to QOL. The sample multiple correlation coefficient was 0.72, and the $R^2$ was 0.52, indicating that approximately 52% of the variance in perception of quality of life can be accounted for by the linear combination of the predictor variables.
Standardized coefficients (Betas), zero-order (bivariate) and partial correlations are shown in Table XIV.

**TABLE XIV**

STANDARDIZED COEFFICIENTS AND BIVARIATE AND PARTIAL CORRELATIONS OF THE PREDICTORS WITH QUALITY OF LIFE

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized Coefficients (Betas)</th>
<th>Bivariate correlation between each predictor and quality of life</th>
<th>Partial correlation between each predictor and quality of life controlling for all other predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>.30*</td>
<td>.63</td>
<td>.29</td>
</tr>
<tr>
<td>Illness demand</td>
<td>-.31**</td>
<td>-.57</td>
<td>-.31</td>
</tr>
<tr>
<td>Supportive family behaviors</td>
<td>.29**</td>
<td>.39</td>
<td>.33</td>
</tr>
<tr>
<td>Non-supportive family behaviors</td>
<td>-.09</td>
<td>-.03</td>
<td>-.12</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>.09</td>
<td>.36</td>
<td>.12</td>
</tr>
</tbody>
</table>

**p < .01  *p < 0.05

Regression analysis (Table XV) indicated that self-efficacy accounted for approximately 40% of the variance in total quality of life score. Supportive family behaviors accounted for an additional 6% and illness demand perception explained 4%. Together, the linear combination of the five predictor variables explained approximately 52% of the variance in total quality of life scores.
TABLE XV
MODEL SUMMARY FOR REGRESSION OF QUALITY OF LIFE ON THE PREDICTOR VARIABLES

<table>
<thead>
<tr>
<th>Model</th>
<th>R</th>
<th>R²</th>
<th>R² Change</th>
<th>F Change</th>
<th>Sig. F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE</td>
<td>.631</td>
<td>.40</td>
<td>.40</td>
<td>49.03</td>
<td>.000</td>
</tr>
<tr>
<td>SE + ADS</td>
<td>.664</td>
<td>.44</td>
<td>.04</td>
<td>5.48</td>
<td>.022</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+)</td>
<td>.708</td>
<td>.50</td>
<td>.06</td>
<td>8.74</td>
<td>.004</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+) + DFBC (-)</td>
<td>.714</td>
<td>.51</td>
<td>.01</td>
<td>1.27</td>
<td>.264</td>
</tr>
<tr>
<td>SE + ADS + DFBC (+) + DFBC (-) + SWC</td>
<td>.719</td>
<td>.516</td>
<td>.006</td>
<td>.94</td>
<td>.336</td>
</tr>
</tbody>
</table>

I. **Summary**

A summary of the major findings related to the results for each of the variables is presented below.

1. **Self-efficacy**

Subjects in this sample reported higher levels of self-efficacy for self-care behaviors related to diabetes medications, blood glucose testing, and foot care. Lower levels of self-efficacy were reported for diet behaviors and self-care behaviors that were necessary in order to adjust for changes in daily routine or health status. High adherers had significantly higher total self-efficacy scores than low adherers. Those in the low adherence group reported greater difficulty in fitting their diabetes self-care activities into their usual lifestyle, as well as greater difficulty in the ability to exercise several times a week. There was a significant difference based on disease duration, with longer duration associated with lower self-efficacy. No difference in self-efficacy scores due to gender or education level was demonstrated.
2. **Illness demand**

Those in the high adherence group had significantly lower scores on the measure of illness demand, indicating lower perception of burden due to diabetes regimen. Persons with longer duration of diabetes reported significantly higher level of illness demand. However, no difference in illness demand was demonstrated due to gender or education level.

3. **Family behaviors**

The majority of items on the scale of supportive (positive) family behaviors were rated as “never” occurring. This was reflected by the total score, which was in the lower half of the possible range. The family member eating meals at the same time as the subject was the most frequently reported positive family behavior. No difference was seen in supportive family behaviors due to adherence level, gender, education level, or disease duration.

Again, the overall score for non-supportive (negative) family behaviors was in the lower half of the possible range of scores, with the majority of items rated as “never” occurring. The most frequently reported negative behavior was the family member eating foods that are not part of the diabetic diet. There was no difference in negative family behavior score based on adherence level, gender, education level, or disease duration.

4. **Satisfaction with care**

The sample reported very high levels of satisfaction with care, an expected finding since this sample was drawn from the clients of a comprehensive diabetes treatment center that adheres to the highest recommended standards of care. No differences in satisfaction with care were found for gender or for varying levels of adherence, education, or disease duration.

5. **Quality of life**

Scores on the health/functioning subscale were significantly lower than other subscale scores. QLI-D total and subscale scores correlated at weak to moderate levels with all of the predictor variables except non-supportive family behaviors. All correlations were in the expected direction. Moderate correlations between total QLI-D score and self-efficacy and
illness demand scores indicated that increased QOL was associated with increased self-efficacy, while decreased QOL was associated with increased illness demand. Significantly higher QLI-D total and subscale scores were found in the high adherence group. Higher total scores, though not subscale scores, were found in the group with college education.

6. **Diabetes self-care activities (adherence)**

The diet and glucose testing subscales were moderately correlated with the DSCA total score, while the exercise subscale had a strong correlation with total DSCA score. All three subscales correlated weakly with each other. Increased overall adherence, as demonstrated by the total DSCA score, was moderately associated with increased self-efficacy, as was dietary adherence. Exercise and glucose testing behaviors demonstrated weak correlations with self-efficacy score. Increased level of illness demand was associated with decreased level of adherence. A weak correlation was observed between adherence scores and satisfaction with care. The total adherence and total QLI-D scores were moderately correlated. Total adherence score correlated with all subscales of the QLI-D, with moderate correlations observed between adherence score and the health/functioning and psychological/spiritual subscales.

Total DSCA scores were significantly different among the three adherence level groups, but no difference was demonstrated in the total DSCA score due to gender, education, or disease duration. Exercise subscale scores were significantly higher than the scores for diet or glucose testing. An interaction effect between adherence level and DSCA subscale scores was demonstrated, with scores for all three subscales significantly higher in the high adherence group. No differences were observed in the diet, exercise, or glucose testing subscale scores due to gender, education level, or disease duration.

7. **Regression analysis**

The predictor variables accounted for 36% of the variability in total adherence score. However, self-efficacy alone accounted for 35% of the variability, with the other four predictors contributing only an additional 1%. Multiple regression analysis demonstrated that the predictor
variables accounted for 52% of the variability in QLI-D score. Again, self-efficacy was responsible for the largest amount of variance, 40%, with illness demand, family behaviors, and satisfaction with care contributing an additional 12%.
V. RESULTS: INTERVIEW DATA

A. Method of Analysis

Data obtained from the interviews were analyzed in order to clarify, explain, and augment the quantitative survey data. The ATLAS.ti software program for qualitative data analysis was used for coding and analysis of the interview data. A preliminary code structure was determined a priori, based upon the conceptual framework of the study (Miles & Huberman, 1994). Codes were created for self-efficacy, illness demand, helpful and unhelpful behaviors, satisfaction with care, quality of life, and adherence. Modifier codes, such as “high,” “low,” “positive,” “negative,” “work,” and “home” were also created.

The code structure was further delineated as coding of each transcribed interview proceeded, with the addition of sub-categories within each code family. For example, “helpful” and “unhelpful” behaviors were also coded according to the agent, i.e., “spouse,” “family,” or “non-family.” In some cases, a comment by a participant seemed particularly illustrative of a response that was echoed by others. For example, the statement, “I know what to do, but I just don’t do it,” or a comment that expressed a similar idea, was made by several of the participants in the low adherence group. These comments were entered into the code structure as in vivo codes. Coding of interviews proceeded in an iterative manner; as new codes were added, previous interviews were reviewed and re-coded as necessary. The final list of codes is presented in Appendix C.

When all interviews were coded, the ATLAS.ti query function was used to combine codes and retrieve relevant quotations from the texts. For example, “self-efficacy,” “high,” and “diet” were combined to create a “super-code” that enabled retrieval of all quotations that had been coded with those three terms. In this way, quotations could be retrieved for various
modifications and combinations of code terms, for example, high or low self-efficacy as related to each aspect of diabetes self-care management.

Interview texts were also grouped into "document families" to enable clustering of data according to high, low, or medium levels of adherence. Assignment to adherence level was based upon the participant's self-report during the interview; the participant's total score on the DSCA; and, where possible, the rating of the individual's adherence level by staff of the diabetes center. Agreement between any two of the three criteria was considered sufficient for assignment of the interview to the adherence level. This process resulted in a group of six interviews that were exemplars of high adherence and seven interviews that were exemplars of low adherence.

Lastly, matrix outputs were created for specific code families within the high and low adherence groups. The matrices allowed comparisons between the two groups in terms of the frequencies with which designated codes appeared within each interview. The results of analysis of the outputs for each code family are described in the following sections. In each table, number of interviewees in the high or low adherence group who made statements that were classified to a particular code is reported as the frequency. The corresponding percentage of interviewees is reported alongside.

B. Self-efficacy

Self-efficacy codes for those in the high and low adherence groups are presented in Table XVI.

The code "high self-efficacy" was used for statements indicating that the interviewee was confident in his or her ability to perform a specific aspect of self-care regimen. Everyone in the high adherence group made statements during the interview that were coded for high self-efficacy. The code "low self-efficacy" was used to indicate statements about being unable to
perform a specific self-care behavior. Half of the high adherence interviewees made statements that were coded to low self-efficacy, reflecting the observation that adherence to regimen behaviors is rarely universal. For example, two high adherers made statements reflecting problems with resisting the temptation of cookies or other sweets, while one high adherer described lack of adherence to the prescribed schedule for glucose testing.

**TABLE XVI**

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High self-efficacy</td>
<td>6 (100)</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Low self-efficacy</td>
<td>3 (50)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>&quot;I know what to do, but I just don't do it&quot;</td>
<td>0 (0)</td>
<td>6 (86)</td>
</tr>
<tr>
<td>Sense of personal responsibility</td>
<td>3 (50)</td>
<td>3 (43)</td>
</tr>
<tr>
<td>Able to adjust to changes in daily routine</td>
<td>3 (50)</td>
<td>3 (43)</td>
</tr>
</tbody>
</table>

* number and percentage of interviews that included statements for the code

The opposite occurred in the low adherence group of interviewees, with 100% making statements that coded to low self-efficacy. High self-efficacy statements were made by 71% of the low adherence interviewees, again reflecting good adherence to specific self-care behaviors, even in those whose overall adherence to regimen is low. Three of the low adherers described a sense of high self-efficacy for taking their medications as prescribed. Two of the low adherers also commented on being able to incorporate physical activity into the daily routine, and another described being able to perform blood glucose tests as recommended.

