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Adolescents' Experience of the Factors Influencing Their Diabetes Treatment Regimen

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ADOLESCENTS' EXPERIENCE OF THE FACTORS INFLUENCING
THEIR DIABETES TREATMENT REGIMEN

by

Roger W. Apple

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Submitted to the
Faculty of The Graduate College
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Advisor: Norman Kiracofe, Ph.D.

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ADOLESCENTS' EXPERIENCE OF THE FACTORS INFLUENCING THEIR DIABETES TREATMENT REGIMEN

Roger W. Apple, Ph.D.

Western Michigan University, 2009

The purpose of this study is to better understand and provide a description of the factors that influence adolescents' adherence to the diabetic treatment regimen from the adolescents' experience. The sample consisted of nine adolescents diagnosed with Type I diabetes. A qualitative phenomenological methodology is used to look for significant statements, meanings, and themes that resulted in an exhaustive description of the adolescents' experience.

In-depth interviews are the primary method of data collection. Data analysis includes: transcribing the interviews and reading the transcripts, extracting significant statements, developing formulated meanings, organizing the formulated meanings into clusters of themes, and developing an exhaustive description of the phenomenon. Arriving at the final description involved writing individual and composite textural and structural descriptions. Through this process, eight overarching structural elements emerge as some of the most salient results of the study and are defined as the eight treatment schemas. Other prominent results include illustrating the highly psychosocial context of diabetes treatment and that each adolescent's experience with diabetes must be viewed individually within his or her unique life context to be most accurately understood.

Implications may have far-reaching effects in helping physicians and adolescents come to a shared perspective regarding the influences affecting diabetes treatment adherence, in helping physicians better understand their adolescent patient's experience of following the diabetic treatment regimen, and in illustrating the importance of counseling psychologists in the treatment of adolescents with diabetes.

The proposed study could fill several needs: (a) provide a voice for adolescents diagnosed with diabetes; (b) fill a void in the literature regarding adolescents' experience with the factors that influence their treatment regimen; (c) illustrate the value and usefulness of counseling psychologists in medical settings; (d) provide valuable information to the medical community, which hopefully will lead to a better understanding of how adolescents experience the factors influencing the diabetes treatment regimen; (e) provide a basis for improved physician/patient relationship; and (f) possibly lead to improved health for adolescents with diabetes.

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CHAPTER I

INTRODUCTION

I began seeking to understand the phenomenon of adolescents' experience with their diabetes treatment regimen while working as a psychologist in a pediatric medical setting and completing a Ph.D. in counseling psychology. Many of the physicians in that facility were often frustrated with the pervasive problem of their adolescent patients not following the prescribed treatment regimen. Soon I understood the physicians' frustrations after seeing adolescents hospitalized due to the consequences of not following the recommended treatment. It became clear, after conversations with several physicians, that understanding how adolescents with diabetes struggle to follow their treatment regimen is, at best, difficult. In addition, first-person accounts of how adolescents experience diabetes treatment were nonexistent in the literature. Even during these preliminary stages, my thoughts about how counseling psychologists could positively impact adolescents' diabetes treatment and the medical community began to form.

As I set out searching for literature on this topic, I found several studies and scholarly papers that discussed factors influencing treatment adherence, but relatively few that discussed the factors as specifically identified by adolescents. It was somewhat alarming that there was very little scholarly activity that directly asked adolescents about this phenomenon, which further increased my interest in the topic. This study does

exactly that—directly discusses with adolescents the factors that influence their diabetes treatment and provides them with a voice that is absent from the literature.

This study fulfills several needs: it (a) provides a voice to adolescents diagnosed with diabetes; (b) fills a void in the literature regarding adolescents' experience of the factors that influence their treatment regimen; (c) provides valuable information to the medical community, which hopefully will lead to a better understanding of diabetic adolescent treatment adherence; (d) provides a basis for improved physician-patient relationship; (e) possibly leads to improved treatment and health for adolescent with diabetes; and (f) illustrates the value and usefulness of counseling psychology in medical settings.

It is both interesting and puzzling to realize that adolescents with diabetes could live relatively healthy lives if they followed their prescribed treatment regimen. Understanding how this phenomenon occurs is what initially piqued my curiosity and desire to learn more about this topic. In general, I wanted to gain a better understanding of the lived experience and essence of diabetes treatment adherence as experienced by adolescents—more specifically, to understand the influences, or combination of influences, that make it extremely challenging for many adolescents to follow their prescribed treatment regimen, and what specifically adolescents would identify as the influences of their treatment regimen.

Overview of the Research

Barriers and Facilitators Overview

The literature regarding the influences affecting diabetes treatment adherence by adolescents is heavily weighted toward barriers that prevent patients from following their treatment regimen. And, to a lesser extent, some literature discusses the facilitators that encourage patients to follow their diabetes treatment regimen. For purposes of clarity, the first part of this section is devoted to discussing barriers, while the second part discusses facilitators. None of the articles reviewed for this paper made such a clear distinction between barriers and facilitators.

The six categories of barriers to diabetes treatment adherence discussed in the literature include treatment regimen, physician characteristics, patient characteristics, psychological and psychosocial factors, structural factors, and bias within the literature. Specific examples of barriers from these six categories include the complex treatment regimen, emerging independence of adolescents (Strawhacker, 2001), acceptance of diabetes (Franciosi et al., 2004), low self-efficacy (Logan, Zelikovsky, Labay, & Spergel, 2003; Strawhacker, 2001), and physicians ignoring psychological and sociocultural factors (Bissel, May, & Noyce, 2004; Rosina, Crisp, & Steinbeck, 2003). Additionally, the literature does not adequately define the terms *adherence* and *compliance* (Koeningsberg, Bartlett, & Cramer, 2004) and characterizes the patients' personality as irresponsible or defiant (Hunt & Arar, 2001).

The review of the literature also yielded six categories of facilitators that appeared surprisingly similar to the six categories of barriers. This could mean that the factors that

function as barriers may also function as facilitators under different circumstances. These categories include treatment regimen, physician-patient relationship, physician characteristics, patient characteristics, psychological factors, and psychosocial factors. Some specific examples of facilitators from these six categories include individualized treatment plans, permanent lifestyle changes, providing the patient with choices (Koenigsberg et al., 2004), a shared understanding, concordance (Mainous, Goodwin, & Stange, 2004), preventive care (Smith, 2004), and physicians' ability to understand personal history of patients (Bissel et al., 2004; Ditmyer & Telljohann, 2003). Additional examples of facilitators include the physicians' ability to enable their patients (Kerse, Buetow, Mainous, Young, Coster, & Arroll, 2004), letting patients know what is expected of them (Smith, 2004) as well as involving the family in treatment (Koenigsberg et al., 2004), and community and social support (Van Boemel & Lee, 1999).

The descriptions of barriers and facilitators within the literature seemed to lack clarity and were often confusing. The overwhelming problem with treatment adherence among adolescents diagnosed with diabetes could suggest that the most salient factors influencing the diabetes treatment regimen have yet to be uncovered. This could also suggest a wide array of variables interrelated in a manner that is difficult to untangle. Qualitative methodology has shown the ability to make sense of and explain complex and unclear phenomena, as well as to uncover hidden variables, all of which support the need for this study.

Purpose of the Study

The purpose of this phenomenological study was to gain a better understanding and provide a description of the influences that affect adolescents' adherence to the diabetes treatment regimen from their experience. Within the literature review, the influences that affect adolescents' ability to adhere to the diabetic treatment regimen were generally defined as barriers and facilitators. A more detailed discussion regarding terminology, including the use of the terms *barriers* and *facilitators*, concludes this chapter.

Primary Research Question

The primary research question is: From the experience of adolescents diagnosed with diabetes, what are the factors influencing the diabetes treatment regimen? In a qualitative phenomenological study, the research question is purposefully written in an open-ended, evolving, and nondirectional manner in order to obtain the patients' true, unbiased recollection of the factors influencing treatment (Creswell, 1998). The question should also seek to explain, describe, and explore the phenomenon (Marshall & Rossman, 1995). Marshall and Rossman explained that "research questions should be general enough to permit exploration but focused enough to delimit the study" (p. 26).

Research Methodology

This study uses a qualitative approach and phenomenological tradition of inquiry to research what adolescents diagnosed with diabetes identify as the factors influencing

their diabetes treatment regimen. Recruitment and criterion selection procedures are discussed specifically in Chapter III. In keeping with the phenomenological tradition of inquiry, in-depth interviews were the primary method of data collection. Participants were asked to discuss, from their personal experience, what factors influence their treatment regimen. The interview protocol utilized 11 interview questions based primarily on the aspects of the treatment regimen identified by Kamboj and Drazin (2006). In order to obtain the most salient responses during the interviews, the researcher addressed the following data collection concerns: access and rapport, purposeful sampling, field issues, the storage of data, and rigor, which are discussed more specifically in Chapter III. Data were digitally recorded, transcribed, and then analyzed, which yielded the exhaustive description of the phenomenon highlighting the essence of the lived experience of diabetes treatment for adolescents.

Scope of the Dissertation

The scope of this study was limited to illuminating adolescents' experience of factors influencing their diabetes treatment adherence. While a broad range of perspectives, including those of caregivers, physicians, medical staff, as well as administrators, teachers, and nurses within school systems could be relevant in relation to diabetes treatment, there is a void in the literature of adolescent first-person accounts. This study is designed to fill that void and provide a qualitative description of how adolescents experience diabetes treatment.

Implications

Studying the adolescents' experience using a qualitative phenomenological method of inquiry provided an extraordinary framework for adolescents to voice their thoughts, feelings, and beliefs, which are virtually nonexistent in the literature. This framework is illustrated in the results by including excerpts taken verbatim from the adolescents' descriptions. In addition, adolescents may have developed a deepened understanding of their experience through the process of participation and simply by having their personal stories heard. To further aid in understanding, future studies using the same methodology investigating other perspectives, such as those of caregivers and medical professionals, could help create a richer and more holistic understanding of adolescents' experience with the diabetes treatment regimen.

Implications of this study may have far-reaching effects for both counseling psychologists and medical professionals. Results indicated that many of the factors affecting adolescents' diabetes treatment regimen are psychosocial in nature. Because of this, counseling psychologists could have considerable impact by functioning as integrated members of medical teams, behavioral consultants, and traditional therapists to help address psychosocial factors and co-occurring mental health conditions that may have a detrimental effect on adolescents' diabetes treatment.

The potential benefits of counseling psychologists could be a tremendous asset to medical teams that simply do not have time to adequately address psychosocial factors at clinic visits that occur only once every 3 months. The results strongly suggest that if medical teams convey to adolescents empathic understanding of their unique life context,

treatment is likely to improve. Hopefully, the vivid descriptions offered by the adolescents help reframe the conceptualization of treatment adherence from one that is problem-focused to one that is holistically oriented and solution-focused.

Limitations

Limitations of this study include adolescent self-report, transferability issues, and lack of caregiver and physician perspectives. Adolescent self-report in qualitative interviews may function as a limitation for this study due to the likelihood that adolescents may not have a strong grasp on the factors influencing treatment adherence. The results of this study will not transfer to other populations and are valid only for the selected participants from the research site, which is customary in qualitative studies. However, as stated by Lincoln and Guba (1985), the researcher is responsible only for developing a working hypothesis, which will allow for consideration of transferability. Thus, each time someone wishes to use the results of this study, transferability must be evaluated.

Terminology

The terminology used to discuss this study presented itself as challenging, even from the beginning of the literature review process when it was discovered that many of the psychosocial and psychological factors were not defined. This concern also arose when several of these factors resulted from the data analysis. What was problematic is that the psychosocial and psychological factors were not the phenomenon being studied

and therefore were not clearly defined. However, future research could specifically set out to clearly define these factors in relationship to diabetes treatment.

During the initial conceptualization of this research, the best way to study diabetes treatment adherence appeared to be to identify the barriers and facilitators of the treatment regimen. However, the terms *barriers*, *facilitators*, and *adherence* became very problematic in describing what was being learned from the emerging data collection and analysis processes about the extreme complexity of diabetes treatment. I found that using such terms created a dichotomous picture of treatment adherence that was unable to capture the true essence of diabetes treatment experienced by adolescents. Because the data guided the research in this direction, the discussion of barriers, facilitators, and adherence gave way to a conversation about the factors that influence the diabetes treatment regimen is implemented. This change removed the dichotomous nature of the conversation and allowed the subtleties within the participants' descriptions to emerge, allowing the adolescents' voice to be heard.

One specific term that needs clarification before reading this study is *A1C*. A1C refers to the amount of glucose that attaches to red blood cells as determined by the glycosylated hemoglobin test. The more glucose attached to the red blood cells, the higher the A1C level. The A1C level is checked approximately every 2 to 3 months, usually during clinic visits, and represents average blood sugar during that time. Considering that daily blood sugar checks can be quite variable, the A1C level helps indicate how well diabetes is being managed overall.

CHAPTER II

LITERATURE REVIEW

This study focuses on illuminating adolescents' experience with the factors influencing their diabetes treatment regimen. The goal of this literature review is to examine literature related to discussing the factors that affect diabetes treatment, and, in particular, how these factors influence adolescents' maintenance of their treatment regimen. Reviewing and understanding the literature in this way provides an overarching and unique vantage point that considers various research studies on individual aspects of the phenomenon of how adolescents experience their diabetes treatment regimen. This perspective helps highlight many already identified factors relating to the phenomenon as well as areas that have received little attention.

Expecting to find an abundance of relevant literature, it was surprising to realize that, although there is literature dealing with adolescents and diabetes, there was not one study that dealt directly with first-person accounts of how adolescents experience diabetes treatment adherence. The lack of these accounts in the literature reveals that little attention has been given to hearing the adolescents' perspective. Furthermore, almost all of the literature emphasized what hinders treatment adherence, while only one article (Koeningsberg et al., 2004) directly discussed what encourages diabetes treatment adherence. The prototypical approach found within the literature was empirical studies and conceptual articles that reviewed treatment adherence of chronic illness in general,

most of which included diabetes in the analysis or discussion. However, reviewing this literature helped achieve greater balance, breadth, and depth in understanding factors that hinder and encourage treatment.

To provide clarity in the discussion of the influences of diabetes treatment adherence identified in the literature, two categories were created: *barriers* and *facilitators*. The creation of these categories provides the two main sections for this review and helps remove the ambiguity created by the various terms used in the original literature. Within each of these two categories, the individual factors are discussed. The goal of this was to gain a better understanding and provide a description of adolescents' experience with the influences that affect their diabetes treatment regimen. The barriers and facilitators currently identified in the literature provide a contextual foundation upon which this study is based.

A wide array of terminology is evident in the literature when describing factors that impede adolescent diabetes treatment adherence. Some have used the term *barriers* (Bissel et al., 2004; Logan et al., 2003), while others (Vinter-Repalust, Petricek, & Katic, 2004) have described impediments to the treatment regime as being *obstacles*. Many other authors described adolescents' difficulties in following their diabetic treatment regimen by discussing specific terms or ideas that could ultimately hinder treatment adherence. These include *noncompliance* (Helme & Harrington, 2003), *trust* (Hunt & Arar, 2001), *physician-patient relationship* (Kerse et al., 2004), *shared experiences* (Mainous et al., 2004), *treatment adherence* (Rosina et al., 2003), and *prevention and treatment* (Franciosi et al., 2004). A review of the terminology in the literature indicates a lack of understanding of the complexities of treatment, as shown by the many terms that

have multiple meanings in multiple contexts. However, the confusion about terminology could also suggest that a more complex view should be developed.

Such ambiguity in the literature also suggests significant problems in identifying the true barriers and facilitators of treatment adherence and supports the need for continued research. This lack of clarity regarding the influences affecting treatment adherence could also suggest many variables in this area. Very few qualitative studies were found in the area of diabetic treatment adherence, and no qualitative studies were discovered regarding the treatment for adolescents. This is interesting because studies with many potential variables may use qualitative methodology to help identify the most salient variables (Marshall & Rossman, 1995).

Six principal categories of barriers to treatment adherence were identified: treatment regimen, physician characteristics, patient characteristics, psychological, psychosocial, and bias within the literature. These categories of barriers identified in the literature will be defined as those used in treatment for adolescents with diabetes. The term *barriers* will be defined as any influence that interferes with the diabetic treatment regimen. Many of the same categories of barriers were also described as those factors contributing to treatment adherence. These factors will be defined as *facilitators* in this study. It would be too simplistic to assume that the same factors from each category function both as barriers and facilitators; it would make more sense that the function of these factors is determined by the context in which they are experienced. Context within which the factors occur is another area that has received very little attention in the literature.

Only one article directly discussed the factors that facilitate diabetic treatment adherence (Koeningsberg et al., 2004). Thus, it would appear that there is a bias in the literature toward identifying factors that impede diabetes treatment as opposed to those that provide encouragement. However, factors that contribute to treatment adherence across many chronic illnesses, including diabetes, were discussed in several empirical studies (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Franciosi et al., 2004; Kraetschmer, Sharpe, Urowitz, & Deber, 2004; Kerse et al., 2004; Mainous et al., 2004; Rosina et al., 2003; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Strawhacker, 2001; Vinter-Repalust et al., 2004) and a few conceptual articles (Koeningsberg et al., 2004; Smith, 2004). A review of the literature yielded six categories of facilitators: treatment regimen, physician-patient relationship, physician characteristics, patient characteristics, psychological, and psychosocial.

The identification of barriers and facilitators of diabetes treatment adherence as influenced by a *shared* physician-patient perspective, and, in particular, the patient perspective, is an area that has not been well studied. While previous studies have looked at the physician-patient relationship, few have considered how discrepancies within this relationship may affect treatment adherence for the chronically ill, especially adolescents diagnosed with diabetes (Helme & Harrington, 2003; Mainous et al., 2004).

Researching focused solely on the discrepancies within the physician-patient relationship could be an important area of study in and of itself. There is also a need to better understand, clarify, and provide a description of obstacles to adherence to the diabetes treatment regimen from the adolescent's experience. Future studies researching

the dynamic physician-patient relationship could yield potentially useful information in identifying these discrepancies.

The literature identified six categories of both barriers and facilitators that impact following the diabetes treatment regimen. The barrier issues will be described first, followed by a description of facilitators. Such a discussion will set the stage for a better understanding of the literature by providing a new perspective that will help highlight many previously identified factors as well as areas that have received little attention.

Barriers in the Treatment of Adolescents with Diabetes

Any discussion of barrier issues in the treatment of adolescents with diabetes is complicated by the fact that those same factors may also function as facilitators of treatment, depending on the unique and complex life context of each individual. The fluid nature of these factors results in an interplay among many of the categories. For purposes of clarity, the identified factors are discussed individually; however, many of the issues are interrelated and cannot be thought of as operating in isolation, as the complex nature of barriers and facilitators would be lost. Making sense of the identified factors by discussing them individually seems contradictory to understanding their complexity; however, it also represents an attempt to unravel the many factors that appear to be haphazardly tangled in the literature. By sorting out the many factors, their complexity can be viewed through a much cleaner lens.

Identifying and explaining the barriers and facilitators of treatment adherence of adolescents diagnosed with diabetes is difficult due to a lack of literature that focused specifically on adolescents. To more fully understand these issues, a review of some of

the treatment adherence literature for chronic illness in general was conducted (Atkinson et al., 2004; Bissel et al., 2004; Hunt & Arar, 2001; Kerse et al., 2004; Logan et al., 2003; Rosina et al., 2003). Many of these studies discussed several chronic illnesses, which usually included diabetes. This review helped provide a greater depth and breadth of information in the conceptualization of the barriers and facilitators of diabetes treatment adherence. For example, the empirical study by Atkinson et al. studied treatment satisfaction for medication for various patient groups, including type I diabetes, major depression, high cholesterol, hypertension, migraine, psoriasis, arthritis, and asthma. Their study discussed how route of medication, such as orally or by injections, plays a role in treatment adherence and specifically how injectable medications are associated with low satisfaction across patient groups, not just patients with diabetes. This information makes it fairly easy to generalize that adolescents with diabetes, who often use injections as their primary treatment method, may have low satisfaction with their treatment. Consequently, the prototypical treatment regimen for diabetes likely functions as a barrier for many adolescents.