Statements coded to the *in vivo* code, "I know what to do, but I just don't do it," occurred in a majority of the low adherence group, but did not occur in any of the high adherence
interviews. The code “sense of personal responsibility” reflected the individual’s perception of being accountable for their own diabetes self-care management. Statements for this code occurred in 50% of the high adherence interviews and 43% of the low adherence interviews, indicating not much difference between the groups in terms of personal responsibility. The code “able to adjust to changes in daily routine” refers to actions taken by the individual to manage their diabetes in response to unusual circumstances. In both groups, approximately half the participants made statements related to this code.

1. **Diet**

Statements related to specific dietary behaviors or problems with adherence to recommended diet were coded separately. Five diet codes were grouped into a code family for adherence to diet. Table XVII presents the frequencies and percentages for each of the diet codes for the high and low adherence interview participants.

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High diet self-efficacy</td>
<td>5 (83)</td>
<td>1 (14)</td>
</tr>
<tr>
<td>Low diet self-efficacy</td>
<td>2 (33)</td>
<td>2 (29)</td>
</tr>
<tr>
<td>Food cravings</td>
<td>2 (33)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Able to adapt diet</td>
<td>3 (50)</td>
<td>3 (43)</td>
</tr>
<tr>
<td>Problems with diet</td>
<td>4 (67)</td>
<td>6 (86)</td>
</tr>
</tbody>
</table>

The code “high diet self-efficacy” referred to statements reflecting that the interviewee was able to follow the recommended dietary patterns. A noticeable difference was observed between the numbers of high and low adherence interview participants who made statements reflecting high diet self-efficacy. A striking difference was also observed between high and low
adherence interview participants in statements coded to "food cravings." Every participant in the low adherence interview group reported difficulties with food cravings, while only one-third of those in the high adherence group described such problems. Several interviewees reported indulging food cravings as a way to relieve stress, as exemplified in this statement:

My rules are that if I'm not in a good mood or it has been a bad day I could have whatever I want. If it's been a good day then I try to eat good. I do for the most part; I really do for the most part try to eat good. I do have a lot of bad habits. I like cookies, I always have to have some cookies, those are like my relief foods. And it's just a matter of do I eat one or do I eat the whole package that day.

Several others commented on problems with controlling themselves once they started to eat a food that was not on their recommended diet. For example, one interviewee stated:

I know you can have it in moderation but that's my problem, I can't control moderation. It's like ok, here's a bag of cookies, you can have one, I can't do it. I don't know if it's because of the way when I was younger, I always think about this, when I drive, I think about things like this, why can't I just say ok here's a box of Fannie May with fifty pieces in it, you can have one piece. I can't do it. It's control; I don't have that control where, ok shut it off, walk away. I'm better off not having it than having it. It's hard to do that.

The code "able to adapt diet" reflected statements in which the individual described adaptations they made in their diet because of changes in daily routine or other aspects of life. Such statements were made by 50% of those in the low adherence group, but somewhat less (43%) of those in the high adherence group. Following is an example of a statement about dietary adaptations:

I generally will get up in the morning and I'll try to have something to eat so I can get my medicine down. If I'm a good girl I will try to have something, but I sometimes have to look at what my day is going to be like. I also have to in the fall figure out when my breaks are gonna be, because my energy level is very, very associated with what I'm doing and my food. So for example, if I'm going to have a normal day and I know that I'm going to be able to have lunch and so forth and so on, and I try to eat and
have lunch. I have this person who will remind me that I’m supposed to sit and eat so we have lunch together. Sometimes when I get too busy, she’ll remind me, you know across the hall, she’ll say no or she’ll remind that you can have a little of this but you can’t have that.

Statements coded to “problems with diet,” reflecting specific areas of concern not covered by other codes, were made by 86% of those in the low adherence group, and somewhat less, 67%, of those in the high adherence group. One interviewee spoke of problems with diet when attending a party:

Q: Let’s say that your daily routine as far as meals is pretty good but what about if there’s some family event or things like that?

A: Well actually when that happens, I usually suffer the next day because if there’s something big going on, I usually overindulge in the festivities. Not the alcohol, I do not drink, but food, desserts and that and not being on insulin where I can just take some extra. I go into the highs and then I’m tired and crabby for a couple days.

2. Exercise

Two codes that were used to classify statements related to exercise self-efficacy were grouped into a code family for “adherence to exercise.” Both were “super-codes” created by using the ATLAS.ti query tool to combine codes. Table XVIII presents the frequencies and percentages for the exercise codes for the high and low adherence interview participants.

Table XVIII

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%)</td>
<td>Frequency (%)</td>
</tr>
<tr>
<td>High exercise self-efficacy</td>
<td>6 (100)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Low exercise self-efficacy</td>
<td>0 (0)</td>
<td>4 (57.1)</td>
</tr>
</tbody>
</table>
Every person in the high adherence interview group made at least one statement related to being able to exercise on a regular basis, while only slightly more than one-fourth of those in the low adherence interview group made statements, such as this:

I’ve been an athlete all my life so I always exercise and I’m active, I do belong to a health club, have a couple of apparatuses at home, so I try to exercise at least 3 or 4 times a week. At least that...maybe five days or seven days a week. It helps I think because I think I’d be way further along, maybe ready for insulin already, if I wasn’t doing those things because I got some bad habits.

On the other hand, more than half of the low adherers remarked about being unable to exercise as much as they knew they should, while the high adherers made no such statements.

Typically, low adherers talked about a life-long dislike for exercise or physical activity.

So yeah I’ve always been terrible with exercise. Even just the thought of, it’s like, I can’t figure out a way to fit it in to my life. Even just to come home, you know a lot of people come home they eat dinner and then they go out for a walk or they take their dog for a walk or they go for a run. It just doesn’t seem like a convenient time. I have a million excuses why I can’t do it. It’s raining. It’s hot. It’s cold. The dog hurt its paw. I don’t want to walk alone. I’ve gotta go over by my Mom’s she wants me to do something. I’ve gotta make my lunch for tomorrow. I mean I have a million excuses why from 6:30 until 9:00 I can’t go out and walk. Besides the fact that my favorite program is on.

Low adherers described problems with motivation to exercise, even when they had favorable conditions, such as exercise equipment or supportive friends, readily available.

Now the one thing I really haven’t done is done a lot of exercise. First of all I hate it. I know I’m supposed to do it. When I talk about exercise I talk about walking. I have a walking park across the street from my house and it has a fence around it. I am too lazy to get in the car, drive around and go to the park.

3. Glucose testing

By combining codes for “high self-efficacy” with “glucose testing” and “low self-efficacy” with “glucose testing,” statements that related to being able to perform blood glucose testing as recommended were retrieved. Analysis of these two codes revealed that only two
statements about this aspect of regimen adherence were made by persons in the high adherence interview group, one statement relating to high self-efficacy and one to low self-efficacy. In the low adherence interview group, four individuals (57.1%) made statements regarding low level of ability to perform glucose testing as recommended, while one individual expressed high confidence in the ability to do blood glucose testing.

4. Medications

Combining codes for "medication," "high self-efficacy," and "low self-efficacy" created two new codes that were included in the family for "adherence to medication." Analysis of statements for these codes indicated little difference between the high and low adherence groups. As was found in the survey data, there were minimal comments about difficulties with adherence to prescribed medications. Some interviewees commented on problems related to scheduling their medication, e.g., in relation to mealtimes, or side effects of medications, but no one described being unable to take their medications.

C. Illness Demand

Because the concept of illness demand includes the individual's psychological responses to the perceived burden of the diabetes regimen, this code family included a variety of codes to describe the range of responses that were manifested in the interviews. Table XIX presents the frequencies and percentages of interviewees in the high and low adherence groups who made statements that were coded to the illness demand family.

Major differences between the high and low adherence groups were observed for the code, "feeling resentful about diabetes." None of those in the high adherence group expressed this sentiment, but more than half of those in the low adherence group made such statements. Statements that indicated ineffective coping strategies were made by a greater percentage of those in the low adherence group, while none of the low adherers made statements that coded to effective coping strategies. The need for routine and organization was mentioned with similar
frequency in both groups. However, while those in the high adherence group credited a consistent routine and organization strategies for helping them to adhere to their recommended

TABLE XIX
ILLNESS DEMAND CODES
FOR HIGH AND LOW ADHERENCE INTERVIEW GROUPS

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence Frequency (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling resentful about diabetes</td>
<td>0 (0)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Ineffective coping strategies</td>
<td>2 (33.3)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Effective coping strategies</td>
<td>4 (66.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Able to follow routine or be organized</td>
<td>5 (83.3)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Stress as an impediment to control</td>
<td>4 (66.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Fear of complications</td>
<td>3 (50)</td>
<td>5 (71.4)</td>
</tr>
</tbody>
</table>

self-care regimen, the comments by low adherers were generally stated as a goal that had not yet been achieved, as exemplified in this statement:

What I've always wanted to do is sit down and plan like on a Sunday afternoon, plan the week out, even just our schedules so we'd know. And as it is right now, I feel like we're going day to day to day. I wake up today and I know that I have to go to work, J's going to work, N's got to go to school. I can't think past tonight... and I can't even think far enough to take anything out for dinner cause I think I'll worry about that later.

Stress was a problem area that was mentioned by two-thirds or more of both groups. Most interviewees discussed stress in their lives—whether physical or psychological—as an impediment to blood glucose control. Thus, stress added to the burden of self-care by creating fluctuations in blood glucose that required extra attention. Some individuals in the high adherence group were able to effectively manage these blood glucose changes through individualized "tricks of the trade" they had learned over time. An example is given in this statement:
Q: Is there anything else that you can think of that you think might be helpful for me to know about in terms of things that make it easier or harder for people with diabetes?

A: Stress is about the hardest one, cause that's when mine [blood sugar] usually goes up.

Q: Have you found any techniques for dealing with stress that help you?

A: Yeah, [laughs] I get out and walk or sew. I'm a seamstress so, I'll either sew or get outside and walk around the courtyard or just go outside and talk to one of the other ladies.

Q: And that helps you?

A: Right, it brings me down and then he [her husband] realizes that he shouldn't have said what he said so then he's trying to butter up, you know.

Half the interviewees in the high adherence group and nearly three-quarters of the low adherers spoke about diabetes-related problems or complications that they feared. Those in the low adherence group had twice the number of statements related to fear of future complications as those in the high adherence group. However, there was no consistent pattern in the types of problems that were mentioned. Individuals' fears included having to go on insulin, fear of blindness, or concerns about kidney damage. Following is an example of a statement indicating fear of a future complication:

You know how you hear stories about them cutting off your feet, and I thought oh jeez, I don't care about the rest of me, I just want to be able to see and walk you know. The rest of me can fall apart.

Persons in the high and low adherence groups tended to have very different responses to their fears. When those in the high adherence group talked about a feared complication, it
was described as something they took action to avoid, at the very least by bringing it up with their physician on a regular basis, as seen in the following statement:

I wanted to mention, too, my biggest fear, my fear for the diabetes is the heart. And I bring this up almost every visit to [Doctor] and he keeps reassuring me because you know my triglycerides look great. But, you know, my Mother had triple bypass. My Grandmother died from a heart attack. My brother had triple bypass when he was thirty-nine. My Father had a heart attack. It's very prevalent and I have thirty-four years under my belt with diabetes and I hear the warnings here, there, and everywhere. And I'm in a higher percentage group and I still can't be comfortable without worrying about that in the back of my mind.

On the other hand, when those in the low adherence group spoke of their fears of future complications, they tended to not have a strategy for confronting the problem, as seen in this statement:

I haven't conquered this, I'm having a very hard time conquering this and the reason why it bothers me is because I don't know what's on the other side of that door. Does it scare me? Yeah but I don't have time to be scared right now, I've got too many other things to focus on. It's like I'm putting stuff in front of what I should be doing.

Some of those in the low adherence group went so far as to acknowledge that they could not bring themselves to make the necessary lifestyle changes, even if they knew with certainty that she would develop a complication. One interviewee had the following comment:

And I don't even know, I know this is going to sound kind of warped, I don't even know if they were to say if you don't walk everyday you're going to die in a year, that I would walk everyday.

Q: Really?
A: I just don't think I would do it.

A comment by one individual in the low adherence group reflected a pervasive sense of helplessness regarding the effectiveness of self-care activities in preventing future complications:
Well I can tell you that my daughter-in-law, her mother was in and we were talking over the weekend, and that is what we said—with diabetes, it’s like you really feel like you got stuck with something...Especially the more I read about it or somebody will say something, and I’m like oh my god you’ll go blind or it will kill you no matter what you do. It’s progressive; all you can do is slow down the progression. So eventually everybody will come to a point where they’re taking insulin unless you die before that. So it’s like what’s the use. So I get an extra year to watch what I am eating, whoopee, big whoopee deal. I mean it’s just ...if there was a point where o.k. if you do all of this well then o.k., I mean if you could see a definite answer at some point, it would make it a lot easier I think.

D. Supportive and non-supportive family behaviors

The “family support” code family included codes that related to positive or negative perceptions about emotional support from spouse or other family members, as well as codes related to specific actions or behaviors that were perceived by the interviewee as either helpful or unhelpful. The frequencies and percentages for these codes are presented in Table XX.

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse helpful behaviors or positive support</td>
<td>5 (83.3)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Family helpful behaviors or positive support</td>
<td>4 (66.7)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>Spouse unhelpful behaviors or negative support</td>
<td>4 (66.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Family unhelpful behaviors or negative support</td>
<td>1 (16.7)</td>
<td>5 (71.4)</td>
</tr>
</tbody>
</table>

Comparison between the two groups revealed that more of the high adherers than low adherers made statements about helpful behaviors or positive support from spouse and other family
members. Several of the helpful behaviors revolved around diet and mealtimes, as indicated in the following statement:

Q: Is there anything that your mother or father do that helps you in managing your diabetes or makes it any easier for you?

A: Yeah when they invite me over to dinner. I mean she makes the vegetable, the potato and the meat. She makes enough meat so that everybody has a piece, do you know what I mean, and there's maybe one piece left or something. She doesn't cook so that she's cooking for twenty and there's three of us there, so yes, she does do that. She sets the table, she says everybody sits at the table and eats where you know I just grab my food and go watch tv or whatever. So yes. And I have tried to convince her into letting me move back home, it's not working [laughs].

Unhelpful or negative behaviors were cited more frequently by low adherers than high adherers. Once again, these behaviors often were related in some way to diet. When the spouse or other family members ate foods that were not allowed on the diabetic diet, the person with diabetes, particularly if a low adherer, was challenged to resist temptation. An example is given below:

Sometimes with the cakes I get a little aggravated but that's about it. But then it's kind of easy to use that as an excuse too. You know, if he wants cake, I'll go in there and think jeez I better have a piece.

Some persons described lack of support from the spouse or other family members that took the form of nagging or reminders about recommended diet or other self-care activities. Most of the time, these reminders were resented, as seen in the following statement:

It's like with somebody being 400 pounds, you don't need to tell me I'm 400 pounds, I know I'm 400 pounds. You don't need to remind me I'm a diabetic, you don't need to remind me that I have hypertension. Why are you doing this?

Often, negative behaviors of spouse or family members were due to their indifference about diabetes. Several persons in both high and low adherence groups described family members
who seemed unaware of the potential seriousness of their disease, for example, in the following statement:

I don't know if my husband even pays attention to it. I mean I don't think he knows anything about diabetes. I mean we really don't talk too much about it. The only thing that he will ever say is well if you didn't eat all them cakes you know, he figures it's the cakes, and if there is trouble with my sugar I must have had a piece of cake. If I don't feel good, or you know, must have been cake.

Occasionally, individuals expressed the struggle of having to follow healthy lifestyle patterns by themselves, as exemplified by this statement:

Q: Has your diabetes influenced your family relationships in any way? Or is there anything that people within your family do that either makes it easier or harder for you?
A: They make it harder. I complained about this with one of the nurses the last couple times I was in here. 'Cause my husband is overweight, and he snacks all day long, and he doesn't want to walk, and he doesn't want to bike. So I feel a little discouraged. I think it would be a lot easier if I had his support and if he was doing it with me. And sometimes I think that he doesn't realize the seriousness of my disease because for what he sees and what the world sees, I'm just, you know, I'm just fine. But you're not; there are a lot of complications that could come along the way.

E. **Satisfaction With Care**

The code family "satisfaction with care" included codes related to helpful or unhelpful behaviors of physicians or other health care professionals, as well as general statements about high or low satisfaction. The frequencies and percentages for these codes are presented in Table XXI.

For both high and low adherence groups, overall satisfaction with the medical management of their diabetes was very high. All of the interviewees in the high adherence group and 86% of those in the low adherence group made statements regarding the helpful behaviors of their physicians and other health care professionals. Only one interviewee
expressed extreme dissatisfaction with her relationship with her physician, to the point where she had considered asking for a new physician.

TABLE XXI
SATISFACTION WITH CARE CODES FOR HIGH AND LOW ADHERENCE INTERVIEW GROUPS

<table>
<thead>
<tr>
<th>Code</th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%)</td>
<td>Frequency (%)</td>
</tr>
<tr>
<td>Helpful behaviors (Physician or health care professional)</td>
<td>6 (100)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>High satisfaction with care</td>
<td>3 (50)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>Unhelpful behaviors (Physician or health care professional)</td>
<td>2 (33.3)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Low satisfaction with care</td>
<td>2 (33.3)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Collaborative attitude (Physician or health care professional)</td>
<td>3 (50)</td>
<td>3 (42.9)</td>
</tr>
</tbody>
</table>

Those in the low adherence group often were grateful for the continuing efforts made by their diabetes treatment team, yet also felt guilty that they did not always follow recommendations, as indicated in this statement:

Q: Is there anything that the doctors you work with, or the staff here, anything they do that makes it harder for you?

A: No, no, not at all. In fact, I felt like I have had nothing but support so I put all the blame on myself as far as not doing what I'm supposed to do.

Some interviewees expressed satisfaction with their health care professionals' attitude of collaboration, flexibility, and willingness to consider the patient's viewpoint. This sentiment was coded as "collaborative attitude (physician or health care professional)." An example of one interviewee's sense of collaboration with her physician was seen in this statement:
They don’t preach to you or like through the years with other physicians they always have a sour face, stem face and you have your diet and you have to do this, this and this. I’ll never forget one of my first visits and Dr. said, well what do you eat? What do you like to eat? About how much? I told him and he goes ok. Then he adjusted the medication around what I, what my diet was, instead of the other way around. No measuring and this, that and the other. So I thought wow, I really like this, I love this man! It just really makes a lot of sense; it makes a lot of sense.

F. Quality of Life

Interviewees were asked to talk about aspects of their lives with which they were very satisfied or very dissatisfied. Responses to these questions characterized the individual’s perceptions about quality of life. Each quality of life statement was coded as “positive” or “negative.” Quality of life was discussed broadly, and not just as it related to having diabetes. The code family for “quality of life” also included a combined code for “regimen effects” plus “quality of life,” which was used for statements where the individual described an actual or potential effect on quality of life due to specific diabetes self-care activities. Table XXII presents the frequencies and percentages for each quality of life code.

<table>
<thead>
<tr>
<th></th>
<th>High Adherence (n = 6)</th>
<th>Low Adherence (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>Frequency (%)</td>
<td>Frequency (%)</td>
</tr>
<tr>
<td>Positive aspects</td>
<td>6 (100)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Negative aspects</td>
<td>2 (33.3)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Quality of life/Regimen effects</td>
<td>3 (50)</td>
<td>5 (71.4)</td>
</tr>
</tbody>
</table>

Overall, more of the high adherers than low adherers made statements regarding positive aspects of quality of life. However, the types of comments that were made about overall
quality of life were similar for both high and low adherence groups. Many of these statements focused on the individual’s overall satisfaction with life in relation to marriage, children, or home, as indicated in this statement:

Parts of my life I'm satisfied with...well... there are different ways to take that question, I guess. I'm very happy with my home, I love my home and garden. My children and the relationship to our older boy is about as good as it could get....I enjoy very much being retired. I worked extremely hard and I feel very comfortable and satisfied really being retired. I'm having the freedom to do things I couldn't take time for before.

Those who were working frequently included comments about their job or coworkers when asked to describe parts of their life with which they were satisfied. An example is given below:

Probably right now I'm very happy with my lifestyle but I mean it's not a frenzied pace. I'm into a job that I know whereas a couple of years ago I was into a job that I had no idea what was going on. I'm with a manager that I feel comfortable with. I have employees that work for me that I'm very comfortable with, they're very good employees. Yeah but I'm very happy with my lifestyle the way that it is. I don't have a lot of friends; I have a few friends. We don't see each other that often but we see each other on the weekends. And I go to my parent's house for holidays.

There were fewer comments about negative aspects of quality of life for both high and low adherers. Aspects of life that were sources of dissatisfaction included work, family relationships, health status, and ability to maintain good diabetes control, as indicated in this interviewee’s statement:

Gosh, I'd like to change the part where my business didn't have such an effect on my personal life as far as my health. I don't want to die at an early age. I want to see my grandkids if I ever have grandkids and stuff like that. I wish I could change that, I think that has a lot to do with as far as my quality of life. What would make me feel better in life, I guess would be the question? I've told my wife this, I says you know what I need to do, I'd just like to go someplace and just sit, somewhere where I could not have to worry about stuff and where I could... Like I love the mountains, I love the west, we haven't been there in a long time, I'd like to go back there and travel but I can't because of this place. I can't get away. [Pauses] I think that's, if I could find a way that to get this
under control where I could know that, it would probably help me where I would have a better outlook in life. I used to be more upbeat than what I am now. I mean it just seems like it's been declining, why? Stress, responsibility. I guess when I can get this all off my back, what I fear is that even though when the day does come, we'll have complications where I can't do that. That concerns me.