The identification and heavy focus on psychosocial and relational categories of barriers is important for this study because previous studies on treatment adherence have often focused on defining barriers in relation to only the medical control of diabetes (Bissel et al., 2004). This is an important distinction that helps shift the focus of attention from a doctor-centered approach to a more collaborative approach in chronic illness disease management. This perspective helps avoid placing sole responsibility on the patient or medical team for problems associated with treatment adherence and begins to view problems with treatment adherence as symptoms of a larger and more systemic

problem. This emerging importance of the significance of psychosocial and relational categories is likely not very consoling to medical teams, as their role is only a small part of what influences their adolescent patients' treatment adherence. Psychosocial and relational barriers reflected in the broad categories of barriers to treatment adherence identified in the literature included: treatment regimen, physician characteristics, patient characteristics, psychological, psychosocial, and bias within the literature.

Treatment Regimen

Treatment regimen issues was one of the most frequently cited categories of barriers throughout primarily empirical studies and some conceptual articles for people diagnosed with diabetes. However, a missing piece from this literature is information to help adolescents overcome the tremendous obstacles in the treatment regimen. Often this was the case, as the discussion on identified barriers and facilitators did not address adolescents' ability to understand these factors and act on the information in a way to improve their treatment.

Several studies and articles combine results from patients with diabetes or other chronic illnesses (Atkinson et al., 2004; Bissel et al., 2004; Logan et al., 2003; Rosina et al., 2003; Strawhacker, 2001; Van Boemel & Lee, 1999; Vinter-Repalust et al., 2004). In a study by Strawhacker (2001) that discussed the management of type I diabetes, it was noted that the complicated nature of the diabetes treatment regimen alone causes significant problems with adherence, especially with adolescents. For optimal treatment adherence, a significant lifestyle change is required. Strawhacker indicated that for adolescents with diabetes, a significant lifestyle change includes a commitment to living a

structured schedule at home and at school, modifying their environments to control their symptoms, attempting to follow their treatment regimen, identifying and managing emergency situations, learning to accept an unpredictable disease course, maintaining adult and peer relationships, and working toward independence. For any researcher to advocate such a dramatic lifestyle change without recommendations as to how to successfully achieve it is surprising.

Strawhacker (2001) also mentioned that working toward independence is particularly difficult for adolescents diagnosed with diabetes, because at the same time they are also learning that dependency on their medical team is required for effective management of their disease. In fact, Logan et al. (2003) found that, in general, adolescents with difficult-to-manage illnesses encounter more barriers. With such an intensive lifestyle change, it is not surprising that following the diabetic treatment regimen can function as a tremendous barrier to overcome for many adolescents. What is not discussed in these studies is the interaction between the many identified barriers, which likely creates hidden challenges to treatment.

In the same vein, Strawhacker (2001) noted that adolescents might choose to ignore the information given to them by their medical team and to downplay the fact that they have diabetes. Many adolescents in this situation will choose to experiment with alcohol and other drugs and even refuse or falsify blood sugar checks. In some cases, adolescents will manipulate their insulin intake to control for weight gain or compensate for dietary intake. Strawhacker also noted that, unfortunately, many adolescents experience the effects of poor treatment adherence before they focus more effort on controlling and managing diabetes. Despite the efforts of medical teams, many

adolescents continue to report a lack of knowledge and understanding of their disease. This can function as a barrier to treatment adherence (Van Boemel & Lee, 1999; Vinter-Repalust et al., 2004) since there is little motivation when one does not understand what is being treated. Unfortunately, much of the research does not address the ability of adolescents to understand diabetes treatment. What is difficult to understand may not be diabetes, but rather the complex nature of the many factors influencing treatment.

In the study by Atkinson et al. (2004) in which a general measure of treatment satisfaction was being validated, other barriers associated with following the treatment regimen were identified, such as medication effectiveness, side effects, aversions to taking medications, and convenience. With all of these concerns combined, many adolescents reported that the demands of treatment adherence took control of their lives (Rosina et al., 2003). Following a complicated treatment regimen comes at a time when adolescents are searching for independence, which sharply contrasts with the suggestion that adolescents become dependent on their medical team to help manage their illness, even after they understand all of the tasks associated with maintaining the treatment regime (Strawhacker, 2001). Not one identified study attempted to explain how adolescents could achieve such a delicate balance between independence and dependence such that it would not be a negative influence on their treatment adherence.

Another barrier affecting the treatment regimen is the medical team. One of the most common negative influences of the medical team is that the team's primary goal is often helping the patient maintain appropriate blood glucose levels to the exclusion of other factors (Bissel et al., 2004). In addition, another factor related to the medical team is the limited support that adolescents receive from the team (Van Boemel & Lee, 1999).

According to Vinter-Repalust et al. (2004) and Strawhacker (2001), adolescents provide approximately 95% of their own diabetes care and routine visits with the team occur only every 3 months. This situation does not provide the adolescent with a sufficient amount of support from the medical team to maintain the diabetic treatment regimen, nor does it provide the diabetic team with much opportunity to learn about the individual needs of the adolescent, as noted by Strawhacker. In an ideal situation, the medical team would meet with the patients more often and spend a significant amount of time addressing psychosocial and relational barriers. If this type of interaction were possible, blood glucose levels should improve, as should overall treatment adherence. It may be unrealistic to dramatically increase the amount of time spent with patients; however, it is realistic to allow more time for discussing psychosocial and relational factors.

Treatment regimen is one of the most cited barriers facing adolescents and is undoubtedly a significant source of frustration for many adolescents. Because there are many factors that influence the treatment regimen, such as significant lifestyle changes, dependency on the medical team, the medical team itself, lack of knowledge, medication effectiveness and side effects, and aversions to medication, it is reasonable to assume that if an adolescent experiences several of these factors simultaneously, treatment adherence will be significantly negatively affected. Adhering to such a complex treatment regimen during the developmental stage of adolescence is difficult, but when combined with other barriers, adherence likely becomes even more challenging.

Physician Characteristics

Physician characteristics is also another frequently cited category of barriers affecting treatment adherence (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Franciosi et al., 2004; Hunt & Arar, 2001; Vinter-Repalust et al., 2004). Hierarchical “doctor-centered” approaches often create a polarizing effect between the physician and patient dialogue (Bissel et al., 2004; Hunt & Arar, 2001). Bissel et al. also noted in their study that such an approach could cause considerable divergence that develops between the professional and lay perspectives of diabetic treatment management. When this happens, according to Hunt and Arar (2001), incongruence occurs between the physician’s and patient’s point of view. This incongruence could result in the physician not listening to a patient’s complex life situation which must take place in order for treatment adherence to occur (Bissel et al., 2004). If the physician does not convey an understanding of the patient’s complex life context, it will be difficult for the doctor to understand how to best approach improving treatment adherence. This literature review consistently emphasizes the importance of understanding the complex life situation of adolescents. However, understanding such complexity requires a highly individualized approach to each adolescent and requires additional time during clinic visits.

The placement of responsibility for compliance with treatment expectations was raised in a study by Vinter-Repalust et al. (2004). They suggested that a doctor-centered approach to the management of diabetes may be patronizing to the patient by placing the focus on the disease rather than the person. Physicians in this situation often lose a

personal relationship with their patients and end up only prescribing the patient's medications. Many physicians with a doctor-centered approach, according to Hunt and Arar (2001), view chronic illness as only a pathophysiological problem and are concerned only with the technical control of the disease. This approach, created in part by specialists with a much-too-narrow focus, according to Vinter-Repalust et al. (2004), does not facilitate treatment adherence. Placing physicians' focus on the person rather than the disease means changing the personal interactions physicians have with their patients and could initially be quite uncomfortable for those accustomed to a more traditional approach.

Ditmyer et al. (2003) reported some surprising findings regarding general practitioners who treat diabetes. Only 15.5% of the sample reported that they felt confident in working with this type of patient. Ditmyer et al. also noted that 89.3% of the general practitioners did not refer patients for exercise, 62.3% did not refer for dietary interventions, and 62.6% did not encourage patients to seek educational services. In addition, Ditmyer et al. found that physician-perceived barriers for non-referral included costs not covered by insurance, lack of family support, and lack of community support. Barriers physicians perceived of themselves included lack of time to counsel, poor adherence of patients, lack of family support, lack of familiarity with American Diabetes Association (ADA) Clinical Practice Recommendations, lack of health care insurance, and lack of knowledge regarding nutrition. In this particular study, there was no distinction between perceived and actual barriers. A follow-up study exploring such a topic could yield very interesting results.

Physicians who practice from a doctor-centered approach often unknowingly create barriers to the treatment process. The trend in the literature is clearly in favor of abandoning a doctor-center approach and adopting a shared perspective approach that emphasizes the personal relationship with the patient as the primary concern, along with the medical management of diabetes. An important but missing piece is how physicians can make the transition from a doctor-centered approach to a more relational focused approach.

Patient Characteristics

The literature identified many characteristics of patients that function as barriers to treatment adherence (Franciosi et al., 2004; Kraetschmer et al., 2004; Logan et al., 2003; Miller & Drotar, 2003; Strawhacker, 2001; Van Boemel & Lee, 1999; Vinter-Replaut et al., 2004). For example, if patients perceive a low level of involvement by the physician, they may be hesitant to delegate any responsibility to the physician, which may lead to lower levels of satisfaction and ultimately poor treatment adherence (Franciosi et al., 2004). According to the study by Logan et al. (2003), if adolescent patients perceive a low level of involvement by the physician, they may not view their illness as severe and may be unmotivated to change. In light of this information it is surprising that many physicians prefer to discuss diabetes as a *condition* rather than a chronic illness, which could suggest to adolescents that their illness is not severe.

An adolescent's relational style is another barrier to treatment adherence. Miller and Drotar (2003) found that autonomous adolescents who perceived they had more decision-making ability in the management of their disease often had difficulty adhering

to their treatment regimen. Strawhacker (2001) points out that adolescence is a time when independence becomes increasingly more important. However, for adolescents with diabetes, interdependency on the medical team, parents, and the school system is necessary. Therefore, an autonomous adolescent who has focused on developing independence may find it particularly difficult to be interdependent.

For many adolescents this transition is not only from an autonomous role but also from a dependent role (Strawhacker, 2001). Many children, especially those diagnosed early in childhood with a chronic illness like diabetes, learn to depend on others very early in life, particularly if the medical team and physician's focus is doctor-centered. However, when these children reach adolescence, their increased desire for independence can begin to function as a barrier to interdependence (Strawhacker, 2001). For those diagnosed during adolescence there is an immediate and abrupt confrontation with their newly developing sense of independence and the necessity of interdependence for good management of their diabetes. This abrupt confrontation of independence and interdependence is likely a tremendous barrier that adolescents, their caregivers, and the medical team may have difficulty understanding. Strawhacker further explained that many physicians and patients alike might initially resist an interdependent style of interaction because it is initially uncomfortable for both, but it is what is needed for increased adherence. Simply, it is the *transition* from the doctor-centered dependent style to an interdependent style that can function as a barrier to following the treatment regimen.

In another study by Kraetschmer, Sharpe, Urowitz, and Deber (2004), autonomous patients often had low levels of trust in their medical team, thus leading to poor treatment

adherence. In the study by Van Boemel and Lee (1999), patients with an external health locus of control found it more difficult to adhere to their treatment regimen. The combination of an external health locus of control with an autonomous relational style may make it particularly difficult for adolescents to follow their treatment regimen. This is very similar to the study by Miller and Drotar (2003), which showed an autonomous relational style combined with other factors can make treatment adherence difficult. These three studies indicated that an autonomous relational style combined with internal or external factors (i.e., strong perception of decision-making ability, low levels of trust in the medical team, and an external locus of control) make following the diabetes treatment regimen very difficult.

Social and emotional barriers may develop for adolescents due to a number of reasons, according to Strawhacker (2001), such as checks on blood sugar, schedule adjustments at school to visit the nurse, trips to the office to take medication, increased attention by having snacks in the classroom, and the feeling of being different from other students. Because of these concerns, adolescents may not maintain diabetic control and, as a result, may not grow normally and may experience delayed puberty. For adolescents already experiencing a changing body image, attempting to integrate the diabetic treatment regimen may be particularly difficult. The absence of these barriers likely functions as reinforcement for not following the treatment regimen unless negative immediate consequences are experienced.

The physical characteristics of the developmental period of adolescence present their own barriers to treatment adherence. When children go through puberty, their bodies become more sensitive to insulin and, as a result, following a treatment regimen and

maintaining metabolic control may become more difficult (Miller & Drotar, 2003). In addition, many adolescents report a belief that taking insulin is connected to a more severe form of the disease and thus they may be unmotivated to follow their treatment regimen (Vinter-Repalust et al., 2004). In this example, the larger the amount of insulin required, the larger the barrier between the adolescent's sense of independence and adherence to the treatment regimen to stay healthy (dependence). Again, if no immediate negative consequences are experienced, it is reasonable to assume that many adolescents will choose to reduce their discomfort in this situation and not follow their treatment regimen.

Another patient characteristic identified by Van Boemel and Lee (1999) as a barrier to treatment adherence is that of traditional sex roles. Men in the family tend to resist the dramatic dietary changes necessary to maintain glycemic control for the person diagnosed with diabetes. Rather than spend the time and money to prepare two meals, the women in the family prepare traditional foods rather than what is recommended by their medical team to maintain glycemic control. Van Boemel and Lee suggested that traditional sex roles, as well as family adherence to a traditional diet, may serve as a hidden barrier to treatment adherence and pointed out that such barriers may be abstract and need to be uncovered. The literature as a whole also appears to be suggesting that many of the factors influencing the diabetes treatment regimen are abstract and have yet to be uncovered.

Patient characteristics that function as barriers are broad in scope, but many have an interwoven theme relating to adolescents' experiences with diabetes treatment. For example, specific barriers are the adolescent's perceptions of several factors, including

the physician's level of involvement, severity of illness, decision-making ability, health locus of control, and how peers view diabetes. Other specific barriers within this category include relational style, interdependence, age of diagnosis, puberty, and social and emotional issues. Such a wide array of patient characteristics that function as barriers supports the idea of the medical team placing significant effort on understanding the complex life history of each patient, as each patient likely experiences a unique combination of these factors. If the medical team does not have a good understanding of patient characteristics, the development of interdependence with the medical team, which is viewed by many as essential for treatment adherence, will likely not develop.

Psychological

Psychological and mental health factors were also cited frequently throughout the literature as barriers to treatment adherence (Atkinson et al., 2004; Bissel et al., 2004; Franciosi et al., 2004; Koeningsberg et al., 2004; Logan et al., 2003; Rosina et al., 2003; Strawhacker, 2001; Van Boemel & Lee, 1999). Franciosi et al. (2004) and Koeningsberg et al. (2004) found that lower levels of psychological adaptation and/or acceptance of diabetes, as well as lower levels of education and more severe clinical conditions, can lead to less patient satisfaction. Other studies (Logan et al., 2003; Strawhacker, 2001) also documented similar findings in which adolescents with low self-efficacy and cognitive difficulties may resist following their treatment regimen; thus, the researchers equated poor diabetic control with a negative self-concept.

Strawhacker (2001) also noted that the psychological concept of normalization, which refers to how families minimize the importance of treatment as if diabetes were not

a serious issue, is a barrier to diabetic treatment regimen. Other studies (Rosina et al., 2003) have reported that if the physician does not pay attention to psychological and social influences, the impact will lead to an increased risk of not following the diabetic treatment regimen. Emotional factors (Bissel et al., 2004), as well as depression, general poor mental health, psychological well-being, and presence of psychological complaint (Van Boemel & Lee, 1999), were all identified as barriers to treatment adherence. It is important to note that many of the terms used to describe psychological and psychosocial type barriers, such as *lower levels of education*, *low self-efficacy*, *poor mental health*, *psychological well-being*, *psychological complaint*, and *cognitive difficulties*, were not clearly, if at all, defined in the literature. This is because these terms are not the variables being researched but rather mentioned in the implications and discussion sections.

Vague descriptions of psychological factors provided in the literature may be due to the fact that such factors are often the results of studies rather than the variables being researched. Another reason could be that much of the information regarding diabetes treatment adherence is found in the medical literature, which does not emphasize psychological factors. Nonetheless, it is surprising that a concept such as *treatment adherence*, which is inherently related to psychological constructs, is viewed by many as only a medical problem. The literature suggests that treatment adherence is a symptom of a very complex problem rather than the problem itself.

Psychosocial

The psychosocial category of barriers also plays a significant role in treatment adherence (Hunt & Arar, 2001; Koeningsberg et al., 2004; Logan et al., 2003; Miller &

Drotar, 2003; Rosina et al., 2003; Strawhacker, 2001; Van Boemel & Lee, 1999).

Psychosocial factors, along with family issues and sociocultural factors, are often ignored by many physicians and, as a result, may function as a barrier to treatment adherence (Bissel et al., 2004). However, it is unclear from the study by Bissel et al. whether physicians are aware of this oversight. Perhaps increased awareness or stronger emphasis on the importance of psychosocial factors, combined with the importance of the medical control of diabetes, would help improve treatment adherence.

Logan et al. (2003) found that family, peers, and the medical team could all function as barriers to treatment adherence. The family of someone with a chronic illness often perceived the barriers to following the treatment regimen as lack of support, lack of resources, and the family members' perception of the illness, which often is in relation to perceived severity of illness. Logan et al. found that unless adolescents perceive their illness to be severe, they may be unmotivated to follow their treatment regimen.

Adolescents' understanding of severity is likely also influenced by the medical team. Many members of medical teams insist on discussing diabetes as a *condition* that must be lived with for the rest of the patient's life. This perspective of the medical team likely reinforces the belief in many adolescents that diabetes is not a severe illness. This also illustrates inconsistent behavior of medical teams who support a belief that diabetes is not a severe illness by referring to it as a *condition*, while attempting to encourage medical control and warning about the severe risks of not following the treatment regimen. Such contradictory behavior likely does not help develop an interdependent relationship. The medical team can also impede the treatment regimen when there is a poor relationship with the family and problems with effective communication. One factor affecting the

medical team's relationship with families is the families' perception of illness. However, other factors may cause poor relationships with families and thus serve as a barrier to treatment adherence.

Other psychosocial barriers identified include lack of social support, level of self-efficacy, depression, denial and distrust, and peer and family issues (Koeningsberg et al., 2004; Logan et al., 2003; Rosina et al., 2003; Van Boemel & Lee, 1999). The study by Miller and Drotar (2003) found that family issues may range from typical adolescent-parent conflict, decreased parental involvement, discrepancies in perceptions of parents and adolescents, parents' worry about how much responsibility to grant to their adolescent in the management of their disease due to the long-term consequences of not following their treatment regimen, to more serious forms of dysfunctional families. Miller and Drotar (2003) and Van Boemel and Lee (1999) also noted that, in some cases, health care professionals do not take into account some of the most extreme cases of family dysfunction. This lack of attention to family issues on the part of health care professionals very likely functions as a barrier to treatment adherence. Health care professionals may be aware that some patients struggle with family issues but are unsure how to address these problems. Health care professionals also are likely not fully aware of the extent to which family issues can affect treatment adherence.

More barriers within the psychosocial category include sociocultural barriers such as differing role expectations, conflicts in values, decreased motivation, race, religion, gender, and cultural influences (Strawhacker, 2001), and structural factors such as financial costs of treatment recommendations, work, housing, and general finances (Bissel et al., 2004; Rosina et al., 2003).