When asked to describe the effects of their diabetes regimen on quality of life, both high and low adherers talked about favorable physical effects, such as more energy to do the things they would like, as indicated in the following statement:

Q: Do you think if you were able to stick with the diet plan and your diabetes regimen to the letter, do you think that would improve your quality of life? Do you think it would make you feel any better about your life?

A: Oh yeah. It would give me....I wouldn't be so tired. I could play golf and walk and not ride in that stupid cart. I would have more energy. I could run up and down the stairs. Yeah. I wouldn't have to think twice when I go into Wal-Mart how far I'm gonna walk. It's even getting better now. Or go to a mall and say ok, if I park here, will I still be able to walk there? Yeah, definitely.

Other comments about the effects of adherence to regimen on quality of life centered on the beneficial psychological effects of knowing they were doing the best they could to manage their diabetes. An example is seen in the following statement:

Q: Overall what would you say you would attribute you? success to in dealing with your diabetes?

A: My desire to feel well, to feel happy, and to know that I tried.

Q: So would you say then that sticking with your regimen overall makes your quality of life better?

A: Yes, it does, there's no guilt there. You know, sometimes if you don't do something you should do, you feel guilty, there's no guilt there at all. I know I am doing everything I can for the diabetes, so whatever is going to be is going to be after that.

However, some interviewees described negative effects of adherence on quality of life.

Those who mentioned negative effects described the loss of freedom and spontaneity that strict
adherence would require, as well as the frustration of not being able to gratify short-term desires, for example, food cravings. A comment by one interviewee in the low-adherence group provided an example of how even minor aspects of recommended self-care activities could interfere with quality of life, at least in the short-term:

Q: Do you ever feel burdened or overwhelmed by all of the things that you need to do?

A: Yes... Usually I start getting depressed and I'll go through this... you know I have to do this, I have to do that, I have to watch out for this, I can't do that, you know. Even just like the little extraneous things like walking around with no shoes on. I love walking around with no shoes on but now because I have diabetes I have to be more careful so I always have to have shoes on. You know when you're used to always walking around with no shoes on and all of a sudden you always have to have shoes on, it's like it's just little things you know what I mean. It's little things like that. I have to make sure that I'm home before—I can't just be out somewhere and say to somebody oh let's go to dinner because I have to go back home because I have to take my insulin so that I could go back out again to have dinner. Do you know what I mean? It's really the little things that get to you. I mean some of them I could probably switch but then you know you have to—hold on I have to go take my insulin, oh now we have to wait a half an hour before I can eat now, this and that.... Or I get all the way to work and I'm like oh god I forgot to take my pills. You know then all day in the back of my mind which is probably making myself more sick, I'm thinking oh god my blood pressure's going to be up, oh my sugar's probably going to be a thousand by the time I get home.

G. Summary

Overall, the results from analysis of the interview data were consistent with the key findings from the analysis of the survey data. The major conclusions that were drawn from the interview data for each of the study variables are described below.

1. Self-efficacy

As expected, every person in the high adherence group made statements related to high self-efficacy, and every person in the low adherence group made statements related to low self-efficacy. However, approximately half the high adherers also had low self-efficacy.
statements, and nearly three-fourths of the low adherers had high self-efficacy statements. This finding is consistent with the results of the survey indicating different levels of adherence to different aspects of the self-care regimen.

For those in the low adherence group, lack of knowledge about diabetes self-care was not an issue. Most made comments reflecting their frustration with their lack of motivation to follow through with what they knew they should be doing. A similar number of persons in both high and low adherence groups made comments reflecting a sense of personal responsibility. These people were not willing to blame others for their problems with self-care. Rather, they accepted that they alone were responsible for adopting the necessary behaviors.

a. Diet

All persons in the high adherence group made statements related to high self-efficacy with regard to diet, while only one person in the low adherence group expressed this. Everyone in the low adherence group reported problems with food cravings, which were frequently exacerbated when they were under stress. Approximately half the persons in both groups reported attempts to make changes in their diet, either to accommodate healthier eating patterns, or to adjust to changes in their daily routine. The difference was that those in the high adherence group usually reported success in these adaptations, while those in the low adherence group tended to be frustrated by their inability to make satisfactory adjustments.

b. Exercise

Those in the high adherence group had a large number of high self-efficacy statements relative to the ability to exercise on a regular basis. Some reported that exercise was an established part of their life, even before they had been diagnosed with diabetes. Half of those in the low adherence group made statements indicating low self-efficacy for exercise, and none of the low adherers had a high exercise self-efficacy statement. The low adherers tended to be acutely aware of the importance of exercise for blood glucose control, but were not motivated to exercise on a consistent basis, even when conditions were favorable.
c. **Glucose testing**

Adherence to recommended blood glucose testing was not a major problem for either high or low adherence groups. While no one reported never performing blood glucose tests, some persons in the low adherence group described that they did not do as many tests each day as recommended. Reasons for lack of adherence included embarrassment about checking blood glucose when at work, or reliance upon their own sensitivity to physical symptoms associated with blood glucose fluctuations.

d. **Medications**

Consistent with the results from the survey, the interview subset reported few problems related to medication adherence. All interviewees were able to state their diabetes medications and dosing schedule. Difficulties that were mentioned related to scheduling medication doses around mealtimes and work schedule or side effects that were attributed to medications, particularly weight gain.

2. **Illness demand**

Most of the statements about illness demand related to the individual's psychological response to having diabetes. A wide range of emotional reactions was described. Half of those in the low adherence group reported a feeling of "being stuck with diabetes," while no one in the high adherence group expressed this sentiment. More of the low adherence group reported ineffective coping strategies, such as eating to relieve stress, and none in this group reported use of effective coping strategies, such as exercise or meditation. Several people in both high and low adherence groups described the need for consistent daily routine and organization, but the low adherers tended to talk about this as an elusive goal, while the high adherers were able to describe strategies that they were already using successfully.

Interviewees in both groups talked about stress, mostly psychological and related to family or work problems. Many mentioned that they observed sharp increases in blood
glucose when they were under stress. High adherers tended to have developed strategies for managing blood glucose fluctuations that were due to stress, while low adherers had not.

Illness demand also included fears about future diabetes-related complications. Three-fourths of those in the low adherence group expressed fears about future physical problems, and this was usually accompanied by guilt about not carefully following their recommended regimen. A comment by one individual in the low adherence group reflected a pervasive sense of helplessness regarding the effectiveness of self-care activities in preventing future complications:

Well I can tell you that my daughter-in-law, her mother was in and we were talking over the weekend, and that is what we said – with diabetes, it's like you really feel like you got stuck with something...Especially the more I read about it or somebody will say something, and I'm like oh my god you'll go blind or it will kill you no matter what you do. It's progressive; all you can do is slow down the progression. So eventually everybody will come to a point where they're taking insulin unless you die before that. So it's like what's the use. So I get an extra year to watch what I am eating, whoopee, big whoopee deal. I mean it's just ...if there was a point where o.k. if you do all of this well then o.k., I mean if you could see a definite answer at some point, it would make it a lot easier I think.

3. Family support

Most of the high adherence interviewees made statements related to positive support or helpful behaviors by spouse or other family members. Helpful behaviors most often were directed to diet or mealtimes, although a few statements were made regarding support for other diabetes-related activities, such as exercise. There was greater frequency of statements about negative support or unhelpful behaviors among those in the low adherence group. Again, unhelpful behaviors often were related to diet, such as when the spouse or family member ate foods that were not on the diabetic diet. This was a particular problem for women who were responsible for cooking, and whose spouses insisted upon foods that were not healthful.
Two behaviors that are direct opposites were described in negative terms by interviewees in both high and low adherence groups. Some individuals complained that family members were indifferent to the demands and problems associated with diabetes, while others were annoyed by family members who nagged them about complying with regimen activities, usually diet.

4. **Satisfaction with care**

Consistent with the results of the survey data, both high and low adherence group interviewees expressed satisfaction with the medical management of their diabetes. In particular, interviewees described satisfaction when health care professionals collaborated with them to adapt self-care strategies to their individual needs. People in the low adherence group expressed relief that they were not scolded when they failed to adhere to recommendations. They were cognizant of the efforts made by their physician and other members of the diabetes care team, and expressed regret that they were not able to live up to perceived expectations.

5. **Quality of life**

Most interviewees expressed a high degree of satisfaction with their overall quality of life and with specific aspects of life such as family relationships, living situation, and work. With regard to diabetes regimen, most held the belief that adherence to recommended self-care practices would lead to improved quality of life. Some spoke of beneficial psychological effects, such as decreased sense of guilt, associated with good adherence. Others, particularly those in the low adherence group, focused more on the physical improvements they would expect from stricter adherence to regimen, such as increased energy and stamina for daily activities.
VI: DISCUSSION

A. **Limitations of the Study**

The findings of this study have limited generalizability due to sampling bias. The convenience sample was drawn from a single diabetes treatment center, located in a middle-class suburban area. Although this was a deliberate choice, in order to ensure a sample of adults with Type 2 diabetes that had received diabetes education and ongoing care that met ADA standards, the findings from this sample may not reflect persons who receive diabetes care in a general medicine or family practice setting. Furthermore, persons living in inner city or rural areas, or whose socioeconomic status is significantly higher or lower than this sample, may respond differently to the examination of the variables of this study.

It should be noted that the sample had significantly more females and was older than the overall population of clients of the diabetes center. Furthermore, the majority of study participants had education beyond the high school level, a characteristic that could have an important influence on the ability to engage in diabetes self-care activities. Finally, the response rate of 24% to the survey was lower than desired and less than that obtained by others with similar data collection methods (Eaker, Bergstrom, Adami, & Nyren, 1998). The length of the survey, as well as an unanticipated interval of approximately six months between the first mailing and second mailing to non-responders may have inhibited the response rate.

A second limitation was that the cross-sectional design of the study restricted its ability to draw inferences related to causation. Although statistically significant correlations were observed between the independent and dependent variables, it is not possible to infer which variables are causal.
Finally, the study was limited by problems associated with measuring adherence to recommended regimen. Although multiple measures of adherence have been recommended to increase reliability, this study utilized only a single self-report measure of adherence for the survey portion. The interview subset provided additional verbal reports of adherence behavior, but the 4-12 month time lag between survey completion and interview may have introduced a threat to internal validity. It is possible that the individual's adherence to diabetes self-care activities increased or decreased in one or more aspects of regimen during the time between completion of the survey and participation in the interview.

Furthermore, some researchers (Toobert, Hampson, & Glasgow, 2000; Johnson, 1992) have criticized the use of a summary score for adherence to regimen, as was used in this study. These experts point out that a single summary score may not adequately reflect variations in adherence to different aspects of diabetes care. This may be a concern in studies that seek to identify changes in adherence behavior over time. However, the focus of this study was to make comparisons between persons with high and low levels of adherence to regimen. For this study, the summary adherence score was used as the means to identify persons in the high and low adherence groups, in order to examine similarities and differences. The total adherence score was calculated as the sum of the subscale scores, and therefore persons with high scores for each of the subscales had total scores at the high end of the range, while those with low scores for each of the subscales had much lower total adherence scores.

B. **Aim 1**

The major findings and conclusions of this study will be addressed in relation to each of the four aims of the study.
The first aim of the study was to compare persons with varying levels of adherence in terms of the influence of self-efficacy, illness demand, support from family members, and satisfaction with medical care.

Clearly, self-efficacy had the greatest influence of any of the variables on the individual's decisions regarding adherence to recommended diabetes regimen. Those with the highest overall adherence scores tended to have higher scores for diabetes self-efficacy as well, while those in the lowest adherence group had significantly lower self-efficacy scores.

It is interesting to speculate about the effect of the distinct characteristics of this sample on the findings regarding self-efficacy. Although diverse in age and racial/ethnic make-up, the sample was homogeneous in terms of the diabetes education and care they had received. Furthermore, the majority of subjects were residents of middle-class suburbs and reported education beyond the high school level. For these individuals, confidence in the ability to carry out recommended diabetes self-care activities may reflect norms of their socioeconomic or cultural groups, namely, self-reliance and independence. It is noteworthy that several interviewees in both high and low-adherence groups described a sense of personal responsibility for management of their diabetes care. This belief may have been instilled through the intensive teaching and coaching provided by the diabetes center staff. Further exploration of the interaction between the sense of personal responsibility and feelings of self-efficacy may provide helpful insights into ways to increase self-efficacy.

On the other hand, as other researchers have found (Glasgow et al., 1989), self-efficacy for diabetes care was not a global attribute, but rather was applied differentially to various aspects of the regimen. Persons in this sample tended to report a higher degree of self-efficacy for discrete, specific diabetes-related tasks such as taking medication, testing blood glucose, and foot care. It would appear that once instruction and supervised practice in these areas had
been provided, most subjects in this sample did not find it difficult to perform these activities. This conclusion was reinforced by the interview participants, most of whom were able to describe in detail their schedule for medications and blood glucose testing. While some interview participants reported that they did not perform blood glucose testing as frequently as recommended, the reason given was not that it was a difficult or demanding procedure to do, but rather because of low outcome expectations for the effectiveness of blood glucose checks in symptom management.

Lower levels of self-efficacy were reported for lifestyle behaviors such as diet or exercise, as well as for adjustment of various aspects of the diabetes regimen for circumstances or situations outside of the typical day's routine. Problems with diet and exercise management have been widely reported by other researchers (Glasgow, Hampson, Strycker, et al., 1997), and it was not surprising that similar findings occurred in this sample. However, the problems in making adjustments in self-care regimen are worth noting. The low adherence group had a significantly lower mean score for the DSES item that asked about confidence in being able to follow the diabetes plan even when daily routine changed. Furthermore, items regarding making changes in medication dose based on blood glucose results or changing the diabetes regimen when ill received low scores and ranking for both the high and low adherence groups. Similar findings were reported in a study of insulin-requiring Hispanic adults that used the original IMDSES scale (Bernal, Woolley, Schensul, & Dickinson, 2000). It may be helpful for diabetes educators to assess the client's ability to make adjustments in their self-care activities and provide teaching and periodic reinforcement of instructions about how to adapt self-care activities to unusual circumstances.

As has been reported by other researchers (Toobert et al., 2000), this sample was highly adherent to their diabetes medication prescription. Subjects in the interview subset tended to
believe that their medications were effective in controlling their blood sugar. Few reported problems with adverse medication effects, although some reported difficulty with incorporating medication dosing into daily routine, particularly if doses had to be coordinated with meals. It may be that people found it easier to adhere to recommendations for medication because this did not involve a major adjustment in lifestyle, unlike diet and exercise. This was confirmed by several of the interview participants in the low adherence group, who denied problems with taking their medications as prescribed, even though their adherence to diet and exercise recommendations was poor. Especially for those whose medication regimen involved one or two pills each day, this self-care activity was not viewed as being a burden.

The total sample had lower scores for the diet self-efficacy subscale of the DSES than for the general or exercise subscales. Diet behaviors involve a constellation of activities that require daily attention to planning and organization in order to maintain consistency in mealtimes, caloric intake, and selection of desired foods (Williamson, Hunt, Pope, & Tolman, 2000). The interview participants who reported the least problems with dietary adherence were individuals whose daily routine was well-established, for example, persons who were retired. Some people reported well-established routines for mealtimes and foods eaten at each meal, with little day-to-day variation. This seemed to have enhanced their ability to follow dietary recommendations.

For those persons who were working, however, strict adherence to diet was often a challenge. Inconsistency in daily work schedule, or the need to attend to work-related crises that interrupted normal schedule made it difficult for many of these subjects to maintain regular breaks and mealtimes while at work. Furthermore, the work environment presented additional challenges to dietary adherence in the form of meetings or social occasions that involved tempting foods. Some interview participants reported that their co-workers were not aware of
their diabetes, or described being embarrassed about calling attention to their particular needs related to diabetes diet requirements.

Food cravings were a major impediment to dietary adherence that was reported by all of those in the low adherence interview group. There was no consistent pattern in the types of foods that were desired, although late afternoon and evening were frequently identified as the peak times of day for food cravings. For many individuals, food cravings were indulged as a means to relieve stress due to work or family situations. The dilemma of being obsessed with food, yet aware of the negative health effects of giving in to cravings, was also reported in a qualitative study of 34 persons with insulin-requiring diabetes (Maclean, 1991). This is an area where a great deal of support is necessary, and it may be a fruitful area for diabetes educators to explore with low adherers.

Another area that presented an obstacle to consistent dietary adherence was the need to make adjustments in diet due to unusual circumstances, for example when on vacation, eating at a friend’s home, or when ill. One interview participant appended her comments, via email, with a description of the challenges she faced whenever her large family had one of its frequent celebrations. She noted that the entire day’s activities revolved around eating and drinking, making it nearly impossible for her to adhere to her usual diet pattern. Several interview participants also commented on difficulties they encountered with dietary adherence when traveling, because of the interruption of typical daily patterns.

Low adherers also reported greater difficulty in following recommendations for exercise. The ranking and mean score for the DSES item that asked about ability to exercise several times a week was significantly lower for the low adherence group. Furthermore, scores on the exercise subscale of the DSCA were significantly lower for those whose overall adherence score was in the lowest third. Comments from the interview participants indicated that low
adherers had usually not been physically active at any time in their lives, and thus found it very difficult to institute a regular exercise routine. Some low adherers described lack of will power to exercise, even in situations where circumstances were favorable, such as having supportive friends to exercise with, or having exercise equipment in the home or workplace.

On the other hand, high adherers tended to report that physical activity had always been part of their lives, whether due to participation in organized athletics or simply because they enjoyed being active. They did not find it burdensome to incorporate exercise into their daily routine, and tended to describe having a very specific regimen of exercise such as walking at a certain time each day.

Because physical activity is an essential component for blood glucose control (ADA, 2001b), it is important for diabetes educators to carefully assess the individual's attitude about exercise and the likelihood that exercise will be incorporated into daily routine. Intervention and ongoing monitoring and support are necessary for those who report a dislike for exercise. It may be helpful to explore a variety of options with the individual, including alternative forms of activity and the types of circumstances that would increase the likelihood of exercising.

Low adherers had a higher mean score and ranking for the DSES item that asked about their ability to recognize when blood glucose level is too high. This was an unexpected finding, particularly since this was the only DSES item for which the low adherence group's mean score was higher than that of the high adherence group. It is possible that low adherers were overly confident about their ability to recognize symptoms of hyperglycemia, or that they did not recognize that they were unaware of these symptoms. This hypothesis was not explored with the interview participants, but would be an interesting area for further study. It is important for people with diabetes to be aware of their own particular manifestations of higher blood glucose, as well as the specific circumstances that lead to hyperglycemia. It may be helpful for the
person with diabetes to keep a log of blood glucose levels with a record of any physical
symptoms that are associated with high levels, until such time as a pattern can be identified. In
this way, the individual can become more sensitive to his or her particular responses and more
accurately identify high blood glucose levels.

It is interesting to note that there was a tendency for those whose diabetes was of longer
duration to have lower self-efficacy scores. While diabetes educators might expect that
confidence in ability to self-manage diabetes care would increase over time, for this sample the
opposite occurred. It is important that diabetes educators avoid making assumptions about their
clients’ level of self-efficacy, regardless of the duration of diabetes. This finding reinforces the
need for ongoing assessment, supportive interventions, and evaluation for people with Type 2
diabetes. Unfortunately, there is often a tendency to focus efforts on the newly-diagnosed client
and to provide minimal supportive aid to maintain or increase self-efficacy in those with long­
standing diabetes. It may be helpful for health care professionals who work with people with
diabetes to periodically assess the individual’s level of confidence in diabetes self-care and to
provide reinforcement and support as needed.

Perception of illness demand had a moderate negative correlation with adherence,
indicating that those whose level of adherence was higher had a decreased sense of burden
due to diabetes. This was reinforced by the interview participants in the high adherence group,
who tended to describe their diabetes self-care activities as being an accepted part of life. As
noted earlier, high adherers tended to report fewer problems with diet or exercise, the two areas
of greatest difficulty for low adherers. On the other hand, similar to the findings of others
(Glasgow, Hampson et al., 1997), low adherers described many obstacles to diet or exercise
adherence, and tended to regard recommendations as additional obligations that were
burdensome to carry out. While high adherers had no difficulty with being motivated to eat
healthy foods or engage in regular physical activity, low adherers tended to regard these behaviors as requiring great discipline and chastised themselves for lacking it. Some interview participants in the low adherence group also reported feelings of resentment about having diabetes, while this was not described by any of the high adhering interviewees.

It is interesting to note that greater perception of illness demand was associated with longer duration of diabetes, a finding that has been reported by others as well (Mazzuca et al., 1986). Perhaps those who had diabetes for many years became disheartened by the constant need for vigilance and attention to self-care activities, thus feeling more burdened than those who had been more recently diagnosed. Again, this finding highlights the need for diabetes educators to be sensitive to changes in the patient's ability to cope with the requirements of diabetes self-care as time goes on. While it may be easy to be supportive to the person newly-diagnosed with diabetes, and facing new challenges of self-care, it is important to keep in mind that the individual who has dealt with diabetes for many years may become discouraged by the chronic and progressive nature of the disease, as well as the need for daily attention to self-care and monitoring.