The lack of sociocultural focus integrated into patients' treatment regimens can be quite problematic for adolescents according to the work of Hunt and Arar (2001). This is supported by Bissel et al. (2004), who found that competition between contrasting factors influenced dietary noncompliance. For example, following a strict diet may not be that challenging but when faced with a combination of many barriers may become a tremendous challenge.

Psychosocial factors such as lack of financial resources, cultural values and beliefs, and family issues call into question the amount of influence of the medical team. The literature suggests that many physicians may not understand how to address many psychosocial factors and, as a result, these factors may function as barriers to treatment adherence. This problem exists in the medical profession as well as in the educational professions, as school systems are consistently forced to fight against negative influence from their students' environment in order to provide the best and most effective education possible. Despite the best efforts of the medical team, their influence over psychosocial factors may be minimal. The resolution of psychosocial barriers may not come from the medical team but from much larger social change initiatives.

Lastly, the literature provides good descriptions and lists of the psychosocial factors that likely have a negative impact on treatment; however, the enormity of these factors is not discussed. When a person suffers from multiple medical concerns, it is understandable how patients could easily become discouraged. But, when a person suffers from multiple psychosocial factors, society is not so kind and may describe any challenges with those factors as personal weaknesses. The literature reviewed does not go

so far as to blame the adolescents for the many psychosocial struggles; however, the emphasis on the significance of those factors appears weak.

Bias in the Literature

As alluded to in the previous paragraph, the style in which treatment adherence is conceptualized in the literature can also function as a barrier. Koeningsberg et al. (2004) stated that patients are often categorized as noncompliant, but the literature offers little explanation as to the meaning of terms such as *noncompliance* and *adherence*.

Interestingly, as noted in the study by Vinter-Repalust et al. (2004), the terms *compliance* and *adherence* imply obedience on the part of the patient and suggest that lack of adherence demonstrates irresponsibility or defiance rather than a legitimate choice.

Problems with treatment adherence are very complex, and adolescents, parents, and medical teams may all have difficulty comprehending the full spectrum of barriers. Thus, when the literature describes problems with treatment adherence in a style that suggests irresponsibility or defiance, an inaccurate and simplistic representation of the problem is portrayed. One positive suggestion found in the literature (Logan et al., 2003) is that adherence should be conceptualized on a continuous and fluid spectrum. This would remove the dichotomy often used to describe patients as only adherent or non-adherent and would provide a place to discuss the complexities of diabetes treatment adherence. This lends support to looking at diabetes from a more overarching perspective with the goal of better understanding problems with treatment adherence.

Similar factors about the literature were found by Hunt and Arar (2001), who noted that the literature makes problematic only the patient's personality with little regard

given to the influence of the physician's personality. However, there is ample contradictory literature cited in the *Physician Characteristics* section above that discusses how physician characteristics also function as barriers. These problems ultimately undermine a team or shared approach to treatment and may also function as a barrier (Bissel et al., 2004; Strawhacker, 2001). The idea that the terminology used to discuss problems with treatment adherence acts as an additional barrier has received little other attention in the literature. If this is the type of information coming from some of the literature, it suggests that not only the literature, but also the professionals treating adolescents with diabetes, are functioning as barriers.

It is not surprising that most adolescents diagnosed with diabetes struggle at times to follow their treatment regimen after reviewing the numerous barriers identified. Within each category of barriers identified thus far there are many barriers, each of which could significantly hinder treatment adherence. Adolescents who experience many barriers within many categories are faced with overwhelming obstacles. For these adolescents, following their treatment regimen is further complicated by their families and medical team who may be struggling with understanding the complex web of barriers in which these adolescents are caught. Simply providing education alone to the patient and family is likely not enough to overcome the barriers to treatment. Providing information about how to manage this complex web of barriers as opposed to discussing the medical control of diabetes could be much more effective.

Another complication to the discussion of specific barriers is the overlap between categories of barriers. For example, depression is identified in the literature as both a psychological factor and a psychosocial factor. This supports the idea that the influences

affecting treatment adherence are complex and interconnected and cannot be viewed in isolation.

What makes the phenomenon of treatment adherence more complex is that many of the identified barriers may also function as facilitators. Because of this, many of the professionals working with adolescents with diabetes may be confused as to what is helpful. In fact, what functions as a barrier to one adolescent may function as a facilitator to another. This supports the need for a highly individualized approach to the treatment of diabetes.

Particularly troublesome within the literature regarding barriers is that, despite the fact that the complexity of adolescents' lives is frequently mentioned, little, if any, mention is made of how to make sense of such complexity. In order to come to a better understanding of complex phenomena, it could be inferred that a more holistic view of the problem would providing additional meaning. However, a more holistic view of the above mentioned areas was not found in the literature.

Facilitators in the Treatment of Adolescents with Diabetes

For the purposes of this study, all factors that contribute to treatment adherence are termed *facilitators*. Factors that contribute to treatment adherence in general were discussed in several empirical studies (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Franciosi et al., 2004; Kraetschmer et al., 2004; Kerse et al., 2004; Mainous et al., 2004; Rosina et al., 2003; Schneider et al., 2004; Strawhacker, 2001; Vinter-Repalust et al., 2004) and conceptual articles (Koeningsberg et al., 2004; Smith, 2004). However, only one article was found that directly discussed the factors that

facilitate diabetic treatment adherence (Koeningsberg et al., 2004). A review of the literature yielded six categories of facilitators, which include treatment regimen, physician-patient relationship, physician characteristics, patient characteristics, psychological, and psychosocial. All of the categories identified as facilitators were also identified as barriers, suggesting that a broader framework to discuss the influences impacting the diabetes treatment regimen is a possibility. The literature was the only category that was not also identified as both a barrier and facilitator. It may in fact function as a facilitator, but no documentation of that was found. Perhaps the most likely reason, as stated previously, is that much of the literature conceptualizes treatment adherence as a dichotomy (Logan et al., 2003), as only adherent or non-adherent, without leaving room to discuss the complexities of diabetes treatment adherence.

Treatment Regimen

Treatment regimen issues include a wide array of factors, including medical concerns, health care, lifestyle, and the medical team. In the study by Franciosi et al. (2004), ease of accessibility to the health care system can function as a facilitator to treatment adherence. According to Koeningsberg et al. (2004), once a patient has accessed the health care system, numerous factors can function as facilitators, such as the medical team, individualized plans developed by the medical team, permanent lifestyle changes in diet and physical activity, providing the patient with choices, keeping track of all foods eaten, keeping a record of physical activity, and utilization of a trial-and-error approach in treatment. Many of these factors were previously identified as barriers

supporting the emerging importance of the psychosocial context in which the factor is experienced.

Koeningsberg et al. (2004) noted that the medical team could function as a facilitator by using a team approach and coaching model, as opposed to a doctor-centered approach. The medical team can also provide frequent and intensive contact with the patient, especially in the first 6 months after diagnosis, and then taper down to once every 3 months, which supports the efficacy of a more systematic and structured approach to treatment. It was not discussed if such an approach would remain effective once the number of visits was reduced; however, it was suggested that treatment should continue to focus on permanent lifestyle changes in diet and physical activity. The study by Strawhacker (2001) contradicts some of these findings and suggests that visits every 3 months are too minimal, not allowing sufficient time for the medical team to address individual needs. It was also found that the longer the period of intervention and level of intensity, the more likely that treatment adherence will maintain over time as well as reduce microvascular complications (Koeningsberg et al., 2001; Strawhacker, 2001). While these studies identified mostly medical control as a facilitator, the study by Bissel, May, and Noyce (2004) suggested medical control as a barrier. Again, this is an example of how one factor can be fluid in nature functioning as a barrier and/or facilitator, depending on the unique characteristics of each adolescent.

Another way that the treatment regimen can function as a facilitator is for the medical team to develop individualized treatment plans for each patient based on that patient's particular needs (Koeningsberg et al., 2004). Without such individualized treatment plans, expecting patients to follow a complicated treatment regimen is not very

likely. Other factors that Koeningsberg et al. recommended were for patients to have choices, track all foods eaten, and keep a record of physical activity to learn what works best for them, and for physicians to utilize a trial-and-error approach to help prevent patients from becoming discouraged. Of these factors, providing the patients with choices is probably one of the most valuable, largely because it deviates from a doctor-centered approach and initiates an interdependent approach that is needed for improved treatment adherence. Providing adolescents with choices likely meshes well with their increasing sense of independence and the desire to be in control of their lives.

In addition to individualized treatment plans, hospitals and nurses, dieticians, diabetes educators, and screening tools can be instrumental in facilitating treatment adherence by identifying adolescents who are at-risk for psychosocial problems and ultimately poor treatment adherence. Depression, poor family participation, and problems acquiring basic needs such as housing, money, and a safe environment often lead to an increased risk of poor treatment adherence (Koeningsberg et al., 2004; Rosina et al., 2003). In addition, Rosina et al. suggested that hospitals could provide a window of opportunity to identify at-risk adolescents and could function as a place to provide clinicians with useful knowledge and interventions, since hospitals are often the first to have contact with adolescents at times of medical emergency related to noncompliance. With such an available resource, the potential hospitals hold in facilitating treatment adherence is likely very great. In addition, Rosina et al. further stated that hospitals could easily help identify high-risk adolescents, but the traditional approaches to care offered by hospital based models are not helpful. Despite the recommendation to identify

adolescents who are at high risk for psychosocial problems, the literature did not present a clear or unified direction to effectively accomplish such a task.

Schools can also function as facilitators to treatment adherence by becoming an integral part of the multidisciplinary team in planning school-related activities to incorporate the patient's diabetic treatment regimen (Strawhacker, 2001). Written orders by the physician are typically required treatment guidelines for diabetes treatment at schools, and providing these orders to an adolescent's school may facilitate treatment adherence. In addition, the school health office should be able to provide the diabetic team with an abundance of information such as blood sugar readings, ketone checks, incidence of hypoglycemia, amount of snacks consumed, lunch menus, and daily physical activity levels (Strawhacker, 2001). These documents can be provided to the physician and parents on a regular basis. Although some medical teams and schools do interact, as suggested by Strawhacker, many schools lack the resources for such interaction. Many school systems have only one nurse who travels between schools and might not be available for each patient when needed. Often in these situations, other staff members are "trained" to help the adolescents with their treatment and are of variable effectiveness.

The literature reviewed concerning treatment regimen focuses in large part on how the identified factors such as the medical team, health care, and lifestyle can facilitate treatment adherence with little regard paid to the specific medical procedures associated with treatment adherence, such as checking blood sugar and injecting insulin. This does highlight some very helpful factors that can promote improved blood sugar levels, but it also brings to light the fact that what constitutes *treatment* is not a concrete construct and could very likely be fluid in nature.

Physician-Patient Relationship

Along with treatment regimen issues, the physician-patient relationship is another frequently cited category of facilitators of treatment adherence (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Kerse et al., 2004; Mainous, 2004; Schneider et al., 2004; Smith, 2004; Strawhacker, 2001; Van Boemel & Lee, 1999; Vinter-Repalust, 2004). The physician-patient relationship is often referred to as the physician's ability to understand the psychosocial context of the patient as well as the personal relationship a patient has with the physician; however, this relationship focuses more on the physician understanding the patient and, to a lesser extent, the patient understanding the physician's perspective of treatment adherence issues. This lack of emphasis of expecting the patient to understand the physician's perspective could be reminiscent of a doctor-centered approach or an example of bias within the literature. This conceptualization of the physician-patient relationship can be problematic due to the *physician's ability* to understand the psychosocial context of the patient. However, as the literature about barriers suggests, even if the physicians do understand their patients psychosocial context, the factors within that context are extremely difficult to identify as barriers or facilitators. This suggests that a good relationship and understanding of the psychosocial context are not operating alone in facilitating treatment.

In terms of the physician-patient relationship, concordance models were studied by several authors (Ditmyer & Telljohann, 2003; Vinter-Repalust, 2004), focusing on a reciprocal relationship between the physician and patient. In concordance models, the physician views the patient as decision-maker and takes into account the patient's life

context. This conceptualization differs from that proposed by many other researchers (Atkinson et al., 2004; Bissel et al., 2004; Kerse et al., 2004; Mainous, 2004; Schneider et al., 2004; Smith, 2004; Strawhacker, 2001; Van Boemel & Lee, 1999; Vinter-Repalust, 2004) in that it emphasizes a reciprocal relationship as opposed to a more one-sided relationship, where the physician is expected to understand psychosocial factors but does not focus on shared decision making with the patient.

In an interesting article about how to begin the physician-patient relationship, Smith (2004) made several recommendations that could facilitate treatment adherence. The first was to conduct an enrollment interview, in which prospective patients receive an explanation of what is expected of them if they decide to join the practice. This is a luxury for most patients and providers who do not have to deal with the constraints of managed care, and for patients who have the ability to choose providers. In addition, the concept of “housekeeping” could facilitate treatment adherence. Smith described “housekeeping” as explaining to the patient how to make appointments, how to navigate the clinic telephone system, and what the office hours are, which will help patients learn what is expected of them and how to interact with the physician and medical office in order to avoid routine problems. Offices that practice housekeeping model what they desire for their patients (i.e., paying attention to all details of effectively managing a complex system).

Concordance (i.e., agreement between physician and patient) and dialogue between physician and patient may lead to more shared experiences between physicians and patients and thus help develop a more personal physician-patient relationship, contributing to increased continuity of care (Mainous et al., 2004). The study by Kerse

et al. (2004) also found that the relationship between treatment adherence and concordance was found to be the most important factor in treatment management. This discussion of concordance is similar to that mentioned by Ditmyer and Telljohann (2003) and Vinter-Repalust (2004) of a reciprocal relationship between the physician and patient where the physician and patient understand each other's perspective of treatment.

Kraetschmer et al. (2004) also discussed how shared decision making between the physician and patient can lead to increased treatment adherence. Their study found that most patients preferred shared decision making and did not wish for an autonomous role in the relationship; but for those patients that were autonomous, levels of trust in physician were usually low. For patients with a passive role in the relationship, blind trust of the physician usually developed. Although blind trust in the physician may seem like a facilitator to treatment adherence, with blind trust there is not an interdependent interaction. In order for shared decision making to occur, a trusting physician-patient relationship is usually required (Kraetschmer et al., 2004). This may mean trust in both directions, to and from the physician and the patient, but this was not explicitly stated in the study. Vinter-Repalust (2004) confirmed those findings and found that sharing the management of diabetes treatment with a patient-centered focus leads to increased treatment adherence.

Furthermore, Schneider et al. (2004) found that, for patients diagnosed with HIV, a better physician-patient relationship leads to increased treatment adherence. The physician-patient relationship was determined using seven multi-item scales that assessed specific factors of the physician-patient relationship, including general communication, provision of HIV-specific information, egalitarian decision-making style, overall

satisfaction with care, willingness to recommend the physician to others, trust in the physician, and quality adherence dialogue. Even though this study concerned HIV, the measures used to assess the physician-patient relationship may provide insight into the physician-patient relationship associated with diabetes.

Interestingly, in the study by Bissel et al. (2004), patients usually did not consider concordance as an option, particularly when there is a doctor-centered approach to treatment. Sometimes this is due to a patient's cultural perspective, which, until recently, taught people to not question a physician. Physicians can help change this perspective by encouraging patients to ask questions about their treatment and to show empathic understanding of their patients' perspective, even if they do not agree with it. The study by Vinter-Repalust et al. (2004) supports this perspective and suggested it is important for physicians to understand family dynamics in order to develop a shared approach to diabetes management and to further develop the physician-patient relationship. The physician's ability to show empathy was also found to be important in the development of the physician-patient relationship, as is closeness with the family physician.

Smith (2004) discussed how a focus on preventive care and the physician-patient relationship might help improve treatment adherence. Allowing time for families to ask questions may help identify confusion about their role and provide an opportunity for the physician to discuss the importance of family in diabetic treatment (Van Boemel & Lee, 1999). Such an interactive style of relating was also noted by Bissel et al. (2004) and Ditmyer and Telljohann (2003), who stressed the importance of dialogue between the physician and patient in facilitating treatment.

Strawhacker (2001) reported that teens who are supported to develop interdependent interactions were more likely to follow their treatment regimen. Strawhacker also found that physicians' willingness to honor a "no" response from a patient in regards to a treatment recommendation can also lead to developing a shared experience and actually lead to increased treatment adherence. However, physicians should be careful and not appear too eager when an adolescent agrees to follow the treatment recommendations, because there is a risk that eagerness could be interpreted as an authoritarian response.

The literature regarding the physician-patient relationship focuses heavily on the reciprocal nature of relationships, which is discussed in many ways, including concordance, dialogue, shared perspective, and shared decision making. The literature suggests that if physicians focus on the relationship with their patients, trust and a more personal relationship will develop and consequently treatment adherence will improve. Even though the literature has a strong emphasis on a shared decision-making relationship between physician and patient, the desire of physicians to develop such a relationship is uncertain.

There is ample literature regarding physician-patient relationships; however, there is an absence of literature specifically regarding the relationship between the patient and the entire medical team. This relationship is likely far more complex as it involves many interactions with many people. Because of this, it is likely that some members of the medical team have a stronger influence on impacting treatment and building a relationships than other team members..

Physician Characteristics

Physician characteristics is another category of facilitators of treatment adherence that has been frequently cited throughout the literature (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Franciosi et al., 2004; Helme & Harrington, 2003; Kerse et al., 2004; Smith, 2004). Ditmyer and Telljohann (2003) noted two physician characteristics that lead to treatment adherence: age of physician and confidence of physicians. Physicians over the age of 50 and those who practiced for more than 20 years felt more confident to treat than younger physicians did. Their study found that confidence was related to “high efficacy expectations,” physicians’ perceived level of preparation for treating patients with diabetes, and physicians’ level of acceptance of the ADA clinical practice recommendations. Confidence to treat is likely responsible in part for helping to create a healthy physician-patient relationship. A concern is that some literature does not always differentiate between family practice physicians and physicians who have specialized in the treatment of diabetes.

Fischer, Jome, and Atkinson (1998) found that in the field of psychology the relationship between the psychologist and client is one of the most important factors in successful treatment. This relationship is strengthened by the characteristic of presenting the patient with a structured form of treatment, in which the psychologist displays confidence and competence. The same phenomenon is likely true for physicians who are confident in treating diabetes; they also present a structured form of treatment to their patients. For physicians who are less confident, it is likely more difficult to present a structured form of treatment and to facilitate treatment.

More important than characteristics of sex, age, and specialty of the physician is the physician's ability to enable patients toward effective self-care, which could lead to increased treatment adherence (Kerse et al., 2004). A very simple way physicians could help improve treatment adherence and enable their patients is to tell them what is expected of them (Smith, 2004). However, telling adolescents with diabetes what is expected of them may not help the physician-patient relationship because of the inherent problem with diabetes treatment: understanding what is expected but not understanding what to do to meet those expectations.

Helme and Harrington (2003) found that the way in which physicians respond to patients who do not follow the prescribed treatment regimen could facilitate treatment adherence. Physicians most often responded to their patients in a neutral manner when patients openly admitted to not following the prescribed treatment regimen. However, Helme and Harrington also found that a neutral response was not the best physician strategy to elicit the best treatment adherence, but rather a combination of positive, neutral, and negative regard strategies was related to greater treatment adherence over time. This information is supported by Bissel et al. (2004), who found that physicians' ability to interpret and understand the individual and complex lifestyles of their patients with chronic illness can facilitate treatment adherence. This is yet another example from the literature stressing the importance of understanding adolescents' individual and complex lifestyles.

Although the literature rarely specifically focuses on the physician's role in treatment adherence, it did offer insight into how physician characteristics facilitate treatment adherence. Probably the most interesting finding revealed that age, sex, and

specialty of physician was less important in treatment adherence than the unique patient characteristics. This supports the importance of the physician's ability to develop a good relationship with the patient. Other physician characteristics include level of confidence, informing patients of what is expected, and response to the patient's level of treatment adherence.