Support from spouse and other family members has been reported by others as an important variable in adherence to diabetes regimen (Glasgow, Toobert, & Gillette, 2001; Samuel-Hodge et al., 2000), but it was not a key aspect for this sample. No difference was found between high and low adherers for either supportive or non-supportive family behaviors. Most of the items on the DFBC scales for supportive and non-supportive behaviors were reported as “never” occurring. It may be that subjects were not aware of these behaviors, even if they were occurring. Perhaps they were not expecting support from family members, as indicated by approximately half of the interviewees from both high and low adherence groups who described the management of their diabetes as being a problem for which they alone were
responsible. The family behaviors that were cited as being important tended to focus on diet and meals. Eating meals at the same time was the most frequently reported supportive behavior, while eating foods not on the diabetic diet was the most frequently reported negative behavior.

Some of those in the interview subset reported difficulty due to a family member's indifference. A few talked about their children showing little or no awareness of the fact that their parent had diabetes. However, it was more problematic for the person with diabetes when his or her spouse showed no interest in their diabetes management. For some, this engendered feelings of isolation that interfered with the motivation to carry on with recommended behaviors. For others, spousal indifference increased the burden of the person with diabetes, again particularly with respect to diet, as when the spouse insisted on having available foods that were desired, but not allowed on the diabetic diet.

Lastly, satisfaction with medical care was not related to adherence for persons in this sample, in contrast with findings of other researchers (Harris, 2000). As noted earlier, this sample was drawn from the clientele of a comprehensive diabetes treatment center in order to ensure a sample of persons who had received the "best of care." Not only had all subjects received wide-ranging diabetes education, but they also benefited from regularly scheduled follow-up visits with the physician, nurse, or dietician and close monitoring of physiological parameters of diabetes. Nearly everyone in the interview subset, whether high or low adherer, had positive comments about their physician and other staff members of the center. Of particular note were comments about their favorable response to the collaborative attitude and flexibility of staff members. Patients were pleased to be included in decision-making about diet, exercise, and other aspects of care. Persons in the low adherence group expressed relief that they were not scolded when they failed to follow recommendations. They were acutely aware that they had not lived up to expectations. Because health care professionals were willing to
accept less adherent behavior and continue working with the individual to promote better self-care, low adherers were encouraged to be honest about their self-care activities.

C. **Aim 2**

The second aim of the study was to describe factors identified by adults with Type 2 diabetes that positively or negatively influenced their decision to adhere to various aspects of the recommended regimen.

Analysis of the interview results focused on examination of the differences between selected groups of low adherence and high adherence exemplars. Interview comments supported the findings of the survey with regard to self-efficacy, illness demand, support from family, and satisfaction with care. Quality of life considerations were also explored in detail with interview participants, and will be discussed under Aim 4 of the study.

Several factors emerged from the analysis of the high adherence interviews that give insight into the personal attributes and situational characteristics that increase the likelihood of adherence to recommended self-care activities. Of great importance was the tendency by those in the high adherence group to accept diet and exercise recommendations as part of their typical daily routine. The diabetes regimen was not viewed as a set of activities that were superimposed on the usual routine, but rather as activities that would be carried out to maintain health even in the absence of diabetes. It is particularly noteworthy that all those in the high adherence group described themselves as enjoying exercise and keeping active. What accounts for this attitude in some persons, while other people find activity to be undesirable and burdensome? This is an area that would benefit from further exploration using qualitative methods to identify cognitive and behavioral patterns that favor positive attitudes about exercise.
A second factor that was described by high adherers as positively influencing adherence was the ability to maintain a consistent daily routine and to be organized in the implementation of diabetes self-care activities. This was particularly important with regards to diet and exercise. A regular pattern for mealtimes was an important strategy that facilitated dietary adherence. Problems occurred when people encountered unusual situations such as parties, vacations, or changes in daily routine. People who worked in environments where alterations in schedule were frequent, or where social diversions such as birthday celebrations were common, found it much more difficult to maintain their recommended diet.

Being organized included diet strategies such as planning meals and shopping for food in advance or having healthy snack foods readily available at work or in the car. These strategies were helpful in resisting the temptation to rely on fast foods or carry-outs for meals. Organizational strategies for exercise centered mostly on advance planning of a time in the daily schedule for exercise. Some high adherers also described other ways of being organized with regard to diabetes self-care, such as carrying glucose tablets, medication, or blood glucose testing equipment when leaving home.

Helpful behaviors by family members with regard to diet and exercise patterns were identified as another important factor that favored adherence to regimen. Although the survey data failed to show a significant difference between high and low adherers with regard to perception of family support, the interview data provided many rich examples of the ways in which spouse and other family members could be helpful or unhelpful to the person with diabetes.

Persons in the high adherence interview group had more frequent comments about helpful family behaviors. Typical comments described support with dietary adherence, for example, by eating the same foods as the person with diabetes. Also cited as being helpful was
having a spouse who enjoyed following a healthy lifestyle. This made it easier for the person with diabetes to adhere to recommendations.

Finally, a collaborative relationship with health care professionals, in which the person with diabetes felt as though they were treated as a partner in managing their diabetes, was mentioned by persons in both the high and low adherence groups as being a factor that positively influenced adherence behavior. A willingness to be flexible in adapting self-care activities to the particular needs and circumstances of the individual was appreciated. Although low adherers sometimes expressed guilt about not meeting expectations, they were nevertheless grateful to health care professionals for their efforts to help them achieve better control of their diabetes.

A number of factors that negatively influence adherence were identified through analysis of the interview data. As has been already mentioned, dietary problems were a key source of concern, especially for low adherers. These problems included food cravings, which were particularly difficult during periods of work- or family-related stress. Low adherers were unable to resist the temptation of foods that seemed to ease the physical and emotional sensations associated with stress. These people were acutely aware, even while eating, that they would feel guilty after yielding to temptation, and they were cognizant of the damaging effect of these binges on blood glucose control, yet they were not able to summon the necessary willpower to resist. Several low adherers also mentioned that they were aware that current dietary guidelines allow occasional small amounts of “forbidden” foods, but described great difficulty in limiting themselves to a small portion. One interviewee commented that it was better for her to avoid these tempting foods altogether, since she found herself unable to control her intake once she started eating the food.
For low adherers, being in situations where the people around them were eating foods that they knew they should avoid made it even more difficult to follow the recommended diet. For some, this situation occurred at home, where the spouse or other family members regularly indulged in foods that the person with diabetes wanted to pass up. A few interviewees described other family members bringing large amounts of cakes, cookies, or other snack foods into the home. Having the food nearby made it impossible to resist, especially when available in a large amount, which the individual rationalized as not wanting to waste.

Low adherers also encountered more problems with dietary adherence during social occasions such as family celebrations or work-related parties. For some, the difficulty was in not wanting to call attention to themselves by not joining others in eating large amounts of food, while for others, the mere presence of foods they enjoyed eating, but knew they should avoid, was more temptation than they could resist.

Aside from unhelpful behaviors related to diet, low adherers also described other family behaviors that interfered with their ability to adhere to recommended diabetes self-management. Frequent reminders by spouse or other family members—about diet, exercise, or any other aspect of self-care—were usually perceived as nagging and unhelpful. This was especially true if the reminder was delivered in a negative way. Low adherers often made comments indicating they were very much aware of what they should be doing or not doing, and they did not need prompting from others.

Just as unhelpful as nagging reminders were family behaviors that indicated indifference to the challenges faced by the person with diabetes. The difficulty of adhering to regimen was greatly increased when family members, particularly spouse, seemed not to care. This engendered a sense of isolation and being alone in the struggle to achieve good diabetes control. This is an area that diabetes educators should explore with their clients. While people
with diabetes did not find it helpful to be reminded constantly of what they should be doing to manage their disease, it was also not beneficial to have their diabetes and its accompanying self-care regimen ignored by family members. It may be useful for the diabetes educator to meet with the spouse or other family members in order to discuss the importance of their involvement to the person with diabetes, and to identify behaviors that will be perceived as being supportive.

Lastly, it was interesting to note the difference between high and low adherers in the way that the potential for diabetes complications was addressed. A majority of interviewees in both groups mentioned one or more potential complications that provoked anxiety. There was no single complication mentioned more frequently than others; each individual seemed to have a particular aspect that they found most distressing, whether blindness, amputation, heart disease, or kidney failure. Fear of diabetes complications was identified in another study as a manifestation of the negative psychological impact of diabetes (Samuel-Hodge et al., 2000). However, the high adherence interview participants who described potential complications tended to confront the problem directly, by discussing it with the physician and doing their best to follow preventive measures.

On the other hand, those in the low adherence group had a greater tendency to use denial or avoidance as a strategy to cope with their anxiety about future complications. While they knew they were at risk, they hoped the problem would not occur. Furthermore, they described themselves as lacking the ability to make the necessary behavior changes, even though they held the belief that these changes would help to postpone or prevent the feared complication. It may be useful for diabetes educators to provide their patients with the opportunity to openly describe their fears about diabetes-related complications, and discuss preventive strategies in the context of a collaborative and collegial relationship.
The sense of anxiety and helplessness about complications in the future has been described by others (Polonsky, 2000) and is understandable when viewed in relation to the general attitude of resentment of having diabetes that was described by half of those in the low adherence group, but none of the high adherers. Comments about “being stuck with diabetes” reflected a sense of victimization that contributed to low levels of self-efficacy. This pervasive negative perspective may influence the ability of the person with diabetes to confront diabetes-related problems, both current and future. It may be helpful for the diabetes educator to provide support to persons with diabetes to re-frame their cognitive representation of their illness, where necessary, in order to help them achieve a more optimistic outlook about their ability to manage their disease and avoid complications.

D. Aim 3

The third aim of the study was to describe the effect of self-efficacy, appraisal of illness demand, support from family members, and satisfaction with interactions with health care professionals on the individual’s appraisal of his/her quality of life.

Quality of life has been recognized as an important criterion variable in studies of adherence to diabetes regimen and the barriers associated with self-management (Glasgow et al., 2001). For this sample, self-efficacy accounted for the majority (40%) of the variance in quality of life scores, when multiple regression analysis was done. The total self-efficacy score also had a moderate correlation with total quality of life score, indicating an association between improved quality of life perception and increased self-efficacy for adherence to diabetes self-care activities. Correlational analysis, however, does not establish causation, and it is interesting to speculate as to whether self-efficacy leads to improved adherence, resulting in increased quality of life, or if a positive perception of quality of life enhances the individual’s sense of self-efficacy. This will be discussed further with the fourth aim of the study.
Quality of life was moderately correlated in the expected negative direction with the score on the ADS, the measure of illness demand. It would appear that those who have the greater perception of burden due to diabetes experience less favorable quality of life. For some people, this is a disincentive to adherence, as the desire for quality of life in the short-term outweighs the long-term benefits associated with strict adherence to a regimen that is viewed as being burdensome, even if believed to be effective for achieving diabetes control (Snoek, 2000).

With regards to family behaviors, a weak, but statistically significant association was found between total quality of life score and the score for supportive family behaviors (DFBC+), but the correlation between quality of life and non-supportive family behaviors (DFBC-) was not significant. This may be partially explained by the fact that the majority of DFBC items for supportive and non-supportive family behaviors were rated as “never” occurring.

This was an unexpected finding, and not consistent with the conceptual underpinnings of the QLI-D, which includes family as one of its four domains. It may be that for this sample, all of whom had received comprehensive diabetes education, subjects were able to separate the influence of family behaviors on diabetes care from other aspects of family relationships. The score on the family subscale for the total sample was the highest of any of the four subscale scores, indicating greater importance of and satisfaction with family than with the areas of health and functioning, social and economic aspects, and psychological and spiritual aspects. Perhaps subjects in this sample, while generally satisfied with family relationships, did not expect or require a great deal of family involvement in their diabetes care. This was implied by some of the interview participants who, when asked about aspects of their lives with which they were greatly satisfied, talked about family relationships; yet these same individuals did not describe high levels of family involvement in the management of their diabetes.
Lastly, satisfaction with medical care was only weakly correlated with quality of life score, a finding which is most likely explained by the high scores overall for satisfaction with care. Authenticity, i.e., genuineness, in relationships with health care professionals has been recognized by diabetes experts as a critical element to foster the client's personal growth and ultimately improve quality of life (Schafer, 2000). Authenticity is achieved when health care professionals demonstrate qualities of cohesion (i.e., sticking with the client), flexibility, and adaptability. Both high and low adherence interviewees described these characteristics as being present in members of their diabetes care team, thus contributing to their high level of satisfaction with care.

**E. Aim 4**

The fourth aim of the study was to examine the relationship between appraisal of quality of life and the individual's decision to adhere to some or all of the recommended regimen. Quality of life issues have been recognized as a critical element in predicting the likelihood that an individual will adhere to recommended diabetes self-care activities (Rubin, 2000). The conceptual framework of this study posited a reciprocal relationship between quality of life and adherence to diabetes self-care regimen. The model proposed that better adherence to self-care activities would lead to improved quality of life, and that positive appraisal of quality of life would facilitate adherence to regimen. Correlational analyses demonstrated a moderate association ($r = 0.47$) between total QLI-D score and total adherence score. Examination of the relationships between total adherence score and the four QLI-D subscales showed moderate associations between adherence and the health/functioning and psychological/spiritual subscales, as well as weak correlations between adherence and the social/economic and family subscales. Due to the cross-sectional nature of this study, however, the direction of causation cannot be substantiated.
However, analysis of the interview data provided evidence of both positive and negative effects of adherence on quality of life. When asked what effect strict adherence to all recommended diabetes self-care activities would have on their quality of life, nearly all interview participants answered that quality of life would be improved. Some framed their response in terms of enhanced psychological status, saying they would experience less guilt if adherence were better. Most however, considered the effect of improved adherence on the health-related aspects of quality of life, anticipating greater energy and fewer physical symptoms. Unfortunately many of the low adherers did not believe they could carry out the required activities, even though they strongly believed that quality of life would be better if they could. In some cases this was attributed to lack of discipline or willpower, i.e., self-efficacy. For others, the obstacles to adherence that were cited included being unable to cope with stress in healthful ways, lack of needed support from family members or coworkers, or co-existing medical problems, such as arthritis or cardiac disease, that impeded the ability to carry out recommended activities.

Not all participants identified positive effects of improved adherence on quality of life. Some of the interviewees acknowledged that strict adherence to regimen would interfere with quality of life, in small yet meaningful ways. For example, in the quote cited above, the participant talked about the loss of freedom to go barefoot or to be spontaneous about making plans with friends as negative outcomes of good adherence. Clearly, it was a dilemma for her whether to accept these small losses in return for long-term health gains. Others talked of similar predicaments in deciding whether or not to indulge a food craving. While knowing that the long-term effects of dietary non-adherence would be deleterious, they were overcome by the need for short-term gratification of needs, especially if food was used as a stress management strategy. Long-term health gains have been described as “poor motivators for adherence to
diabetes treatment regimens when those gains go hand in hand with acute and bothersome side effects and lifestyle restrictions" (Testa, 2000, p. 34).

Rubin (2000) has proposed that diabetes educators should help their clients develop effective coping strategies as a way to enhance the overall sense of well-being and improve quality of life perception. Evidence from this study lends support to this recommendation, as it appears that those with better quality of life also had better adherence to regimen. However, the extent to which intrinsic personality factors influence the individual's perception of quality of life is not known. It may be that support for development of effective coping strategies may help to modify personality characteristics and have a positive effect on the individual's overall perspective on life, thereby enhancing both quality of life and adherence to regimen.

F. Implications for Diabetes Educators

In summary, while some of the findings of this study reinforce or replicate findings of other researchers, there were several aspects that emerged from the analysis of the survey and interview data that have implications for health care professionals who work with adults with Type 2 diabetes. The following suggestions are offered as strategies to enhance the effectiveness of diabetes teaching and ongoing monitoring and support:

- Include teaching about ways to recognize the need for adjustment in self-care activities and strategies for making changes safely and effectively.
- Assist clients to learn their individual pattern of response to high blood glucose levels, so that they may more accurately recognize when they are hyperglycemic and take steps to manage it.
- Explore problems related to food cravings, including types of foods, time of day, and situational factors, such as family- or work-related stress, that increase cravings.
• Assist clients to identify or plan a daily routine for diabetes self-care activities, including meals and activity.

• Assess the individual's need for problem-solving and support related to dietary problems in the work environment, including problems such as inconsistent daily routine or work-related social occasions.

• Assess the individual's perception of burden associated with diabetes self-care activities, especially with regard to diet and exercise.

• Be sensitive to the need for ongoing support for people with longer duration of Type 2 diabetes in order to maintain an optimal level of self-efficacy and decrease the perception of illness burden.

• Assist clients to identify and verbalize their beliefs about diabetes, its prognosis, and the effectiveness of treatment and provide support to foster a positive perspective on their ability to effectively manage the disease.

• Assist clients to identify and implement effective coping strategies that will enhance their sense of well-being and improve quality of life.

• Explore feelings of isolation related to perceived indifference of family members.

• Include the spouse and other significant family members in discussions regarding behaviors that are perceived as being helpful or unhelpful.

• Provide opportunities for the individual to discuss fears related to diabetes-related complications and assist him or her to identify strategies to prevent these complications.

• Maintain collegial and collaborative relationships with clients and emphasize flexibility in adapting the regimen to individual needs and circumstances.
G. Recommendations for Further Study

Self-efficacy, illness demand, and quality of life were clearly associated with adherence behavior for this sample of adults with type 2 diabetes, while family support and satisfaction with care were less important variables. However, the distinct characteristics of this sample, including their education level and socioeconomic status, may have had an important influence on the findings. Exploration of the relationships among these variables in populations with different educational and socioeconomic characteristics and from other geographic areas and health care settings would be helpful in order to make comparisons of adherence behavior among varying groups.

While this study yielded findings that help to explain the association between quality of life and adherence, further study is needed in order to clarify this relationship. Improved quality of life for people with Type 2 diabetes, as well as other chronic illnesses, is widely regarded as a desirable goal. A deeper understanding of the role that quality of life plays in adherence behavior, and vice versa, will enable diabetes educators to assist their clients more effectively. Many of the low adherence participants in the interview subset expressed the belief that improved adherence would lead to better quality of life. It would be of interest to examine this hypothesis using a prospective experimental or quasi-experimental design, as has been recommended by others who have researched diabetes-related quality of life (Testa, 2000). Longitudinal qualitative studies of people with Type 2 diabetes could also provide insight regarding the experience of living with diabetes, following recommended self-care practices, and their effects on quality of life.

Despite having received diabetes education that met recommended guidelines, many of the subjects in this sample reported difficulty with adhering to some or all aspects of their regimen. It has been pointed out that knowledge is not sufficient for adherence, and it has been
recommended that behavioral strategies be combined with education in an ongoing program of support in order to maximize adherence (Brown, 1999). Studies that involve the implementation of one or more strategies to improve self-efficacy over time could potentially demonstrate more clearly the dynamic nature of the relationships among self-efficacy, quality of life, and adherence.

Although adherence to diabetes self-care activities has been the subject of numerous studies, none has reported a satisfactory answer to the question of why some people are able to follow a regimen without difficulty while others perceive enormous obstacles to adherence. The implications of this question will continue to grow as health care professionals attempt to cope with the ever-rising prevalence of Type 2 diabetes and the ever-increasing complexity of the recommended regimen of medications and other self-care activities.

The design of this study had three features that built upon previous research in this area:

1) This study examined adherence to diabetes regimen from both objective and subjective perspectives. Quantitative analysis was used to examine the associations among the four independent variables—self-efficacy, illness demand, family support, and satisfaction with medical care—and the two dependent variables, adherence and quality of life. Analysis of the qualitative data enhanced the interpretation and understanding of quantitative data. Both types of data contributed to attaining a fuller understanding of adherence or nonadherence to regimen among persons with Type 2 diabetes.

2) This study focused on individuals with Type 2 diabetes who do not require insulin. Although 90% of persons with diabetes are classified as Type 2, most of the previous research on nonadherence has focused on persons with Type 1 diabetes and/or those who require insulin.
3) Finally, this study was unique in its examination of the influence of quality of life assessment as both an input into, and outcome of, decisions regarding adherence to regimen.

The findings of this study have contributed to the body of knowledge of adherence to self-care activities in adults with Type 2 diabetes. Although further research is needed to clarify the relationships among self-efficacy, quality of life, and adherence, several implications have been identified for the practice of clinicians who work with this population.
CITED LITERATURE


## APPENDIX A

### Table of Variables and Instruments

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<thead>
<tr>
<th>Study Variable</th>
<th>Instrument(s)</th>
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<tr>
<td>Illness demand</td>
<td>Appraisal of Diabetes Scale</td>
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<tr>
<td>Self-efficacy</td>
<td>Insulin Management Diabetes Self-Efficacy Scale (modified)</td>
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<tr>
<td>Support from family members</td>
<td>Diabetes Family Behavior Checklist</td>
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<tr>
<td>Satisfaction with medical care</td>
<td>Satisfaction With Care Questionnaire (modified)</td>
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<td>Quality of life</td>
<td>Quality of Life Index-Diabetes version</td>
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<tr>
<td>Adherence to regimen</td>
<td>Diabetes Self-Care Activities</td>
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APPENDIX B
INTERVIEW QUESTIONS

1. Tell me about yourself: how long have you had diabetes and what has it meant for you to take care your diabetes? (What are some problems you’ve been having taking care of your diabetes?) (At some point during interview, ask about average blood sugars and HbA1c’s)

2. From your point of view, what do you think you are expected to do in order to manage your condition?

3. Tell me about a typical day for you. What do you do each day to take care of your diabetes? (How easy or difficult is it for you to do each of these things?) To what extent do you feel able to do what is necessary to control your diabetes? How much does following your treatment plan make a difference in controlling your blood sugar and in how you feel?

4. To what extent do you think managing diabetes is “tricks of the trade” compared with following professional advice? Do you ever make changes in your regimen? If so, how and when do you make changes? (Do you consult with your doctor or another professional at the Diabetes Center?)