Patient Characteristics

An interesting discovery was made in the study by Franciosi et al. (2004), in that many of the identified physician characteristics were not as important as the personal characteristics of their patients in terms of influencing treatment satisfaction. Patient characteristics are a frequently cited category of facilitators (Atkinson et al., 2004; Bissel et al., 2004; Ditmyer & Telljohann, 2003; Koeningsberg et al., 2004; Miller & Drotar, 2003; Rosina et al., 2003; Strawhacker, 2001; Vinter-Repalust, 2004). How patients interpret and understand their own complex life context related to chronic illness is a patient characteristic that influences treatment adherence (Bissell et al., 2004). This supports the need to emphasize the magnitude of psychosocial characteristics in diabetes treatment. In addition, helping adolescents understand the complex factors within their own lives and how these factors are related to treatment is a daunting task that physicians most likely do not have time to accomplish, supporting the need for interventions from other sources.

Other patient characteristics that function as facilitators are conviction and confidence (Koeningsberg et al., 2004), and dependency and interdependence, as well as parent-adolescent teamwork (Strawhacker, 2001). Again, just as there is a complex web

of factors that functions as barriers, there is a complex web of factors that functions as facilitators. This point cannot be emphasized enough as it is essential for physicians, patients, and families to all have a shared understanding of how this complexity uniquely influences treatment adherence.

In addition, Vinter-Repalust et al. (2004) stated that patients who were able to change their medication dosages felt freer. However, it is not clear if the idea of changing dosages of medications and the concept of self-responsibility may be difficult for children and adolescents to understand and may function as facilitators only for adults. However, if adolescents are given the ability to share decision making with their physician regarding medication dosage, they may be more inclined to follow their treatment.

If personal characteristics of patients such as low levels of school education, lower levels of psychological adaptation to diabetes, and more severe clinical conditions tend to function as barriers to treatment adherence (Franciosi et al., 2004), it can be speculated that if attention were focused on these areas, they could improve or facilitate treatment adherence. However, factors such as educational level and psychological adaptation are not usually in the scope of what a physician is able to accomplish. Thus, some factors are not influenced by the medical team and require intervention from other sources, such as psychologists and school systems, in order to improve and function as facilitators.

Many people assume that conflict between parent and adolescent functions as a barrier to treatment adherence. However, Miller and Drotar (2003) found that conflicting perceptions between adolescents and parents about treatment adherence may be problematic but may not actually affect treatment adherence. Because the conflict can be differentiated from the actual tasks of treatment adherence, there can be a high level of

conflict between adolescent and parent while the adolescent continues to maintain the tasks of the treatment regimen. Thus, even though conflict does not necessarily function as a barrier, it also does not function as a facilitator. It is important for physicians to remember that parent-adolescent conflict should not cloud other more salient barriers and facilitators.

Patient characteristics that may function as facilitators to treatment adherence include patient understanding of complex life context, conviction and confidence, dependency and interdependency, parent adolescent teamwork, ability to change medication dosage, level of education and psychological adaptation, and less severe clinical conditions. It is interesting to note that patients may not understand all the factors that influence their treatment adherence, which is consistent with the literature that indicates parents and physicians also may not understand all the factors that influence treatment adherence. That patients, parents, and physicians struggle to understand some of these factors offers some explanation as to why so many adolescents are hospitalized due to complications from their illness. Helping adolescents to better understand the factors influencing their treatment may therefore lead to improved treatment adherence.

Psychological

Psychological factors found to function as facilitators to treatment adherence include screening for psychological problems and treatment adherence problems during hospital admissions (Koeningsberg et al., 2004; Rosina et al., 2003). Incorporating the patient's belief system regarding treatment also may help facilitate treatment adherence (Schneider et al., 2004). Trust was also mentioned as a facilitator (Kraetschmer et al.,

2004; Kerse et al., 2004), as was increased mental health (Rosina et al., 2003). Presenting the patient with specific outcome goals, short-term behavior targets, as well as the use of shaping are ways to avoid overwhelming the patient and function as facilitators (Koeningsberg et al., 2004). Very little literature describes specific psychological characteristics as facilitators, rather than barriers, of treatment adherence. Additional research in the area of psychological and psychosocial characteristics that facilitate treatment adherence is needed, as it is becoming abundantly clear that these factors dramatically influence diabetes treatment adherence more than knowledge about treatment tasks.

Psychosocial

The literature also indicates many psychosocial factors that can facilitate treatment adherence (Koeningsberg et al., 2004; Rosina et al., 2003; Smith, 2004; Strawhacker, 2001; Van Boemel & Lee, 1999; Vinter-Repalust et al., 2004). Koeningsberg et al. suggested involving the family in diabetic treatment and providing case management to address the immediate needs of the patient. They also recommended stepped care, in which the patient moves from simple to more complex treatment recommendations, as well as brainstorming with patients in order to find solutions to problems by offering tips or options and then encouraging the patient to choose a possible solution. These psychosocial factors also support a shared perspective among physicians, patients, and their families and likely lead to a better physician-patient relationship.

Discussing treatment issues individually as well as with the adolescent's family is also recommended (Smith, 2004) and will likely facilitate treatment adherence. In

addition, Strawhacker (2001) noted that the school can be instrumental as a psychosocial facilitator in helping to build a strong foundation for lifelong disease management, provide mentoring, help raise self-esteem of the adolescent, and create a sense of community support. Community and social support as well as family support have been identified as important psychosocial facilitators by Van Boemel and Lee (1999) and as essential in diabetes management by Vinter-Repalust et al. (2004). In addition to community, family, and social support, Vinter-Repalust et al. identified the general practitioner as a source of social support, as well as group therapy with other patients diagnosed with the same illness. All of these factors support a shared perspective model of treatment adherence.

Many of the factors in this section appear as valuable means to improve treatment adherence. However, some of the factors, such as the involvement of the school system and family, may not be easy to obtain due to financial restrictions. Also, the medical team is not able to influence all of these factors and may have to rely on other sources for success.

Concluding Remarks

The literature regarding diabetes treatment adherence for adolescents identified many barriers in the areas of treatment regimen, physician characteristics, patient characteristics, psychological, psychosocial, and bias in the literature. The literature also indicated many facilitators in the areas of treatment regimen, physician-patient relationship, physician characteristics, patient characteristics, psychological, and psychosocial. Possible areas of future research might include the psychological

characteristics of patients, clearly distinguishing between barriers and facilitators, psychosocial factors, traditional sex roles, concordance models, and the conceptualization used to discuss treatment adherence in the literature.

Reviewing the literature with the conceptualization of discussing barriers and facilitators of treatment proved challenging due to the complex and dynamic interaction of factors. Reviewing individual barriers and facilitators offered clarity to the numerous influences impacting diabetes treatment; however, when conceptualizing why treatment is difficult for many adolescents, it is necessary to look at all the factors from an overarching or holistic approach.

The purpose of this study is to explore, from a qualitative phenomenological perspective, the following research question: *From the experiences of adolescents diagnosed with diabetes, what are the influences affecting adhering to the diabetic treatment regimen?* A qualitative perspective is appropriate to help answer the research question because qualitative methods are useful to help identify previously unidentified variables (Creswell, 1998; Marshall & Rossman, 1995). A qualitative perspective is also appropriate for this study because it searches for a deeper understanding of the participants' lived experiences (Creswell, 1998; Kvale, 1996; Marshall & Rossman, 1995), in this case, how adolescents experience the barriers and facilitators of their diabetes treatment regimen. This study could also provide a voice to adolescents diagnosed with diabetes and help the medical and psychological communities come to a better understanding of the complex web of factors affecting treatment adherence.

CHAPTER III

METHODS

The purpose of this qualitative phenomenological study is to gain a better understanding and provide a description of the influences that affect adolescents' adherence to the diabetic treatment regimen from the adolescents' experience. The essence of this purpose is to gain insight into the lived experience and an increased ability to understand how diabetes treatment unfolds for adolescents. For this study, these influences were initially described as barriers and facilitators but eventually, through the use of the methodology described below, emerged as a much more fluid conversation of factors influencing diabetes treatment adherence.

Participants

This study investigated only one category of participants: adolescents with Type I Insulin Dependent Diabetes Mellitus. A total of 9 participants, who had been diagnosed with diabetes, were from a diabetes clinic at a medical training center in the Midwest region of the United States and ranged in age from 16 to 19 years. Participants were selected based in part due to how well they followed the prescribed treatment regimen. Two participants followed their treatment above average, 4 were average, and 3 were below average. One participant was African-American and the other 8 were European-American. Culturally, all came from the Midwest and shared traditional Midwestern

American cultural practices with the exception of 1 participant who practiced traditional Greek cultural practices.

Participants were selected using purposeful and criterion sampling to diversify the sample population, which consisted of adolescents ranging from those who had considerable difficulty following their diabetic treatment regimen to those who had minimal difficulty. The sample was also diversified according to race, gender, socioeconomic status, and culture. Diversifying the sample helped with transferability and provided an information-rich sample in order to best capture the true essence of the factors affecting diabetes treatment adherence of adolescents—not only those doing well with treatment interviewed but also those struggling with treatment. This helped provide much broader and richer data. A phenomenological approach was used to analyze data to identify adolescents' perspectives regarding the influences affecting the diabetic treatment regimen.

This chapter describes the rationale and methods for this qualitative phenomenological study of adolescents' experience of the factors influencing their diabetes treatment regimen. First, research questions are addressed; second, the qualitative approach and phenomenological tradition of inquiry as related to this study are discussed; third, methodological procedures including recruitment of participants, criterion selection, data collection, confidentiality, and data analysis are presented; and fourth, the researcher's background, experience, and assumptions regarding the influences affecting treatment adherence of adolescents diagnosed with diabetes are outlined. The final section of this chapter discusses the rigor of this study.

Research Questions

The purpose of this phenomenological study is to better understand and provide a description of the influences that affect the diabetic treatment regimen from the adolescents' experience. The primary research question is: *From the experience of adolescents diagnosed with diabetes, what are the factors influencing the diabetes treatment regimen?* Although other factors may contribute to understanding treatment adherence from an adolescent perspective, this study focuses only on the lived experiences described by adolescents.

Research questions in qualitative phenomenological studies are usually less formally stated and evolve as the themes are suggested in interviews (Rubin & Rubin, 2005). The research question is purposefully written in an open-ended, evolving, and non-directional manner to obtain the participants' true, unbiased perspective of the factors affecting treatment adherence (Creswell, 1998). Thus, the researcher is not restricted to exploring only the original hypothesis for the study but is provided the flexibility to explore themes that evolve during the interview. The question should also seek to explain, describe, and explore the phenomenon (Marshall & Rossman, 1995). Marshall and Rossman explained that "research questions should be general enough to permit exploration but focused enough to delimit the study" (p. 26).

In qualitative studies, questions that ask "what" and "why" should be asked and answered before "how" questions (Marshall & Rossman, 1995). However, Kvale (1996) suggested that "why" questions should not be asked because people tend to intellectualize answers to these questions and, as explained by Kvale, it is the researcher's job to figure

out and provide explanations for why something happened. This study focuses on “what” questions, such as “What helps you follow your meal plan as indicated by your health care team?”

The main questions of this study are descriptive in nature, such as “What is the recommended normal range for your blood glucose level?” Main questions help translate the overall research topic and question into conversational terms the participants can understand and relate to. The goal is to encourage participants to talk about their experiences, perceptions, and understandings of diabetes treatment. Rubin and Rubin (2005) suggested having up to 6 main questions that are prewritten. This study used 11 main questions, significantly more than recommended, because these questions were based on the various aspects of diabetes treatment. Using this many questions did limit the amount of time spent on each question; however, it also offered the ability to understand the phenomenon from a large and holistic perspective. In addition, a few questions were added based on the review of the first two interviews. For example, a main question concerning insulin use was “What encourages you to take your insulin as prescribed by your health care team?” Other main questions asked about other aspects of the treatment regimen, such as the medical team, blood sugar levels, A1C levels, meal plan, physical activity, insulin, family, school, independence, and embarrassment.

In addition to main questions, follow-up questions and probes were used in response to specific comments made by the interviewees (Kvale, 1996; Rubin & Rubin, 2005). Follow-up questions help to explore themes, concepts, and ideas brought up by the interviewee and are crucial in developing depth, detail, and nuance. Probes help keep the conversation going in order to gain further detail or for clarification. Various types of

probes encourage the participant to continue with a discussion, elaborate, or clarify, as well as help keep the conversation on track (Rubin & Rubin, 2005). Probing questions can help narrow questions without asking closed-ended questions. Several specific types of probing questions were used as needed: amplificatory, exploratory, explanatory, and clarification (Ritchie & Lewis, 2003). Neither follow-up questions nor probes were written into the interview protocol, but rather were used when needed.

The first question asked during the interview process was a general overarching question that this study will refer to as a “grand tour question.” Several authors have recommended using such a question to begin an interview (Kvale, 1996; Ritchie & Lewis, 2003; Rubin & Rubin, 2005; Seidman, 2006). This type of overarching question, which is open-ended, asks the participant to reconstruct a significant segment of an experience and is intended to open up the conversation and encourage spontaneity. The grand tour question for this study is, *Briefly tell me about all parts of your diabetes treatment. In other words, what are your doctor, nurses, and the entire medical team recommending that you do to manage your diabetes and stay healthy?* This helped set the stage for the broad scope of this study but may have been somewhat vague as a grand tour question. Rubin and Rubin also recommended such a question to allow interviewees to walk the researcher through the topic, letting the researcher know what they think is important. The grand tour question then was followed by main questions, follow-up questions, and probes.

Qualitative Research and Phenomenology

A qualitative approach was chosen for this study because of the nature of the problem being investigated: understanding adolescent perceptions of diabetes treatment adherence. Studies that ask “what” or “why” type of questions fit very well into qualitative methodology (Marshall & Rossman, 1995). Prior to deciding to study diabetes treatment adherence of adolescents, this researcher heard physicians asking questions such as “What is the problem?” “Why won’t adolescents follow their treatment regimen?” and “How can we improve treatment adherence?” As Marshall and Rossman explained, deciding to conduct a qualitative study often occurs out of the researcher’s personal interest, based on his or her own experience. This is also true for this study. This researcher’s experience as a psychologist in a medical setting sparked his interest in helping the medical community better understand diabetes treatment adherence issues of adolescent patients and in showing the value of counseling psychology in a pediatric medical setting.

Furthermore, qualitative methods are well suited for studying little-known phenomenon and for researching variables that have yet to be defined (Creswell, 1998; Marshall & Rossman, 1995). In fact, many variables (i.e., barriers and facilitators) have already been identified regarding treatment adherence; however, factors from first-person adolescents’ accounts have not been identified. Therefore, a qualitative approach is useful to help identify variables affecting the diabetic treatment regimen, specifically from the adolescents’ experience. Qualitative research is a paradigm that is exploratory or descriptive, assumes the value of context and setting, respects participants’ interpretation

of the meanings, and searches for a deeper understanding of participants' lived experiences of the phenomenon (Creswell, 1998; Kvale, 1996; Marshall & Rossman, 1995).

For this qualitative study, a phenomenological tradition of inquiry was chosen. In phenomenology, the in-depth interview is one of the primary sources for data collection (Kvale, 1996; Rubin & Rubin, 2005; Seidman, 2006). In qualitative research, when the primary data collection activity is in-depth interviewing, the researcher is the data-gathering instrument (Rubin & Rubin, 2005). The researcher must have the flexibility to change or modify the interview script to meet the needs of each participant, since each one has a unique set of experiences. In-depth interviewing is appropriate when the participants will likely have to explain their answers, give examples, shed light on an old problem, describe their experience, or when their lived experiences are very different from those of the researcher. Without a firsthand account, it is difficult to develop thick description (Rubin & Rubin, 2005). This is especially true of adolescents diagnosed with diabetes. Although all the adolescents in this study have diabetes, they have very different life circumstances, temperaments, and cultural differences that make each participant's experience with diabetes treatment adherence unique—all of which support in-depth interviewing.

Procedures

This section describes the methodological procedures for this qualitative phenomenological study. First, participant recruitment is discussed; second, criterion selection; third, data collection; and lastly, data analysis. Within the data collection phase,

the interview process is reviewed, followed by the specific procedural steps of data analysis.

Recruitment

Participants were recruited from a moderately sized pediatric diabetes clinic in the Midwest. Permission to conduct the study was sought from the physicians running the clinic and the site's research committee. After permission was received, a nurse asked the caregivers of each patient, upon arrival to the clinic, if they would consider talking to a researcher about the possibility of participating in a study about diabetes treatment adherence. A script titled *Invitation to Participate in a Research Project* (Appendix A) was provided to the nurses. To minimize potential coercion in recruitment, the nurses were individually trained by the student investigator to read the standardized script verbatim to each adolescent patient and caregiver. The nurses were also instructed not to discuss the study in any form unless asked if services in the clinic would be affected. In this situation, the nurses informed potential participants that their services in the clinic would not be affected in any way. All other questions were referred to the student investigator.

At this point, if the adolescent and caregiver agreed to talk to the researcher, the nurse notified the researcher, who then met with them to discuss the study. After all questions were answered and the caregiver and adolescent agreed to participate, the caregiver was asked to sign an informed consent (Appendix D), and the adolescent was asked to review and, if willing, sign the informed assent (Appendix E). For adolescents aged 18-19, caregivers were asked to sign an informed consent (Appendix I) agreeing to

participate in the study by completing a background questionnaire. Adolescents aged 18-19 are legal adults and therefore do not need to sign an assent form, but were asked to sign an informed consent (Appendix J). The sample consisted of approximately 9 adolescent participants. The sample also included one caregiver per participant, making the final sample a total of 18 participants. The role of the caregivers in this study was limited to completing only the background questionnaire. The role of the adolescents was to meet with the researcher and participate in two interviews to gather information about their diabetes treatment. A final meeting with the adolescents validated the generated themes from the two interviews. The adolescents ranged in age from 16 to 19 years and came from diverse backgrounds. Specific criteria for participant selection is discussed in more detail in the Criterion Selection section below.

If at any time either the caregiver or the adolescent appeared hesitant about participating in the research, he or she assured that participation was completely voluntary and did not affect the services in the clinic in any way. At the first interview, if selected as a participant, the caregiver was asked to sign consent (Appendix F) and the adolescent was asked to sign assent (Appendix G) for digital recording. Adolescents aged 18-19 were also asked to sign consent for digital recording (Appendix K).

Criterion Selection

Selection of adolescent participants is very important due to the complex nature of diabetes treatment adherence of adolescents. The goal for this study was to select participants who would provide an information-rich sample with “vivid, dense, and full descriptions in natural language of the phenomenon under study” (Polkinghorne, 1994,

p. 510). The first step in obtaining such a sample was to use stratified purposeful sampling as recommended by Morrow and Smith (2000). This was accomplished by selecting participants who represented above average, average, and below average adherence to treatment. Thus, for this study, adolescents with diabetes were chosen who were adhering to their treatment regimen at an above average, average, or below average level as reported by the caregivers and adolescents, not as defined by physicians. This information was gathered on the caregiver and adolescent background questionnaires (Appendices B and C, respectively), only if consent and assent had already been given. These background questionnaires were completed during the initial contact with the caregiver and adolescent in the diabetes clinic at the research site. The adolescent and caregiver responded to questions regarding age, ability to follow the treatment regimen as prescribed, number of years since first diagnosed with diabetes, gender, race, and cultural background. This information helped in the selection of an information-rich sample of adolescents who had few problems adhering to their treatment regimen as well as those with moderate and significant problems with adherence. Such a sample helped to more accurately describe the phenomenon and identify the factors influencing treatment regimen as experienced by adolescents.