5. How long have you been a patient at the Diabetes Center? Can you tell me about your relationship with the staff at the Center? What do they do that helps you manage your condition? What do they do that makes it harder? Do you think your doctors and the other staff members understand your situation pretty well? Describe how you feel about this.

6. In what ways has your family life or relationships within your family changed because of your diabetes? Is there anyone who is especially helpful to you? What do they do that helps you? Is there anyone in your family who makes it harder for you to manage your condition? If so, what do they do that makes things harder?

7. What parts of your life are you very satisfied with, and what parts are you not satisfied with? What effect would it have on your quality of life if you did everything in your diabetes regimen exactly as recommended (would QOL be better or worse)? What, if anything, would you like to change in your life in order to make it better?
APPENDIX C

CODE LIST

"I know what to do but I just don’t do it."
"If I would have known"
"It's just something you deal with"
"it's such a individual thing."
"maybe I can trick myself"
"You've got to use your head."
"you have to help yourself"
*Quality of life and Regimen effe..*
*self-efficacy & high & Glucose Te..*
*self-efficacy & high & Medicati..*
*self-efficacy & low & Glucose Te..*
*self-efficacy & low & Medicati..*
*support & Negative & Family*
*support & Negative & Non-family..*
*support & Negative & Spouse*
*support & Positive & Family*
*support & Positive & Non-family..*
*support & Positive & Spouse*
Able to adapt diet
Able to adjust to changes in routine
Able to follow routine or be organized
Collaborative attitude (MD or HCP)
complications of DM
Diet Change OR Problems
Effective coping strategies
Exercise aspects
Family helpful behaviors
Family helpful behaviors or positive support
Family unhelpful behaviors
Family unhelpful behaviors or negative support
Fear of complications
Feeling resentful about diabetes
food cravings
Glucose Testing
Helpful behaviors
Helpful behaviors HCP’s
Helpful behaviors MD
High diet self-efficacy
High exercise self-efficacy
High satisfaction with care
High self-efficacy
illness demand
Ineffective coping strategies
Limitations d/t DM or complications
Losses
Low diet self-efficacy
Low exercise self-efficacy
APPENDIX C (continued)

Low satisfaction with care
Low self-efficacy
Outside home or work
Problems with diet
quality of life
quality of life hi OR pos
quality of life low OR neg
Regimen effects
satisfaction with care
self-efficacy
Sense of personal responsibility
spiritual aspects
Spouse
Spouse helpful behaviors
Spouse helpful behaviors or positive support
Spouse unhelpful behaviors
Spouse unhelpful behaviors or negative support
stress as an impediment to control
support
Typical Day
unhelpful behaviors
Unhelpful behaviors HCP's
Unhelpful behaviors MD
Weekend/non-work days
will power/discipline
Work
NOTICE OF APPROVAL FOR AN EXPERIMENTAL PROJECT ON HUMAN SUBJECTS

INSTITUTIONAL REVIEW BOARD

Board #2
IRBNO: H-99-182

Project Title: Quality of Life and Adherence in Adults with Type 2 Diabetes

Principal Investigator: Michele Poradzisz, Carol Ferrans,
Department: Medical-Surgical Nsg

Sponsoring Agency: 
Grant or Contract No: 

Campus: New X

The above research project has been reviewed by the Institutional Review Board. The Board approved, as appropriate and ethical:

(1) the procedures to be used to protect the rights and welfare of the human subjects involved;
(2) the method(s) for obtaining informed consent of the participants.

The Board concurs that the risks to the human subjects involved are consonant with the potential benefit of the knowledge to be derived.

It is the investigator's responsibility to note and abide by the dates specified above. Approval of a protocol which is not renewed or which has been active three (3) years is automatically terminated. The investigator has the individual responsibility for securing the above rights and consent for using procedures that involve minimum risk. The investigator is to be guided in his or her conduct by The NIH OPRR Protecting Human Research Subjects IRB Guidebook available in the UIC Office for Protection from Research Risks. It is understood that review of this experimental project for conformity with policy regarding use of human subjects will be the responsibility of the following members of the Departmental Review and Surveillance Committee:

Saundra L. Theis, Ph.D Julia A. Zerwic, Ph.D Sharon L. Merritt, EdD

The Institutional Review Board trusts that all concerned parties will fulfill the responsibilities which they have accepted as outlined in the Assurance of Compliance with the Department of Health and Human Services (Assurance Identification Number M-1095). The Assurance of Compliance is available on line at http://www.uic.edu/depts/over/oprr/irb/mpa or a copy may be obtained from the OPRR office. No changes may be made in procedures to be followed nor the consent form(s) to be used until such modifications have been submitted to the IRB for review and approval has been given. Any unanticipated problems involving risk to human subjects and any serious adverse effects must be reported promptly to the IRB.

Comments:

Chairman, Institutional Review Board Date 05/21/99

Phone

oppfl

c:

UIC
VITA

NAME
Michele Poradzisz

EDUCATION
Ph.D., Nursing Science, Department of Medical-Surgical Nursing
University of Illinois at Chicago, College of Nursing, 2001

Master of Science in Rehabilitation Nursing, Cum Laude, 1982
Saint Xavier College, Chicago, Illinois

Bachelor of Science, Nursing Major, 1969
Saint Xavier College

ACADEMIC
APPOINTMENTS
Assistant Professor, School of Nursing, Saint Xavier University
9/94 - present

Teaching Assistant, College of Nursing, University of Illinois at Chicago
Summer, 1997; Summer, 1998

Clinical Instructor, Department of Medical-Surgical Nursing
University of Illinois at Chicago College of Nursing
Spring semester, 1994

Instructor, Department of Nursing, DePaul University, Chicago, IL
9/86 - 6/93

Medical-Surgical Nursing Instructor
South Chicago Community Hospital School of Nursing
3/71 - 8/76 and 6/83 - 6/86

Course Instructor, Pharmacology for Nurses, Kennedy-King College
Spring semester, 1986

Instructor, Basic Certified Nursing Assistant Training Program
Chicago City-Wide College
6/83 - 8/83

OTHER
APPOINTMENTS
Project Faculty, Chicago Institute for Nursing Education
Saint Xavier University
9/97 - present

Project Coordinator, Nursing Continuing Education
Moraine Valley Community College
9/81 - 2/82

Coordinator, Nursing Continuing Education, Chicago City-Wide College
5/81 - 3/82
Nursing Education Instructor, Palos Community Hospital
Palos Heights, IL
7/78 - 11/79

Media Coordinator, South Chicago Community Hospital School of Nursing
10/76 - 6/78

CLINICAL EXPERIENCE

Staff Nurse, Mercy Hospital and Medical Center (Casual basis)
6/90 - 4/97

Staff Nurse, Medical Personnel Pool
5/80 - 5/83

Staff Nurse, Mercy Hospital and Medical Center
6/69 - 3/71

Funded Research

Principal Investigator, "Variables Affecting Adherence and Quality of Life in Adults with Type 2 Diabetes," funded by American Association of Diabetes Educators, 9/1/99-8/31/00 ($5,000) and by American Nurses Foundation, 10/1/99-5/31/01 ($3,500)

Funded Projects

Co-recipient of grant to investigate interactive video at National Library of Medicine, funded by Quality of Instruction Council, DePaul University, 6/90, $2,000.

Awards

1999 Kate Doyle New Investigator Award, American Association of Diabetes Educators

1999 American Nurses Foundation Scholar

Publications


Presentations

"Variables Affecting Quality of Life and Adherence in Adults With Type 2 Diabetes"
Research presentation at Annual Meeting of the American Association of Diabetes Educators, Louisville, KY, 8/01

"Concept Mapping: A Multi-Purpose Tool in the Nursing Curriculum"
Presentation at "Assessing Program Outcomes: 5th National Conference for Nurse Educators," Indianapolis, IN, 11/00

"Using Concept Maps as a Tool for Teaching, Learning, and Evaluation"
Presentation at Chicago Institute for Nursing Education 4th Annual Summer Institute, Schaumburg, IL, 7/00
“Psychometric Properties of the Quality of Life Index—Diabetes Version,”
Poster presented at the 59th Scientific Sessions of the American Diabetes
Association
San Diego, CA, 6/99

“Discharge Planning Conferences on a Surgical Unit,“
Poster presented at Quest for Quality,
National Medical-Surgical Nursing Conference
Rochester, MN 9/91

Workshops Presented:

Co-Organizer,
Use of Interactive Video in the Nursing Curriculum
DePaul University, 11/90

Instructor, NCLEX Excel! Review Course

Tutoring Sessions for NCLEX-RN Candidates
Evangelical Health Systems, 1/87

Medical-Surgical Nursing Review for NCLEX-RN
Evangelical School of Nursing, 1/87

Surgical Nursing Review
(Preparation for NCLEX-RN)
Moraine Valley Community College
6/81, 1/82, 1/83, 2/84, 1/85

Continuing Education Programs for RN’s:
Nursing Care Process, Moraine Valley Community College, 2/84

Patient Education: Strategies and Methods
Moraine Valley Community College, 2/84

Drugs and the Nervous System, Moraine Valley Community College, 2/83

Current Drug Update
(Sponsored by Chicago City-Wide College)
Bethany Methodist Hospital, 1/83
Holy Cross Hospital, 10/82
Belmont Community Hospital, 9/82

Pharmacology Update: A Systems Approach, Palos Community Hospital, 2/79

Coping with Nursing Audit, Palos Community Hospital. 1/79

CREATIVE ACTIVITIES

“Nursing Department—40 Years”
Display for DePaul University Library, 5/89

Editor, INA District 20 Monthly membership newsletter, 5/88-5/90
Reviewer for the following texts:

Mosby’s Drug Reference, 11/92
Medical-Surgical Nursing, Mosby, 12/88
Fundamentals of Nursing, Addison-Wesley, 11/88
Clinical Nursing Skills, Saunders, 3/88
Mosby’s Nursing Pharmacology, 3/88

MEMBERSHIPS

American Nurses Association
IN Illinois Nurses Association, District 20
PROFESSIONAL
ORGANIZATIONS
Membership Committee Chairperson, 5/94 - 5/96
Treasurer, 5/90 - 5/94
2nd Vice-President, 5/88 - 5/90
Nominations Committee Member, 1988
District delegate to INA Biennial Convention, 12/89, 12/91, and 10/97

Sigma Theta Tau International, Alpha Omicron Chapter
Bylaws Committee Member, 1988-91
Corresponding Secretary, 1986-88
Sister Annette Walsh Symposium Planning Committee, 1986-88
Co-editor of chapter newsletter, 1986-88

Sigma Theta Tau International, Alpha Lambda Chapter

American Diabetes Association, Professional Section

American Association of Diabetes Educators

COMMUNITY
SERVICE
Member of Parish Nurse Group,
Saint Christina Church, Chicago, IL, 5/97 - present