Another very important participant selection issue was finding adolescents willing to openly discuss issues of treatment adherence. Deciding whether an adolescent was open to discussing such issues began at the first meeting in the clinic when the consent forms were signed. This was accomplished in two ways: (a) the adolescent was asked to complete a background questionnaire (Appendix C), only if consent and assent had already been given; and (b) the researcher identified those adolescents who appeared

willing to openly discuss their experiences with treatment adherence by placing a check mark at the top of their background questionnaire. The primary criteria that was used to determine if adolescents appeared willing to discuss their experiences was (a) the adolescents were able to verbally articulate their desire to participate in the study and discuss their treatment regimen, and (b) the appropriate consent and assent forms had been signed. Because the concept of *willingness* varies across cultures, it was important for the researcher to understand that some willing adolescents could be very verbal and outgoing, while others might be much less verbal and very reserved. However, for a phenomenological qualitative study, it is absolutely essential that all participants be able to engage in a conversation about their experience with their treatment regimen.

The participant selection process began by reviewing the background questionnaires in order to select participants based on stratified purposeful sampling as recommended by Morrow and Smith (2000). Next, criterion sampling was used to select participants who met the required criteria. The first criterion was that participants must be between the ages of 16 and 19. This age range was chosen because it fits well into the late adolescence developmental period, which is typically between the ages of 15 and 21 (Anders & Morrison, 1999). Participants were chosen from the late adolescence developmental period due to increased cognitive ability and abstract thinking ability. Adolescents within this age range also typically develop improved judgment and become more serious about the direction of their lives (Anders & Morrison, 1999). Depending on the adolescent's degree of maturity, as described by Anders and Morrison, most interview techniques used with adults can be used when interviewing adolescents.

The second criterion was that each adolescent must have been diagnosed with diabetes for at least 3 years. This criterion was established in order to obtain participants who were not newly diagnosed and thus were familiar with diabetes treatment. The third criterion was willingness to discuss treatment adherence issues; the procedures previously discussed were used to identify adolescents who met this criterion. From the potential participants who were chosen from the stratified purposeful sampling and met the criteria, the final participant sample was chosen based on the diversity of gender, race, and cultural background of the available and willing participants. This sampling strategy allowed for richness, breadth, and depth during the data collection process. A similar sampling process was recommended by Rubin and Rubin (2005) to obtain participants who are experienced and knowledgeable about the topic and able to provide useful information from various perspectives. After reviewing this information, caregivers of selected participants were called to schedule face-to-face interviews with the adolescent in a small private conference room at the medical center where the diabetes clinic is located.

Data Collection

For this qualitative phenomenological study, the following data collection activities are discussed, as recommended by Creswell (1998): (a) research site and individuals, (b) access and rapport, (c) purposeful sampling strategies, (d) forms of data, (e) recording procedures, (f) data collection issues or field issues, and (g) storing of data. This section describes how the study addresses each of these data collection activities. In addition to the seven steps recommended by Creswell, the final part of this section is

devoted to describing the in-depth interview process and interview structure for this study.

Research site. The research site was a pediatric diabetes clinic at a moderately sized Midwest medical center. In *quantitative* research, it is often expected that participants are selected from various sites in order to aid generalization; however, for a *qualitative* phenomenological study, participants may be located at a single site (Creswell, 1998). Therefore, the data collected represent only the demographics of the site and the selected participants; the Defining and Attaining Rigor section addresses these concerns in more detail. All participants were adolescents between the ages of 16 and 19 and patients of the medical center and diabetes clinic. A phenomenological study investigates “multiple individuals who have experienced the phenomenon” (Creswell, 1998, p. 112). Finding multiple individuals who have experienced the phenomenon of adherence to the diabetic treatment regimen was relatively simple, since the research site had several hundred adolescent patients diagnosed with diabetes who were potential participants.

Access and rapport. Access and rapport are both very important concepts in qualitative research. The researcher was employed at the same facility where the diabetes clinic is located and, in fact, was invited by the pediatrics department to conduct a research study on diabetes treatment adherence. Obtaining access to the site was easily achieved.

It was important that rapport with participants develop quickly in order to obtain the most honest responses to interview questions. The researcher had been volunteering

in the diabetes clinic, assisting another doctoral student in collecting data, and therefore was able to meet many adolescents who were patients in the clinic. As a result, many of these patients had already been exposed to other researchers and were comfortable participating in a research study.

Adolescents usually require more time than do adults or children to build rapport and trust with a researcher (Anders & Morrison, 1999). In interviewing adolescents, it is extremely important to establish rapport due to their growing self-consciousness and sometimes insecure sense of identity (McConaughy, 2005). McConaughy suggested showing openness to their points of view, explaining clearly the limits of confidentiality, and inquiring about thoughts and feelings without making judgmental comments. Kvale (1996) suggested that rapport should be established with adolescents by showing interest, understanding, and respect for what they are saying.

Adolescents are often emotionally labile; thus, it is important to acknowledge such shifts in emotion and ask them to explain, while remaining respectful (McConaughy, 2005). McConaughy recommends using everyday language and avoiding the use of psychological terminology to build rapport. The researcher built rapport also by meeting with each participant a minimum of four times; first, in the diabetes clinic during recruitment; second, at the first interview; third, at the second interview; and the last time, at the final meeting.

Sampling. Purposeful sampling is best for qualitative phenomenological studies (Creswell, 1998; Morrow & Smith, 2000). Two types of purposeful sampling were used in this study: stratified purposeful sampling and criterion sampling, which yielded the 9

participants interviewed. Purposeful sampling ensures that all participants meet the specified criterion of the study. Criterion samples are useful for phenomenological studies because it is essential that each participant has experienced the phenomenon, in this case, the diabetes treatment regimen. Specific criteria for this study are specifically discussed in the Criterion Selection section.

Forms of data. Data were collected primarily in the form of in-depth interviews (Ritchie & Lewis, 2003) with 9 adolescent participants, using an interview protocol (Appendix H) and a digital recorder (Creswell, 1998). Data were also collected using caregiver and adolescent background questionnaires (Appendices B and C, respectively). The original interview transcripts are kept in the Western Michigan University Archives. Transcripts are also stored in NVIVO files on the co-investigator's computer.

The NVIVO software, described more in the Data Analysis section, was used to organize, code, and identify meanings and themes. The co-investigator is the only person with access to the data stored on the NVIVO software through the use of his username and password on his personal computer. Written consent was obtained for participation in the study, along with another written consent for the digital recording (Appendix F). All participants were informed that they could stop the recording or remove themselves from the study at any point. Participants could also choose to stop the recording if they became uncomfortable, needed a break, wanted to ask a question, etc. However, for participants to remain in the study, the digital recording needed to be recording while they responded to the interview questions.

Recording procedures. In addition to digital recording procedures, an interview protocol (Appendix H) was also used, allowing the researcher to record handwritten responses to the questions, take notes, organize thoughts, and record information that would otherwise be unidentifiable on the digital recording, such as the participants' nonverbal behavior during the interview. The interview protocol also contained, as recommended by Creswell (1998), the project title, a reminder to briefly explain the project to the participant, and a reminder to thank the participant at the end of the interview and stress that all information would be kept confidential.

The questions on the interview protocol were determined by asking about the major parts of diabetes treatment. Rubin and Rubin (2005) recommended developing questions by breaking apart large or complex activities (i.e., diabetes treatment). The major parts of diabetes treatment were identified by Kamboj and Drazin (2006), the National Diabetes Education Program (NDEP) (2006), and the categories of barriers and facilitators cited in the literature review. These parts of diabetes treatment include: (a) medical team, (b) maintenance of blood sugar level, (c) meal plan, (d) physical activity, (e) insulin, (f) special events, (g) sense of independence, and (h) feelings of embarrassment. After the first two interviews, the following categories were added: maintenance of A1C level, family, and school.

Field issues. Field issues often arise during qualitative research and the researcher should be prepared for them before data collection begins. This study reviewed several field issues, as recommended by Creswell (1998). First, time to collect data was estimated during the initial interview. This allowed the researcher to estimate the total amount of

time required to collect data. In addition, a substantial amount of time was needed to transcribe the recorded interviews. The researcher typed the transcripts himself and estimated the total amount of time for transcription based on the time to transcribe the first interview. Second, the digital recording equipment was organized and checked for functionality before the interview. Third, special care was taken to match the level of questions to the ability of the participants (see Interview Process section for complete details). Fourth, participants were asked to keep a journal of their thoughts and experiences of diabetes treatment adherence between the first and second interviews. However, journaling can pose several problems, such as varying writing ability among participants, willingness to write in a journal, and the researcher's ability to read the journal. For this study, the journals were used to help the adolescents develop their awareness and understanding of their diabetes treatment adherence and were not read or analyzed by the researcher. However, the challenge with journaling is that participants often do not write in their journals. Fifth, maintaining confidentiality was a field issue of importance to both the researcher and the adolescent. This issue is thoroughly addressed in the Confidentiality section.

Storing of data. Once each interview was completed, the digital recordings were downloaded onto the co-investigator's computer and the original recordings were deleted from the recording device. After the digital recordings were transcribed, an electronic version was stored in NVIVO files and a hard copy was placed in the Western Michigan University Archives. More information regarding storage of data is discussed in the Confidentiality section.

Throughout the process of collecting data, the interviewer experienced his own personal biases and values, as it is very difficult to ignore our own personal perspective. To account for such biasing, the researcher used the concept of bracketing his own personal values and beliefs so as not to influence the data collection process. Thus, the researcher attempted to set aside his own personal values and beliefs in order to collect the participants' true meaning of their experience. If the researcher's thoughts were shared with the participants, bias could cloud the participants' description of their true experience with diabetes treatment adherence.

Interview Process

Data were collected with personal in-depth interviews, each lasting approximately 60 to 90 minutes; however, no time limit was specified. This allowed participants to fully respond to all of the questions and allowed the researcher to ask follow-up and probing questions or new questions that arose during the interview process. The responses of the first two participants interviewed were reviewed to assess the appropriateness and effectiveness of the interview protocol. This process ensured that the questions were easy for the adolescents to understand. After this review, the questions were modified as needed, particularly the addition of questions inquiring about the role of family and school. A qualitative phenomenological interview does not need to be cast in stone but should define the situation and introduce the topics of conversation (Kvale, 1996). The complete interview protocol can be found in Appendix H. The remainder of this section discusses some of the basic characteristics of the interview process in a qualitative phenomenological study.

One basic yet important skill of interviewing is to listen more and talk less.

According to Seidman (2006), the researcher needs to listen to what the participant is saying, listen for the “inner voice,” and listen while remaining aware of the process and substance of the interview. This researcher took special care to ensure that the adolescents interviewed provided the best possible and most accurate account of their experience.

Anders and Morrison (1999) suggested using a nondirective approach when working with adolescents and open-ended questions without complicated wording that allow them to speak at length about a topic. This approach allows the adolescents to talk freely and share feelings and ideas about their experiences, and also helps build rapport, which is essential. This format works well for adolescents who have not developed good abstract thinking skills. Anders and Morrison stated that a nondirective format does not constrain answers and, in fact, increases the accuracy of answers for adolescents.

Another basic concept of interviewing is encouraging the participant to accurately recall past experiences with diabetes treatment adherence. Seidman (2006) suggested asking the participant to reconstruct an experience rather than to remember something that happened. Strategies that help accomplish this include:

1. Ask participants to reconstruct, not remember, an experience. Asking a participant to remember encourages them only to recall facts; asking them to reconstruct an experience helps capture how the participant sensed the experience and helps achieve greater depth of meaning.
2. Follow up on what the participant says and what the researcher does not understand without interrupting the participant.

3. Achieve appropriate distance by avoiding a therapeutic relationship. This helps interviewees to develop their responses as independently as possible.

The goals of therapy and an interview are different; in an interview, the interviewer's goal is to learn, not treat the patient (Seidman, 2006).

Throughout the process of an interview, the issues of rapport, race and ethnicity, gender, class, hierarchy, status, and age all deserve close attention (Seidman, 2006). Most importantly, the researcher must be knowledgeable about each issue prior to the interview to help mitigate the influence of each factor on the data collected. For this study, the researcher needed to review his knowledge and further familiarize himself with the issues of race and ethnicity, gender, class, hierarchy, and status, after the initial meeting with each potential participant.

Interview structure. This section describes the interview structure by discussing the interview protocol; interview stages; length of the interview; and the concepts of depth and detail, vividness, nuance, and richness. In qualitative research, the interview protocol can contain rough topics or a detailed sequence of questions that relate to the research topic (Kvale, 1996). This study used a semistructured interview protocol consisting of an outline of topics to be covered. The interview protocol included suggested questions but remained open and flexible, as recommended by Kvale, allowing the researcher ample opportunity for follow-ups, probes, and additional questions. It is not always necessary to use a prewritten interview protocol, but such a tool helps the researcher cover all intended areas and establish direction and scope of conversation (McCracken, 1998). In addition, the protocol helps protect the larger structure of the

interview so the researcher can attend to the immediate tasks at hand. During the interview, the protocol allows the researcher to explore the interviewee's responses and then get back on track with the next question.

In qualitative research, the researcher must decide whether to use a protocol and, if so, he or she can determine how flexible it will be. The protocol can also be ignored if the interview follows a different path than intended (Rubin & Rubin, 2005). The questions on protocols are not cast in stone and are often changed by the researcher as new information emerges during the course of the interview. If any new information is deemed important, the protocol should be revised to inquire about this new information, which may be important for subsequent interviews (Rubin & Rubin, 2005). Rather than topic questions, a topic outline can be used and later revised for subsequent interviews. The researcher can also use the interview protocol to jot notes to review later for possible probing questions. An outline or interview protocol functions only as a guide to the conversation and points the researcher and participant in a general direction. In addition, the guide should be simple and reasonably short to avoid building in too many assumptions about the topic (Rubin & Rubin, 2005).

Seidman (2006) recommends a three-stage process for in-depth interviews; however, stages one and two can be combined for a two-stage process. This study used a two-stage process, combining stages one and two. For this study, the purpose of interview one was to establish the context of the participants' experience with the topic. During this interview, participants were asked to reconstruct their experiences related to diabetes treatment adherence. Then the researcher gathered concrete details of the participants' lived experience in relation to diabetes treatment adherence. During the second portion of

the first interview, the participants were again asked to reconstruct their experiences, but in more detail than during the first portion of the interview. The participants were encouraged to reconstruct a typical day of the experience of following their diabetes treatment regimen.

The time between interviews one and two (approximately 1 week) was designed to give the participant time to reflect on the meaning of the experiences described during interview one. Interview two was designed for the participant to verbally reflect on the meaning of those experiences. The focus was on the participants' understanding of their experience. The adolescents and the researcher met after the second interview for a final meeting. This was to validate the researcher's meanings and themes and to ask the participants if the meanings and themes substantiated and contained the essence of their original experience. For this study, the participant's understandings represented the participant's experience of the factors influencing their diabetes treatment regimen. The time between the second interview and the final meetings ranged from 1½ years to 2 years; however, only 3 months were originally planned. This increase in timeframe occurred due to complicating events in the life of the researcher. The implications of this will be discussed in Chapter IV.

This study also divided the interview structurally into six stages as suggested by Kvale (1996) and Ritchie and Lewis (2003). These stages helped guide the interview: (1) establishing a relationship, (2) introducing the research or briefing the participant, (3) reviewing background information, (4) guiding the interviewee through the body of the interview, (5) indicating to the interviewee that the interview is about to end, and (6) ending the interview or debriefing the participant. At the end of the interview, the

main points were reviewed and the interviewees were asked if they had any final questions or comments. After the interview had ended, the interviewer took 10 minutes to reflect on the interview and to write down any immediate thoughts or impressions.

The interview structure is also strengthened by trying not to vary from the intent of each interview, by keeping each interview at approximately 90 minutes, and by not continuing the interview after the recording has stopped (Seidman, 2006). Interviews in this study were spaced approximately 1 week apart, which allowed the interviewee time to think about the preceding interview but not lose the connection between the two. This also allowed the interviewee and interviewer to work together over the course of approximately 3 weeks or longer, depending on the length of time between the initial contact and the first interview.

The structure of the interview also addresses the concepts of depth and detail, vividness, nuance, and richness (Rubin & Rubin, 2005). Depth and detail are achieved by asking about a process or sequence of events; vividness is achieved by asking questions that evoke vivid descriptions or follow-up to access vivid details; nuance is achieved by asking questions that obtain precise answers to help make subtle shades of gray more distinguishable; and richness is achieved by allowing extended descriptions and narrative about the experience and looking for multiple themes within a single answer. The techniques described by Rubin and Rubin to achieve depth and detail, nuance, and richness were applied throughout the interview process as needed and appropriate.

Confidentiality

Protecting participant confidentiality is important for an adolescent population, especially adolescents with diabetes, just as it is in any research. Many adolescents with a chronic illness are often embarrassed about their illness and do not want others, particularly peers, to find out. To provide confidentiality, a nurse asked each potential participant and caregiver if they would consider participating in a research study while attending one of their regularly scheduled appointments at the diabetes clinic. If the caregiver and adolescent agreed to meet with a researcher to discuss participation, the nurse notified the researcher and at that time he entered the room and reviewed the study with the potential participants.

Nurses working at the diabetes clinic received training regarding the issues of privacy and confidentiality by the research site. In addition, when the researcher trained the nurses to minimize coercion, as explained above, he also discussed the issues of privacy and confidentiality. Nurses were held to the same standards of confidentiality as the researcher. Nurses were also instructed not to discuss any of the details of the project with the potential participants, other than the question, “Would you like to discuss the project with the researcher?”

After being given an opportunity to ask questions, caregivers who agreed to participate and allow their adolescent to participate were asked to sign a consent form, and adolescents who agreed to participate were asked to sign the assent form. Adolescents aged 18-19 were asked to sign the consent form. Next, the caregiver and adolescent were asked to complete background questionnaires (Appendices B and C,

respectively). After the researcher reviewed the background questionnaires, a time and place for the interviews were arranged.

Additional steps were taken to protect participant confidentiality during the transcription process. All digital recording files were identified with a code number (i.e., Participant #1, etc.) rather than a name. After the transcripts were collected, the digital recordings were destroyed. The principal investigator kept a separate master list with the names of the adolescent participants and the corresponding code numbers. Once the data were collected and analyzed, the master list was destroyed. The transcripts were then reviewed and cleaned of identifying information, such as all demographic information, personal names, geographic location, diagnoses other than diabetes, physician names, teacher and school names, and names of any institution. Any additional information that the researcher decided could break confidentiality was removed or changed. After the transcripts were cleaned of all identifying information, the original transcripts were stored in the university archives. The co-investigator kept a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants were sent, via email, an electronic copy of their transcripts and were asked to review for confidential information. Any confidential information identified by the participants was removed. No names will be used if the results are published or reported at a professional meeting.

Data Analysis

As previously mentioned, the researcher is the data-gathering instrument when the primary data collection activity is in-depth interviewing (Rubin & Rubin, 2005). The researcher in this study also analyzed the data as described below and used the NVIVO

software to organize, code, and help identify meanings and themes found within the 296 pages of transcripts. The NVIVO software does not analyze the data; it only assists in managing the large amounts of text.

The transcripts, labeled Participant #1 through Participant #9, were downloaded into the NVIVO software. The transcripts were then coded, when the researcher extracted significant statements and units of meaning from the text, after which he created nodes (categories) to label the various categories of statements and meanings. *Acceptance of diabetes* and *medical team facilitator* are two examples of nodes identified for this study. The development of nodes was the first step in organizing the data and identifying themes for the study. Meanings were later derived through the analysis procedures described below.

Using the NVIVO software provided some benefits compared to using Microsoft Word to cut and paste significant statements and units of meaning into the various categories. The most useful feature of NVIVO, after the coding was completed, was being able to view the node, click it on, and immediately be taken directly back to the transcript to review the node in its original context. The NVIVO software also organized the nodes so the researcher could compare statements and meanings from multiple participants simultaneously. The software also kept track of which statements and meanings belonged to which participants so there was no risk of confusing which data came from which participant.

Forms of data for this study include digitally recorded in-depth interviews and background questionnaires completed by the adolescents and caregivers. Data collected from the background questionnaires were used for participant selection purposes and to

help describe the sample and were not part of the formal data analysis, which analyzed the in-depth interviews according to the six procedural steps described by Colazzi (1978). The data analysis also utilized the guidelines presented by Moustakas (1994) to further expand upon and support the six procedural steps: (1) read participant transcripts, (2) extract significant statements, (3) develop formulated meanings, (4) organize formulated meanings into clusters of themes, (5) integrate results into a textural-structural synthesis (exhaustive narrative description) of the phenomenon, and (6) validate meanings and themes with participants.

The first step was to read participants' descriptions to acquire a sense of the essential meaning of their responses (Colazzi, 1978). The data from each interview had been transcribed and recorded verbatim from the digitally recorded interviews. Each of the transcripts was analyzed using phenomenological methodology described below. During this step, Moustakas (1994) also recommended looking for significant descriptions of the experience, or, in this case, adolescent experiences of the influences affecting adherence to the diabetic treatment regimen.

Second, significant statements, phrases, and sentences that directly pertain to the investigated phenomenon were extracted from the data. (Colazzi, 1978) and became the raw data for the analysis. When extracting significant statements, it is important to "list each nonrepetitive, nonoverlapping statement" (Moustakas, 1994, p. 122); thus, redundant statements are eliminated and thus delimit the study. These statements, in this study, pertained to the units of meaning of how adolescents experience adhering to their diabetic treatment regimen.

Third, developing formulated meanings was accomplished by describing the meaning of each significant statement and units of meaning. Redundant statements were eliminated, and meanings were formulated from the various meanings hidden within the context of the phenomenon present in the original description. This was determined by reading, rereading, and reflecting upon the significant statements in the original transcriptions (Colazzi, 1978).

Fourth, the formulated units of meanings were organized into clusters of themes. These cluster themes were referenced to the original descriptions to validate them and to be sure everything was accounted for in the original descriptions. If it was not, a re-examination of the data was necessary. This was accomplished by reviewing the formulated meanings, and, if necessary, the original units of meaning within the original transcript (Colazzi, 1978). The themes that emerged were common to all of the participants' descriptions (Colazzi, 1978).

Fifth, a textural-structural synthesis of the phenomenon of the barriers and facilitators of treatment adherence as experienced by adolescents diagnosed with diabetes was developed from the integration of results of the data analysis. The textural-structural synthesis refers to an integration of the textural descriptions (what is experienced as diabetes treatment) and structural descriptions (how diabetes treatment is experienced). The exhaustive written description (i.e., textural-structural synthesis) of the phenomenon was an attempt to develop as unequivocal a statement of the essential structure of the phenomenon as possible (Colazzi, 1978).

To develop the textural-structural synthesis, Moustakas (1994) recommended taking the units of meanings and themes into a textural-structural description of the

experience. First, individual textural descriptions were developed and helped describe the nature and focus of what the participants' experienced. To illuminate the individual textural descriptions, verbatim responses from the transcripts were included. Second, individual structural descriptions of the experience were developed, providing "a vivid account of the underlying dynamics of the experience" (Moustakas, 1994, p. 135). Third, a composite textural description was developed by integrating all the individual textural descriptions. Fourth, a composite structural description, representing all the interviewed adolescents as a whole, was developed. And, lastly, a textural-structural synthesis was achieved by constructing a composite textural-structural description of the *meanings and essences of the experience from all participants*.

The sixth and final step was to take the textural-structural synthesis of the phenomenon back to the original participants, which allowed the researcher to review the accuracy of his understandings of the phenomenon with the adolescent participants. After considering what was learned from the interviews as a whole, the researcher gathered the necessary information to confirm the meanings. This step occurred in a final meeting with the participants. Any new information gathered was integrated into the data of this study (Colazzi, 1978).

Duration of the Study

Each interview was scheduled for approximately 60 to 90 minutes. After completing the first interview, participants were to return to the clinic after 1 week to complete the second interview. After the second interview, the researcher transcribed the digital recordings, analyzed the data, and wrote summaries and follow-up questions. This

process took between 1½ to 2 years, after which the researcher, to validate the meanings, asked the participants to review the textural-structural synthesis of the phenomenon to be sure it substantiated and contained the essence of their original experience. This occurred in the final meeting with the participants. Any new information gathered here was integrated into the data of this study (Colazzi, 1978). After the final meeting, the participants had no further obligation to the study. Adolescent participation lasted approximately 2 years, from the time when consent/assent forms were signed in the clinic and until the final meeting.

The time between the initial contact with the adolescent in the clinic and the first interview was limited to 2 weeks. Participation of the caregivers was limited to completing the background questionnaire at the initial contact in the clinic. The background questionnaire took approximately 10 minutes for caregivers and adolescents to complete. The entire study, once data collection began, was completed within 2 years.

Researcher's Background, Experience, and Assumptions

Because the researcher is the data analysis instrument (Rubin & Rubin, 2005), it is important to identify his background, experiences, and assumptions to help prevent a biased view of the data. With the exception of writing the literature review, a majority of this researcher's background with diabetes treatment adherence has come from his employment as a psychologist in a pediatrics department at the same location as the diabetes clinic used for participant recruitment and data collection. Because of this close proximity, the researcher has been able to work directly with the physicians who oversee the diabetes clinic.

Working among these physicians was a valuable experience in that it created an almost limitless opportunity to talk with them about their perspectives of diabetes treatment adherence and to access a wealth of information. This working arrangement lasted 4 years until I left to begin my pre-doctoral internship. However, such prolonged exposure to the physicians' perspectives could have created a significant amount of bias for the researcher. For example, many of the physicians often expressed their frustrations and opinions about patients who were not doing a good job of adhering to their treatment. Fortunately, I was able to access other perspectives by talking to my supervisor, who was a clinical psychologist; by volunteering to help another researcher collect data, which allowed me to talk to adolescents with diabetes in the clinic; and by gathering the information presented in the literature review. These experiences helped mitigate the prolonged exposure to the physicians' influence.

From these experiences, several assumptions developed:

1. Physicians do not always take into account the complex life situations of their adolescent patients.
2. Many physicians continue to practice from a doctor-centered perspective.
3. Many members of the medical team are truly frustrated and do not know what else to do to help their patients struggling with adherence.
4. Adolescents are consciously aware of the barriers and facilitators of diabetes treatment.

Identifying these assumptions helped the researcher to not impose these beliefs on the participants and brought into his awareness the importance of not expressing to the participants any negative sentiments regarding physicians.

Defining and Attaining Rigor

Establishing rigor in qualitative research is often referred to as *trustworthiness* (Lincoln & Guba, 1985), which is different than in quantitative research where the rigor comes from sample size, significance, and numerical data. In qualitative research, the power comes in the form of words from the participants (Morrow & Smith, 2000). For qualitative research, a sample size of 8 to 15 is found to be ideal, with more cases typically adding only minimal data (Hill, Thompson, & Williams, 1997). Lincoln and Guba stated that in conventional quantitative research, measures of internal validity, external validity, reliability, and objectivity are used to establish trustworthiness; for qualitative research, the correlates to these measures are credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity). This researcher established trustworthiness using these criteria and guidelines as outlined by Lincoln and Guba.

First, credibility was established and accomplished using the techniques of prolonged engagement and member checks. Prolonged engagement helped the researcher thoroughly understand the cultural context of adolescents with Type I Diabetes and their complex life context, the medical staff, and his own personal distortions and values. It is also important to become familiar with the research site in order to observe any distortions that might influence the data. This was accomplished through volunteering in the diabetes clinic. Prolonged engagement also provided an opportunity to build trust with the adolescent participants, helping to ensure confidentiality and also helping them to

have input into the inquiry process and to know they could be open and honest, rather than feeling they had to please the researcher.

In addition, this researcher previously attended a 2-week school observation to gain insight into the structure and demands of a typical school day for children. Also, to help this researcher understand the dynamics of adhering to the diabetes treatment regimen, he monitored his own blood sugar and diet for 1 week. This experience helped the researcher empathize with the participants and gain insight into what it might be like to experience diabetes in one's own environment, adding further credibility to the study.

Member checks, along with prolonged engagement, were also used to establish credibility (Lincoln & Guba, 1985). After the interviews were transcribed and meanings and themes were formulated, this information was provided to each participant for review and discussion. The member checks were carried out in respect to the participant's "constructions," rather than checking for accuracy within the text of the transcripts. This was done by reviewing the accuracy of meanings and themes with each participant. The categories, interpretations, and conclusions were also tested with participants, which gave them an opportunity to react to the representations of their own reality. The member checks took place during the final meeting with the participants, where the results from the data analysis were reviewed. Participants were able to voice their opinion regarding the accuracy of the formulated meanings, themes, categories, interpretations, and conclusions originating from the transcripts of their original interviews.

Second is establishing transferability, which for a qualitative study is very different than establishing external validity in a quantitative study. In qualitative studies, according to Lincoln and Guba (1985), the researcher is responsible only for setting a

working hypothesis with a description of the time and context in which the data were gathered. Lincoln and Guba further stated that a qualitative researcher “cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility” (p. 316). The responsibility is to provide a database that makes transferability judgments possible. This study established transferability by describing the participants experience and using quotations directly from their interviews.

Third, dependability was established by creating an audit trail reviewed by an auditor (Morrow, 2005). The auditor used in this study was a doctoral student in the clinical psychology program at Western Michigan University. The auditor’s role was to review all documents and methodological procedures without bias toward any particular qualitative approach or outcome.

For this study, an audit trail as described by Morrow and Smith (2000) was used. The researcher kept a chronological record of research events, including conceptualization, interview schedule, contacts with participants, emerging codes and themes, and changes made as the study evolves. Then the auditor reviewed the researcher’s detailed account of research activities, including data collection and analysis, emerging themes, and categories. The auditor’s role for this study was to attest to the participants’ accounts and was limited to ensuring that the methods and procedures were followed correctly (Lincoln & Guba, 1985). The auditor was not given access to the transcripts until all identifying information had been removed as described in the Confidentiality section. This type of audit is sometimes viewed as triangulation when the

auditor reviews the findings of the primary researchers (Heppner, Kivlighan, & Wampold, 1999). For this study, triangulation occurred between the participants, researchers, and auditor and helped establish dependability. Lincoln and Guba (1985) stated that one audit can establish both dependability and confirmability.

The fourth and final step, confirmability, was established by having the same auditor review an audit trail consisting of the following three parts: raw data (transcripts); data reduction and analysis products (individual nodes, significant statements and formulated meanings, individual themes, individual theme organization, clusters of themes, and emerging themes [structures]); and data reconstruction and synthesis products (treatment schemas, textural descriptions, inserted themes, structural descriptions, and the textural-structural synthesis). Table 1 provides brief descriptions of what the auditor reviewed in each of these areas. The auditor made a statement regarding the overall determination of trustworthiness, confirmability, and dependability. This researcher reviewed information discovered by the auditor and took into consideration any changes, additions, or eliminations.

Table 1

Audit Trail Description

Activity Reviewed by Auditor	Description
Dissertation Activities	<p>Provided a detailed list and dates activities occurred:</p> <ul style="list-style-type: none"> • conceptualization • data analysis activities • changes made as the study evolved • interviews and contacts with participants
Individual Nodes	<ul style="list-style-type: none"> • beginning stage of data analysis • nodes represent categorizations of individual codes • 47 nodes were developed from 3019 individual codes
Significant Statements and Formulated Meanings	Formulated meanings were arrived at by described the significant statements within each node for each participant.
Individual Themes	Individual themes were identified for each participant within each node.
Individual Theme Organization	Often similar themes were found across nodes which necessitated organizing the individual themes for each participant.
Clusters of Themes	The individual themes for each participant were organized into 32 pages of clusters of themes for all participants.
Emerging Themes (Structures)	Developed from the clusters of themes. At this point the reduction of themes into larger overarching structures began to emerge and resulted in 9 pages of structural elements.
Treatment Schemas	Further reduction of the emerging structures into 8 overarching structures which became known as the treatment schemas.
Textural Descriptions	individual and composite textural descriptions were developed to describe “what” participants experienced.
Inserted Themes for Development of Structural Descriptions	Themes and treatment schemas were inserted into the textural descriptions to help organize structural elements for each participant.
Structural Descriptions	Individual and composite structural descriptions were developed to describe “how” participants experienced the phenomenon.
Textural-Structural Synthesis	The textural-structural synthesis weaves together the composite textural and composite structural descriptions, as well as the treatment schemas to provide an exhaustive description of the phenomenon.

CHAPTER IV

RESULTS

This chapter presents the findings of the qualitative phenomenological research study conducted on what adolescents experience as the barriers and facilitators influencing their diabetes treatment regimen. Results obtained through the process of data collection and analysis are discussed and presented representing the participants as a whole. Using a phenomenological tradition of inquiry presenting each of the individual results would not be useful and would require a voluminous description. A hallmark of qualitative phenomenological research is the ability to take vast amounts of narrative data and reduce it to an exhaustive description of the phenomenon for all participants collectively. In this chapter, the results can be viewed as a representation of all participants. First, a composite textural description was written to highlight the most salient features among participants and to uniformly develop the structural elements of all participants. It is presented to aid in understanding what adolescents experienced as their diabetes treatment regimen.

Following the development of the composite textural description, through the process of data analysis, eight treatment schemas emerged that were common to all participants. These schemas were developed as overarching structures representing the numerous themes that were illuminated. The discussion of the schemas includes excerpts from the individual textural descriptions in order to interweave the texture of treatment

(what was experienced) with the structure (how treatment was experienced). Next, the textural-structural synthesis that merges the textural and structural descriptions provides a narrative of how adolescents experience the factors influencing their diabetes treatment. Finally, the results conclude with a discussion of the final meeting with participants.

Composite Textural Description

The composite textural description highlights what is experienced as diabetes treatment by the participants collectively. This description provides a detailed description of the many factors that adolescents consider part of their diabetes treatment. What is interesting to note about the composite textural description is that what adolescents consider treatment is far more than just the basics of treatment. The categories considered part of treatment include: treatment basics, blood sugar/A1C/insulin influences, diet, physical activity and physical sensations, special events, school, the medical team, family and friends, independence, and affective characteristics.

Treatment Basics

Participants described the basics of diabetes treatment as consisting of checking blood sugar, injecting insulin before eating, and counting carbohydrates. Other factors included as important but not necessarily part of treatment were family influence, visits to the diabetes clinic, charting, results of blood sugar checks since the last clinic visit, A1C level, adjustments to insulin dosage if needed, physical activity, and a healthy diet. Overall, participants described the purpose of treatment as the need to keep blood sugar levels within acceptable limits.

Several problems with maintaining the basics of treatment were identified, the most challenging being calculating carbohydrates and insulin dosages correctly, checking blood sugar as often as recommended, and experiencing the inconvenience of treatment, particularly in public places. Other problems identified were the large size of monitors, access to supplies, and forgetting about treatment.

The use of insulin pumps was described very differently by those who experienced good treatment than by those with poorer treatment. Those doing well universally reported a dislike of insulin pumps due to the feeling of being “attached” to equipment and losing independence. However, those not doing well with treatment almost universally reported that insulin pumps have resulted in more convenient and simplified treatment.

Blood Sugar/A1C/Insulin Influences

A large source of discontent among participants was due to meter printouts, blood sugar checks, and A1C levels. Participants often indicated that meter printouts are not accurate, showing only blood sugar levels that are not normal. This occurs because most participants check their blood sugar only if they think it is too high or too low. This is upsetting to participants who say their blood sugar can be normal most of the time, but the printouts show only when they have actually checked their blood sugar, thus giving an inaccurate representation of their treatment.

Participants were frustrated when the medical team bases decisions on these often incomplete meter printouts and neglects their whole experience with diabetes. They also indicated they do not understand why the medical team is so concerned with blood sugar

checks if their A1C remains within a normal range, because this indicates that blood sugar is stabilized overall.

Participants reported that frequently and consistently checking blood sugar and accurately calculating insulin injections was an extremely important, if not the most important, part of treatment, because an accurate insulin dosage is the only medical means of controlling blood sugar. According to participants, the medical team recommends checking blood sugar about seven times per day—once before every meal, before bed, and additional times if exercising or having a snack. However, most check their blood sugar between one and four times per day. The primary reason offered for checking less than recommended was that most check only if they physically feel the symptoms of high or low blood sugar. When feeling fine physically, most found checking blood sugar to be annoying and unnecessary. In fact, some do not even bother checking their blood sugar when they feel symptoms, but instead just simply treat it. Those doing well with treatment often discussed prevention of high or low blood sugar as a key to good treatment and said they have learned to watch for trends with blood sugar fluctuation. Participants also prevent abnormal blood sugar levels by reviewing data sheets during clinic visits, which helps some learn how blood sugar reacts as a result of different physical activities or illness. Another aspect of prevention and an overarching key to treatment success was consistently following treatment for a long duration.

Those doing poorly with treatment reported busy work schedules, inconsistent sleep schedules, and environmental structural problems as barriers to consistently checking blood sugar and injecting insulin. Even tangible rewards such as gifts or money were reported as ineffective in encouraging better treatment. For these adolescents,

discussing treatment was difficult because it appears they have rarely given much conscious or insightful thought to successful treatment. However, some have reported purposefully making decisions that would not help treatment, such as injecting too little insulin to avoid the risk of low blood sugar, or injecting insulin after eating simply because it is easier. These adolescents often reported improved treatment, usually after a clinic visit, that typically lasts only about 2 weeks.

Diet

Overwhelmingly participants reported that their medical team did not give much emphasis to diet. They did, however, say that eating a healthy diet was very important in maintaining normal blood sugar levels. Those with good treatment considered a healthy diet to be part of the basics of treatment, unlike those with poor treatment, who identified it as important but not necessarily part of treatment. As with most parts of treatment, consistency with diet is important; carbohydrates and insulin dosages must be accurately calculated in order to maintain good treatment. Also, consistently eating the same foods makes counting carbohydrates a little easier. All participants reported that the most difficult part of meal planning was accurately counting carbohydrates, making accurate insulin calculations difficult, which then results in guessing.

Factors discussed that help maintain a diet that encourages treatment include having the entire family involved in meal planning; the Lantus form of insulin, which allows greater freedom with diet; and mothers counting carbohydrates, calculating insulin dosages, and preparing meals. Factors discussed that do not help maintain a diet that

facilitates treatment include a busy work schedule, restricting diet to avoid larger insulin shots, and poor role models such as peers and family who eat unhealthy food.

Physical Activity and Physical Sensations

Physical activity is one of the few parts of treatment that appeared to motivate adolescents to pay close attention to their treatment. Most participants reported enjoying physical activity so much that the medical team rarely had to encourage it. In fact, participants reported paying closer attention to their blood sugar in order to participate in physical activity.

Factors that encourage physical activity include higher levels of self-esteem, role models who are physically active, a desire to maintain physical health and feel good, and understanding the risks and benefits of physical health. Factors that do not encourage physical activity include a busy work schedule, lack of motivation, lack of peers to interact with, and poor role models suffering the consequences of little physical activity.

The physical sensations of low blood sugar reported include becoming easily irritable, shakiness, extreme hunger, sluggishness, dry mouth, frequent urination, dehydration, and increased desire to sleep. The physical sensations of high blood sugar were reported as easily becoming agitated, dizziness, feeling “drunk,” excess thirst, and poor concentration. One significant problem with injecting insulin is that it causes blood sugar to drop, which in turn results in the same physical sensations as when blood sugar drops to a normal level. The pain of insulin shots was also reported as a significant problem for some.

Special Events

The most challenging aspect of treatment reported during special events was the difficulty counting carbohydrates and calculating a correct insulin dose due to an abundance of unhealthy food with unknown amounts of carbohydrates. This was especially difficult because participants also reported a desire to enjoy the event (eat the unhealthy food), which could often mean choosing to sacrifice treatment (not counting carbohydrates and injecting insulin).

Another challenging aspect of special events is that most adolescents diagnosed with diabetes described an awareness that they are not the same as everybody else, which provides significant motivation to sacrifice treatment. Having strong internal motivation to do well with treatment, planning ahead, keeping supplies accessible, and letting others eat first were all identified as factors that help support treatment at special events.

School

Participants had an overwhelmingly negative reaction to the role of school in their diabetes treatment. The negative aspects included the repeated unwanted attention from managing their treatment at school, feeling different from peers, teasing by peers, and eating school lunches that do not contain carbohydrate information, forcing them to guess at insulin dosages.

Participants described how they often had to explain their diabetes treatment to teachers in order to manage their treatment, even though the teachers had been made aware of the concern. They also reported that most school staff lacked the knowledge to

help with their treatment if necessary. Positive aspects of the school environment included an occasional office staff member who showed kindness and caring; a teacher with diabetes who showed a greater sense of understanding; a hall pass, which provided the freedom to leave class and manage treatment; a place to manage treatment and keep supplies; and prepackaged food that contained carbohydrate information.

Medical Team

Lack of empathy was consistently reported by adolescents as one of the largest obstacles in working with the medical team. Participants said the medical team has an overall inability to understand how each individual adolescent's unique life context influences his or her diabetes treatment. Participants often complained that the team did not take into account factors in their lives when making recommendations and, as a result, the recommendations did not function well. This lack of empathy was reported more frequently by those doing poorly with treatment.

Other challenging aspects of working with the medical team included recommendations that frequently changed (particularly insulin dosage); recommendations that were repeated; "harsh," "angry," and "mean" physician characteristics; lack of personal relationship; and the sense that the physician was not listening. In regards to physician anger, participants reported being very annoyed with such a response, but indicated that their physician's anger neither hurt nor helped treatment in any way. What they did stress is the importance of a caring relationship with their physician. Overall, participants reported the medical team as minimally influential in regards to successful treatment.

Even though participants reported several challenging aspects of working with the medical team, they also reported several positive aspects: being allowed to choose how they wished to follow their treatment and not being forced to follow recommendations, being honest about difficulties with treatment without experiencing a negative reaction, being understood as a whole person, having a good relationship with the medical team, and integrating the team's recommendations into everyday life. Participants universally reported that team members who are funny, easy to get along with, and can relate to adolescents make their clinic visits much more pleasurable. Interestingly, those with good treatment could often give detailed descriptions of the members and responsibilities of those on their medical team, while those with poor adherence often struggled even to list all of the members.

Family and Friends

Participants stressed the importance of family and friends as one of the most important parts of treatment. Family and friends were credited with providing immense amounts of emotional and physical support to the extent that some participants would give up without such support. The challenging aspects of family and friends include their overinvolvement to the point of annoyance, arguments with parents, friends and family who are poor role models, and significant relationship problems such as divorce.

Despite the challenging aspects of family and friends, participants reported many positive aspects, including the integration of their treatment into family life, mothers who generally provide the primary support, help with actual tasks of treatment, consistent

reminders, physically active friends, good role models, immense emotional support, and help with understanding that dependence on others is important.

Independence

Participants reported mixed views of how diabetes affects independence. Some said diabetes is a big “freedom killer” because they cannot just pick up and go somewhere without planning ahead; however, if things are planned out, then diabetes does not significantly hinder independence. Others said diabetes had no impact at all on independence. Interestingly, for those struggling with treatment, diabetes did not make much impact on their sense of independence because they purposely did not make diabetes a priority in their lives.

Participants in this study ranged in age from 16 to 19 years and were in various stages of transitioning into adulthood. This emerging independence and transition were often more challenging than they would have been had the individual not had diabetes. They said that their general emerging independence in life often did not match their independence with their treatment. Often, parents were very reluctant to allow greater independence with treatment out of fear that their child’s treatment would worsen. This was true of those with both good and poor adherence. Overall, emerging independence and transitioning into adulthood initially caused treatment to suffer, but eventually as maturity increased, so too did quality of treatment.

One last factor that had a significant impact on participants’ sense of independence was the use of an insulin pump. For those doing well with treatment, the insulin pump was seen as something that diminished a sense of independence because it

was a constant reminder of diabetes. For those doing poorly, the insulin pump was seen as increasing independence because less effort had to be made to manage treatment.

Affective Characteristics

Attempting to maintain normal blood sugar levels is extremely frustrating for many adolescents. Blood sugar levels tend to have a sense of unpredictability and often fluctuate outside of the normal range, even when the participants believe they are following treatment as recommended. This experience often results in a sense of hopelessness about treatment, which encourages adolescents not to follow their treatment as strictly as recommended. In other words, they seem to be choosing not to follow their treatment very closely because it often appears futile.

Affective characteristics that pose a challenge to treatment far outweigh those that encourage treatment, according to participants' descriptions. One of the most frequently reported affective characteristics was fear. All participants reported fear of serious and long-term health consequences as something that encouraged them to follow their treatment. However, those with poor adherence reported the existence of fear but could not identify why they still struggled to follow their treatment as recommended.

Other affective characteristics that pose a challenge to treatment included a passive and/or apathetic view of treatment, extreme dislike of attention gained from diabetes treatment, a generally poor attitude toward treatment, worry, depression, a strong desire not to have diabetes, and lack of motivation. Another complicated affective characteristic is that of embarrassment. Overwhelmingly, participants reported not feeling embarrassed about diabetes treatment, but rather experiencing a sense of difference from

their peers. All of these factors were reported to influence many to purposefully sacrifice their treatment.

Affective characteristics that appear to encourage treatment included feeling guilt and anger from parents and/or others, maintaining a positive attitude, understanding tolerance and responsibility, having a personal understanding of why treatment is important, not letting diabetes define themselves, and being able to view diabetes treatment as “cool” or as something that sets them apart from others in a positive way. Those who experience a sense of *coolness* reported a sense of pride in the accomplishment of such a difficult task (diabetes treatment) that many other adolescents might not be able to achieve.

Two affective characteristics that can be challenging and/or encouraging are self-esteem and acceptance. These two characteristics can be challenging if experienced at low levels and encouraging if experienced at high levels. Most participants described these characteristics in a fluid sense, in that they occur in a process that is very slow and can last for years. Level of treatment success appears related to how well the participant has accepted the diagnosis and treatment of diabetes. Level of self-esteem also appears to impact level of acceptance and treatment success.

Summary

Participants’ descriptions of diabetes treatment helped illuminate the complicated and dynamically interrelated structure of many of the factors influencing their treatment. Many factors that challenge and/or encourage treatment occur across many areas, as opposed to just one area of treatment. This composite textural description revealed that

the factors influencing treatment are often dynamic and can function as challenging, encouraging, challenging and encouraging, or serve no function, depending on each adolescent's unique life context. Thus, it is almost impossible to discuss the factors influencing treatment as barriers and facilitators, because the concept of barriers and facilitators is too simplistic of a concept to yield understanding from an extremely complicated phenomenon.

Treatment Schemas

The following eight treatment schemas were developed as the overarching structural themes of this study and emerged as the most prominent results. The overarching structures were developed as a higher level organization of the categories of themes that resulted from the researcher's need to have a structured format from which to conceptualize and understand the vast amounts of data. Once these overarching structural themes were developed, the term *schema* was used rather than theme. This was done because the treatment schemas were developed from the adolescents' cognitive recollection of their experience. The following eight treatment schemas not only offered the researcher a means to understand the data but also provided the adolescents with a framework from which to understand their own experience with treatment.

The section below provides brief descriptions of each treatment schema as illustrated in Table 2 and is followed by more comprehensive descriptions that include excerpts taken directly from the participants' description of the phenomenon. This allows for the textural (what was experienced) and the structural (how the phenomenon was experienced) descriptions to be read and considered simultaneously.

Table 2

Treatment Schema Descriptions

Treatment Schema	Description
1. Treatment Tasks	<ul style="list-style-type: none"> ▪ checking blood sugar as often as recommended ▪ counting carbohydrates ▪ calculating the correct insulin dose ▪ precision of treatment ▪ pain and time of insulin injections ▪ unpleasant taste of glucose tabs ▪ accessibility and ease of use of equipment and supplies ▪ physical activity ▪ healthy diet
2. Affective	<p>Affective Themes</p> <ul style="list-style-type: none"> ▪ empathic understanding ▪ confusion about treatment ▪ self-esteem ▪ enjoyment <p>Specific affective characteristics: Anger, Anxiety/Worry, Depression, Awkwardness, Sense of Balance in life, Feeling blamed or judged by others, Feeling comfort or accepted, Embarrassment, Peer Pressure / Avoidance – not wanting to appear different, Enjoyment, Fear, Frustration, Honesty, Hopelessness/Helplessness/Worthlessness/ Discouragement, Level of Motivation, Overwhelmed, Self-awareness, Self-esteem, Stress, Nuisance</p>
3. Relationship	<p>The relationship schema describes the social interaction between the adolescent and the following factors:</p> <ul style="list-style-type: none"> ▪ family and friends ▪ medical team ▪ school ▪ emerging independence
4. Personal Uniqueness	<p>The factors influencing adherence to the diabetes treatment regimen are unique to each adolescent and are often a dynamic inter-relation of the following influences:</p> <ul style="list-style-type: none"> ▪ treatment tasks ▪ environmental ▪ cultural ▪ psychological ▪ social ▪ unique personal characteristic of each adolescent
5. Treatment Integration	<ul style="list-style-type: none"> ▪ integrating diabetes treatment regimen into normal routines of everyday life is essential for maintaining good blood sugar control ▪ treatment integration was viewed as an essential factor to live a normal life by those doing well with treatment ▪ treatment integration was almost nonexistent or outright rejected for those struggling with treatment

Table 2—Continued

Treatment Schema	Description
6. Acceptance	<ul style="list-style-type: none"> ▪ acceptance is a process that occurs slowly over the course of several years as maturity and independence increase ▪ acceptance, treatment integration, and level of self-esteem appear to be inter-related ▪ acceptance tends to increase as adolescents mature and transition into adulthood ▪ treatment usually declines during the transition into adulthood and then improves
7. Cognition	<p>Cognition is impacted by many variables including:</p> <ul style="list-style-type: none"> ▪ attitude toward treatment ▪ worldview relating to optimistic or pessimistic outlook ▪ belief system (faulty or functional beliefs about treatment) ▪ coping skills ▪ cognitive ability
8. Intentionality	<p>Intentionality refers to the adolescents making purposeful (intentional) decisions about their treatment. Examples include:</p> <ul style="list-style-type: none"> ▪ purposefully sacrificing treatment ▪ restricting the amount of insulin to avoid pain, bruising, and lumps ▪ restricting food intake to reduce the size of insulin injections ▪ accepting personal responsibility for level of treatment success ▪ making health their number one priority ▪ choosing to eat a healthy diet ▪ choosing to make diabetes treatment an integrated part of life

Treatment Tasks Schema

The treatment tasks schema refers to what the adolescent participants universally conceptualized as the treatment regimen tasks required to maintain normal blood sugar levels and the factors that influence their ability to maintain medical control of diabetes. Treatment tasks include checking blood sugar as often as recommended, counting carbohydrates accurately, calculating the correct insulin dose, and injecting insulin at the appropriate times. Many other factors that influenced treatment were identified, such as family and physical activity; however, these were not universally considered as treatment

tasks that were essential to maintaining normal blood sugar levels and thus were incorporated into other schemas.

The treatment tasks are all considered critically important to one another; otherwise, a chain reaction of treatment problems begins to occur. For example, if blood sugar is not checked as often as recommended, the adolescents will simply have less knowledge about how their blood sugar responds to various factors such as diet and exercise. For most adolescents, if they are not checking their blood sugar as often as recommended, they are likely not always calculating the amount of carbohydrates in the food they are eating, which then makes calculating the correct insulin dosage almost impossible. As a direct result of not checking frequently enough and not counting carbohydrates accurately, adolescents have no choice but to guess at their insulin dose. Participant #9 described his challenges with the tasks of treatment and how other factors, such as loss of his primary support, affect these tasks:

Probably two out of the four meals I do have to guesstimate. Especially with being in college, I don't know, I mean I know some information on what has how many carbs, but not all of it, so, kind of, if I eat a bowl of macaroni and cheese, I'll have two cups here, it's kind of like, you know, it's this kind of noodle, you know, a little cheese affect anything being dairy. You got to take those things into consideration. Yeah, just adjustment in general, you know, stress of being away from home, away from family. You know, I'm 12 hours away, 10–12 hours away. It's definitely different relying more on yourself and friends than relying on yourself and family. So, that's harder and stress related.

The problems just described about the tasks of treatment illustrate the importance of precision with treatment. If all the basic aspects of treatment are not followed precisely, treatment will suffer. Other factors that influence such precision are the pain and time of insulin injections, as well as the unpleasant taste of glucose tabs. Participant #3 described his dislike of insulin shots but quickly changed focus to how he is

encouraged to follow his treatment. His description illustrates a theme of pain as well as healthy coping skills of a positive attitude and a desire to stay healthy.

Those shots are killer. It's just the pain is really all it is. It burns going in and mostly what encourages me is basically I want to live a long healthy life. I don't want to die. I don't want to go blind—that's my biggest thing. If I had to choose between amputations and going blind and stuff like that or death, you know I'm pretty sure it would be death.

What a powerful statement from an adolescent that death would be preferred over long-term health consequences. Such statements were quite common among participants and help illustrate that maintaining diabetes treatment is an emotionally laden experience that is difficult to discuss in dichotomous terms such as barriers and facilitators. This participant's description also contains a theme of fear, which would fall under the Affective Schema representing the dynamic interaction among schemas.

Also included in the treatment tasks schema were equipment and supplies. Participants universally reported that having supplies that are easy to use and easily accessed dramatically affects treatment adherence. Additionally, some reported that insulin pumps make treatment much easier, while others (usually those with good adherence) do not want to use pumps because they do not want to be attached to equipment. Problems with equipment include inconvenience of keeping supplies easily accessible, such as at school or at special events; meters that are too large and cumbersome; and printouts that do not accurately portray information. Participant #5, who struggled with treatment, described his experience with how an insulin pump simplified his treatment:

I just . . . I dial up insulin on my pump . . . give it to myself, whatever my blood sugar is. However, many points over 150 I get . . . if it's 200 I get one unit, 250—

two units. I don't have to stick a needle in my stomach. All I gotta do is press a couple of buttons and it is already giving me insulin.

Participant #2 helped shed some light on why meter printouts are not always complete. The primary reason is that blood sugar is not always checked, thus making meter printouts only as complete as the frequency of blood sugar checking. Participant #2 explained:

I can feel it. You can feel if you have high blood sugar. So, instead of like, if I'm, I don't know if I'm doing something instead of stopping what I'm doing to go check myself and all that, I'll just give myself a couple units on my pump and just keep doing what I was doing.

This is a good example of why meter printouts for some people tend to indicate far better blood sugar levels than what actually exist; this participant tended not to check his blood sugar levels if he knew they were not within normal limits.

Physical activity and a healthy diet were two factors considered part of the treatment task schema by those who were doing well with treatment. These participants discussed how monitoring their diet and physical activity in relationship to their blood sugar level had a significant impact on helping them learn how to understand the intricacies of treatment and how their body responds to various factors. Conversely, those with poor treatment generally did not emphasize the role of diet or physical activity as part of treatment and referred to treatment as consisting only of checking blood sugar, counting carbohydrates, and taking insulin. Even though this group reported counting carbohydrates as a treatment task, they did not seem to understand the importance of a healthy diet. Participant #4, who likely had the best control over his blood sugar, gave an extremely detailed account of his diet. Even though his account is more detailed than most, it illustrates the importance of understanding the role of diet and the precision

required with diet to maintain normal blood sugar levels. His description also illustrates the important role of family, which shows how treatment schemas are dynamically interrelated.

I usually get up around six and around seven I have breakfast. I have something quick, a ½ bagel with peanut butter on it and some tea. But, on the weekend I would have one plum or two plums and then some oatmeal with tea. And then, for lunch, which runs between 11 to 1, depends on whether it's a weekday or weekend, I would have either a sandwich—I usually go for the Subway sandwiches since they're close to my grandmother's house which I go to everyday when my parents have work. I would be considered the local Jared because I go there so often. I usually go, I go across the menu. I don't just stick with one thing. I used to do that for school. It would be a six-inch cold cut trio with, uh, provolone, lettuce, cucumbers. I would do a six-inch oven-roasted chicken breast, maybe with some ranch dressing, spinach, lettuce, tomatoes, cucumbers, green peppers, American cheese, and, yeah, would usually stay with the same condiments such as tomatoes, cucumbers, green peppers, lettuce. I would usually stick with that for all of my sandwiches. Except for maybe a meatball sub; I just went with tomatoes and lettuce with provolone cheese on there. But, yeah, usually I have whatever is on the menu. Turkey breast and ham or turkey breast sandwich, six-inch usually. It's all on wheat bread. I always pick wheat except for sometimes I may take Italian, but . . . and, um, for dinner, it's usually what my grandmother cooks. I mean, sometimes I have about two cupfuls of spaghetti with, uh, ground beef on it and her homemade tomato sauce. She usually does it homemade. Sometimes she puts garlic in there, which is also very healthy. She, uh, it's usually on set days. I mean, she does change it. It's usually a Thursday. I might have that or I might have, well, lamb with garlic stuff in it and some, uh, oven-baked potatoes, and bread, and salad, and that would usually go about 4 o'clock and on the weekends it's usually six o'clock. It's whatever we're making at home.

. . . at the end of the day I usually follow that up with a snack at around 8 or 9 o'clock. It depends on how late I've had dinner. We usually go by a four-hour schedule. Four hours after I eat, I eat again. I usually have a snack to hold me over till breakfast. It usually includes, uh, protein, carbs, something that'll hold on long enough to maintain my level through the night. Usually I have beef jerky, either pistachios or cashews, and sometimes I might have like Oreo cookies, ice cream, whatever, I mean, that's when I indulge myself is at night.

This participant's interview made me wondering about how psychological characteristics of perfectionism and obsessive compulsiveness might play a role in his management of diabetes. However, questioning him about psychological concerns did not

seem fair or respectful to this participant, who had only agreed to share his experience with treatment. Future studies investigating the impact of specific psychological characteristic on treatment would likely yield some very interesting results.

Affective Schema

The affective schema highlights the emotionality experienced by adolescents with diabetes that is fueled by the constant challenge of maintaining treatment. Within this schema, several affective themes emerged, including empathic understanding, confusion, self-esteem, and enjoyment. Empathic understanding was a theme that repeatedly rose to the forefront of the adolescents' descriptions of their treatment. The participants shared how people around them, particularly the medical team, often have a difficult time understanding how each individual experiences diabetes treatment. Even if the medical team did understand each unique experience, they definitely struggled to convey their understanding to the participants. Participants indicated the team's understanding would be more evident if they made recommendations based on the adolescent's unique experience with diabetes. Participant #6 expressed her desire for more understanding from the medical team:

Yeah, I think it would be a lot better if they wouldn't just judge us all as the same person. Oh, she has diabetes. She's just like him because she has diabetes. But, like, if they stopped and actually looked at the person, and was like, she had a troubled childhood, maybe I should care a little bit more about her than I do about him because he's all good and he's taking care of himself. I think they should just focus on each person as who they are, not because they are diagnosed with diabetes.

This description also represents the complexity in which adolescents speak of diabetes treatment. This participant's description illustrates themes of empathic

understand, frustration, and the personal uniqueness schema all within a few sentences. Utilizing the eight treatment schemas to help understand what is being said by adolescents may provide some hope to adolescents, similar to this participant, that their voices can be heard.

Confusion was another theme common within the affective schema and it occurred in several areas of treatment, including counting carbohydrates and calculating insulin dosages, understanding the relationship between blood sugar checks and A1C levels, comprehending the information downloaded from meters at clinic visits, realizing why the team may frequently change recommendations, understanding how diet influences treatment, and having a general sense of ambiguity about what makes treatment so challenging. Generally, it appeared that the more adolescents struggled with treatment, the more confusion they experienced. Participant #1 explained how some simple confusion about carbohydrate counting led to a very frustrating interaction with her medical team:

Oh, it sucks 'cause then if you eat and there's no carbohydrate listing, you can't really write it down, so you just guess and then when the doctor sees the chart says, "How come you boliced this for that much carbohydrate?" And then all you can say is, "I don't know. I just guessed," and then it's like, "Why'd you guess?" And just a whole bunch of questions afterwards, afterwards, afterwards, and all you can say is, "I don't know."

Participant #1 went on to discuss her confusion regarding the frequently changing recommendations from her medical team:

Yeah, they tell me to take it like at a certain part of day, but I'm like, man, 'cause last time I was here they told me then; the next time I came they said, "Take it in the afternoon or, no, wait, no, not in the morning." They told me to take it before I eat, and then the next time I came they told me to take it after I eat, and I was like, "Make up your mind," so . . . Um, it's like they change their mind often because they see my blood sugar, they see my charts all bad and everything, they say

maybe you should try this way, and then they see it's bad again. It's like, oh, maybe should I try this way, and then when it gets normal, then they still end up switching it sometimes just to see what happens, what went wrong with that, so it just, it's . . .

Participant #2 illustrated a general sense of ambiguity regarding treatment that was all too common in many of the participants' descriptions, which helps illustrate the fact that adolescents struggle to understand why diabetes treatment is so challenging to follow. He said, "because that's why every meeting they say that they know I can do it, because I did it then, but I don't know why I don't."

Self-esteem was a theme within the affective schema that appeared to significantly impact treatment adherence and acceptance of diabetes. Simply, those with low levels of self-esteem reported the most challenges with treatment and significant difficulties with acceptance of diabetes, while those with higher levels of self-esteem reported fewer challenges with treatment and a greater acceptance. There appeared to be a relationship between increasing self-esteem, increasing acceptance, and improved treatment. If self-esteem and acceptance increased, treatment generally and gradually improved; however, if self-esteem and acceptance were low, treatment was unlikely to improve.

Enjoyment was another theme highlighted within the affective schema. Participants indicated they paid closer attention to their treatment if it would help them enjoy something; however, if treatment interfered with enjoyment, they would pay less attention to it. Enjoyment of physical activity was universally reported by adolescents as one area that motivated them to pay closer attention to their treatment. Figure 1 lists specific affective characteristics found within the affective treatment schema.

Anger	Honesty
Anxiety / Worry	Hopelessness
Avoidance	Motivation
Awkwardness	Nuisance
Confusion	Overwhelmed
Depression	Peer Pressure
Discouragement	Self-awareness
Embarrassment	Self-esteem
Enjoyment	Sense of balance in life
Fear	Stress
Feeling blamed or judged	Worthlessness
Helplessness	

Figure 1. Specific Affective Characteristics

Relationship Schema

The relationship schema described how social interaction between the adolescent and family and friends, medical team, and school influences their treatment. The first factor, family and friends, was not considered an aspect of treatment until one participant suggested that specific questions about family and friends be added to the interview protocol. Once that was done, it became clear that family and friends is one of the greatest influences of diabetes treatment and should probably be considered part of treatment. Participants reported that caring and healthy relationships as well as significant parental involvement in most aspects of treatment are extremely helpful. Both those doing well and those doing poorly with treatment said they would likely be much worse without the help of their families. Negative influences of family include poor relationships, poor communication, poor parental role models, and parental overinvolvement with treatment. Participant #1 described how she likely would give up without the help of her family:

Uh, really I don't think I would even bother with—I'd probably just lay there and get a nurse to press the button and do everything for me. Like, if I didn't have friends and family, I would not be here right now; I probably wouldn't. I don't know; they just motivate me to keep staying alive 'cause they're such good people . . . they tell me keep in shape and, um, like give me hugs and everything. It's like my family, they like check my blood sugar, they play around with, "Ha ha ha, your blood sugar's low." So, it just makes me laugh. I'm like, "Ha," so it's no big deal with them.

This excerpt illustrates that having family and friends aware of diabetes helps remove negative stigma and embarrassment about the illness. Generally, participants doing well with treatment usually reported a sense of comfort treating their diabetes in the presence of friends and family, while those doing poorly with treatment were extremely hesitant and feared appearing different.

Participant #6 discussed how her relationship with her family motivated her to follow her treatment; however, her description is not nearly as positive as the previous one.

She puts a guilt trip on me all the time. She's like, "You're going to end up blind. You're going to lose your feet." And, I'm like, "Stop!" So, like, but she helps me a lot. She tells me when I need to take my insulin. She asks me if I've taken my insulin. She continuously asks me if I've tested my sugar. She asks me what my sugar was at. She's like, after dinner, she's usually telling me, "Did you take your insulin? You just ate this, this, and this. Did you make sure to take your insulin?" And, I'm like, "No." And, she's like, "You better take it." And so I have to take it.

Participant #7 offered yet another perspective on how family plays a significant role in treatment. His description is quite common, in that family provides a lot of support but, at the same time, can be quite bothersome.

I know my family, they support me a lot. I remember my cousins going on one of the diabetes walks and over in another town, it's like a town, over next week, or sometime in the near immediate future. But family has been supporting me such much and reminding me, which to a point sounds like nagging because you hear it so many times. But I know they've been behind me on it. I had quite a few problems with that. Like, when my mom reminds me time and time again. I know,

because deep down I know she's just trying to help me, but it just sounds like a broken record, I've heard this before and . . .

Participants reported a very similar role for their friends, who provided a great deal of treatment support. Interestingly, there was a distinct difference between those doing well and those doing poorly with treatment in their perception of the role of friends. Those doing well said that having friends aware of their diabetes and treatment was almost always helpful. Friends could help with treatment if needed and could also provide a sense of comfort. Those doing poorly consistently reported attempting to hide their treatment from friends, believing that their treatment would somehow threaten or disrupt their friendships. Participant #2 was able to provide examples of how friends can facilitate and hinder treatment:

Um, if my friends say something, like to check myself, they'll remind me that, I don't know, that helps me check myself. Then if I don't feel good, that's like my first thing you do is to check myself. That's pretty much it.

He went on to describe his discomfort checking his blood sugar around others. This helps illustrate a theme often referred to as *not wanting to appear different from others*. Even though his description sounds strikingly like feelings of embarrassment, most adolescents adamantly denied those feelings, insisting that they simply did not want to feel different. Here, participant #2 describes his experience:

I guess like if it was somewhere new, then I guess I'll be like, um, I don't wanna check myself in front of all these people. I don't know, 'cause like people ask questions a lot. They'll be like, "What is that?" so stuff like that.

The concept of relationship also emerged as quite significant in the adolescents' interactions with their medical team. Participants frequently talked about how they valued being treated as "whole persons" during their clinic visits, rather than just someone with

diabetes. They frequently mentioned that they enjoyed talking to their team about all aspects of life and not just treatment. Some of the most important aspects of this relationship were the team's ability to talk about developmentally appropriate subjects such as college or school activities, to have a good sense of humor, and to make the adolescent feel comfortable in the clinic. Without a caring relationship, adolescents were more likely to not listen to the recommendations of the team. Participant #6 highlights how important a personal relationship is with her team in maintaining treatment.

Well, it makes me, like when people are concerned, and they try to get involved in my life and stuff, it makes me feel that, wow, you know there's actually people out there that care. When like back in the day I was, I was one of those psychotic kids that thought nobody cared and nobody just thought nothing of me, and then all of a sudden I have [two people in the clinic—titles and names removed for confidentiality] that are trying to get involved and I'm like, wow, you know these people actually care, so, and knowing that people are out there that do care, it just makes me want to be like, hey, why not? Just try something, try to take care of my life so I don't have to upset and make these people who do care feel bad.

Participant #1 described how she may resort to being dishonest with her team in order to keep a pleasant relationship, when she fears that relationship might be threatened due to poor treatment.

Yeah, it's like, you know, you wanna tell them how you doin' it. You wanna like keep them happy so you tell them how that like what they wanna hear about how much you boliced and everything, and then really you're bolicing a different number than what they want. Yeah, I was like I don't wanna hear it, so I just tell them what they wanna hear sometimes.

In yet another dynamic relationship with the medical team, participant #7 talked about how he perceived his medical team's growing frustration with his continued poor treatment.

Well, I can tell they're disturbed by that and they know that I need to do something, and I know that I need to do something about it. I think they're just to the point, I've had a lot of high numbers in the past, that they just feel like they

aren't giving me the same old broken record because I haven't done much to improve upon it. Just because they really want to see, I don't think they just really see any difference in the way they're doing it and they're trying to think of something different to tell me, but they're just not sure what to do at this point in time.

The concept of relationship also emerged as significant for adolescents within the school environment. Overwhelmingly, participants reported very few factors that helped them follow their treatment while at school, unless they were able to develop a caring relationship with one of the school staff. If such a relationship was developed, usually with an office staff member, the adolescent reported a much more positive interaction with the school. However, if such a relationship did not exist, adolescents generally described the school as a difficult place to maintain treatment due to several barriers, including frequent disagreements with teachers about the need to leave class, unwanted attention, inability of school staff to help if needed, structure of the school day, and unknown amounts of carbohydrates in school food. Participant #3 discussed how the hall pass was probably the most important thing his school had done to help with his treatment.

Yeah, the hall pass is really the big thing that helps. That's not even the school. The school would actually like to get rid of these. The principal absolutely hates these, but the nurse requires that the diabetics have them. So, the principal absolutely hates this pass. Everyone hates this pass. People say it's special privileges. Well, we need it.

Finally, the concept of relationship appeared significant with adolescents' emerging independence. Developing independence is difficult because adolescents with diabetes are often very dependent on caregivers and the medical team. Participants described how their caregivers are often quite anxious about the adolescent's ability to solely care for his or her diabetes. As a result, emerging independence from caregivers

may not occur at the same time as emerging independence with treatment, causing considerable frustration and tension within the relationship. Generally, emerging independence causes treatment to deteriorate until the adolescent is accustomed to doing it on his or her own.

The participants often had dichotomous views about how diabetes treatment impacts their sense of independence. Participant #8 described his perception of the limitations diabetes places on his independence.

It's a big freedom killer. I can't really just pick up and leave forever. Because, I have my insurance and I have to get my insulin or I'm not going to make it, you know. I can't, I won't go to a pump because I don't feel independent. I feel like I'm on life support. You know, having an extra organ attached to me. Plus you got this long needle that's inside you and I don't really want to hit that.

The opposite viewpoint was expressed by participant #4, who described how diabetes does not at all limit his independence. Participant #8 had a more pessimistic outlook on treatment, while participant #4 had a very optimistic view of treatment and overall worldview. The concepts of pessimism and optimism are also characteristics discussed in the Cognition schema, thus illustrating how the various schemas are dynamically interrelated.

It doesn't restrict me from doing anything. I can go out with my friends. If I have to do my shot, then we just typically adjust it so if I do any activities with them, then my level will not go low, or if I met with my friends and then I need a shot at that time, we—I usually would check my level at that time. To see how it is, and maybe I, when I get back home, I would do my shot then. Or we're just doing an activity such as walking around maybe at some stores, it doesn't affect me at all.

Personal Uniqueness Schema

The combination of factors influencing adherence to the diabetes treatment regimen is unique to each adolescent, as was strongly emphasized by the participants in this study. Because the interaction of these factors is so complex, it is nearly impossible for most to accurately identify what functions as barriers and facilitators to their treatment. One reason is that the factors emerge not only from the specific tasks of treatment but also from environmental, cultural, psychological, and social influences, as well as the personal characteristics of each adolescent. Many of these factors seem to be dynamically interrelated, further complicating accurate identification. Another complication is that many factors do not function the same for all adolescents. This complex array of factors influencing treatment adherence can be better understood by considering all the treatment schemas and developing an overarching treatment schema that fits the uniqueness of each adolescent. Excerpts from participants #3 and #9 offer two examples that illustrate the importance of the medical team being able to understand the personal uniqueness of each adolescent.

Participant #3

A lot of what they're doing is basing it off numbers and they're trying—because they don't live with this 24/7. They don't know what you go through. So they're trying to judge a significant part of your life without really deeply knowing you.

Participant #9

For me, it's mainly, they don't have it, so they don't know what I'm experiencing. They don't know the rocky road that I'm experiencing. They can do it by all the facts they might have learned or experienced just by being a doctor, but as being a diabetic, they don't know how that is.

Participant #3 described how the medical team makes decisions about treatment based on his meter readings and not how the unique factors in his life impact his treatment. He explained that his meter readings are not complete because he usually checks his blood sugar only if it is too high or too low, which results in meter printouts that might indicate very poor treatment when, in fact, he managed his treatment very well. Participant #9 seemed to believe that just because the members of his team do not have diabetes, they cannot understand what he is experiencing. This is yet another example of how the various schemas are dynamically interrelated. In his example, the medical team may or may not have understood what he is experiencing, but, from his experience, any understanding was not made clear to him.

Treatment Integration Schema

Integrating the diabetes treatment regimen into the normal everyday routines of the adolescent's life appears essential for maintaining normal blood sugar levels and is one schema consistently reported by those doing well with their treatment. The concept of treatment integration either was almost nonexistent or was clearly rejected by those with poor adherence. Those rejecting treatment integration did so out of fear that diabetes treatment would overwhelm them and prevent them from living normal lives. Interestingly, those with good treatment said that integration must occur and, as a result, they could continue living normal lives and be much healthier. Participant #4 offered an explanation of how his personality has allowed for successful treatment integration:

I'm already on a plane where no other adolescent at this moment would be on. I, some consider me a health nut. I just have that engrained into every fiber of my mind. I'm doped on order and just doing a certain job I'm assigned to do.

A very different viewpoint was offered by participant #6, who rejected the idea of integrating diabetes treatment into her life. Unfortunately, her treatment was not well under control. The following description also illustrates how life factors (work) can complicate treatment.

It pretty much, it's supposed to control my life. If it pretty much took over my life, it would mean that possibly I would be eating healthier and I wouldn't be sick and I would know that later on down the road. I'm not going to be blind or feeble sitting in a wheelchair going nowhere. I truly wish that it did dominate my life, but my life is busy being dominated by work . . . But, reality is that is I have to work. I have a life. I can't have this pretty much controlling it. I would love it to control my life, but it doesn't.

This participant continually referred to her work as the reason she could not manage her treatment well to the almost complete exclusion of other factors. Identifying one factor to the exclusion of most others came to be known as the theme: *universal reason for poor treatment*. For this participant, it appeared as if she drew upon this theme out of her inability to understand the complex factors impacting her treatment and desire to make sense of her treatment.

Acceptance Schema

Themes of acceptance emerged from the data as the use of probes and clarifying questions illuminated a very significant theme that neither the adolescents nor the researcher initially considered. The participants described acceptance as a process that very slowly occurs, sometimes over several years, as they mature and gain independence. As this process unfolds, adherence to the treatment regimen and integration also appears to increase. This relationship, as described above, appears to be reciprocal with all factors reinforcing each other.

Those with poor adherence have rarely integrated diabetes into their daily lives and generally experience low levels of acceptance. Those with good adherence who have been fairly successful with integration tend to have much higher levels of acceptance. Additionally, acceptance of diabetes tends to increase as adolescents become more mature and transition into adulthood. However, for a brief period of time, adherence usually declines during the transition into adulthood, because the adolescent is learning how to function with much more autonomy. Participant #7 described how his struggle with accepting the diagnosis of diabetes affected the success of his treatment:

Well, I don't think it's as much about knowing I'm having a hard time following my treatment as I have just really didn't want to accept it. It was mostly, I knew I had to treat it, and I knew I needed to do something or something a lot worse would happen, but just accepting the fact that I had diabetes and I was different had to help change . . . I really needed to change when I was in middle school, because I really didn't want to accept it.

Participant #7 described himself as a child that was often teased by other children, never really fit in, and likely experienced clinical depression after the divorce of his parents. Due to these circumstances, accepting diabetes meant standing out as different to a world that was already an uninviting place. For him, refusing to accept diabetes likely functioned as a defense mechanism to avoid any further discomfort in his world.

Cognition Schema

The cognition schema did not emerge from the data until very late into the data analysis when the themes were reviewed. At that point, it became clear that the cognition (thinking) of adolescents has a significant impact on the influences impacting their diabetes treatment. By the time the analysis was complete, the cognition schema appeared

to have a tremendous influence on adolescents' level of treatment success. Cognition is impacted by many variables, including attitude toward treatment, an optimistic or pessimistic worldview, belief system (faulty or functional beliefs about treatment), coping skills, and, possibly, cognitive ability. Participant #4 provided an explanation of what he calls his pessimism, which helps him follow and improve his treatment:

I try to make that outlook because I'm usually pessimistic about my own self. I want myself to be a lot better than what could be. I mean, a lot better than what most people want to be. I like to be an overachiever.

Participant #8 offered an interesting explanation of how having diabetes can teach healthy coping skills and responsibility toward treatment:

I think it teaches tolerance, you know. And when you have to do something from a very young age for your health and you keep doing it, you become tolerant of, you understand responsibility from a younger age. It helps understand the importance of a lot of things. Because, it wasn't like I was doing it just because I thought my parents made me; it's because I knew how sick I got if I didn't do it. It's, I mean, it's not fun to be have high glucose or low. It's actually quite painful.

Participant #9 illustrated the use of a functional belief that health must be a priority to encourage successful treatment, even though he has significant difficulty accepting his diagnosis of diabetes.

That's part of the reason I don't do my shots before I eat. You know, I kind of want to feel like I don't have diabetes. I want, I just don't want to have it but, you know, it's something I have and something I need to deal with to stay healthy and keep myself going and not end up with all the heart problems and things like that down the road.

This participant was a young college student living in the dorms who did not want to check his blood sugar in front of others in the dining hall. In addition, for him, it was much easier to calculate an insulin shot after eating as opposed to before eating. For this

participant, it appeared as though every attempt was made to minimize the role diabetes played in his life and to try and appear as if it did not exist.

One of the most troubling themes from the cognition schema was that of the *universal reason for poor treatment*. Those with poor treatment often repeated one universal reason they were struggling with treatment. Some of the most common reasons were forgetting and a busy and chaotic work schedule. Participant #6 most frequently employed a universal reason for poor treatment. Throughout her entire interview she consistently said that her job was the primary reason she could not follow her treatment as prescribed.

I'm so busy with work and everything I barely have time to sit down and relax; I just have to go. And, if I eat something, I usually don't test my sugar; I'm so busy I usually don't have to test my sugar; I only have time to take my insulin so I . . . most of the time I usually check it when I get home at 10 o'clock and I can finally sit down and relax. But, any other time I'm like, I'll be all right, just gotta take some insulin, and then go. 'Cause it just takes so long.

Intentionality Schema

The schema of intentionality is the only structure in which the themes appeared distinctly different between those with poor treatment and those with good treatment. Intentionality refers to the adolescents making purposeful (intentional) decisions about their treatment. Those with good adherence reported searching for solutions to treatment-related problems, while those with poor adherence had a more pessimistic view of treatment and struggled to identify solutions. Examples of intentionality for those with poor treatment include purposefully sacrificing treatment for many reasons, in particular, attempting to fit in and enjoy special events; restricting the amount of insulin to avoid

pain, bruising, and lumps; and restricting food intake to reduce the size of insulin injections. Participant #9 offered the following description, which illustrates how he intentionally chose when he injected his insulin, even though it was counter to what was recommended.

I don't want to have to think about what I'm going to eat but that didn't fill me or I really should have something . . . I'm going to exercise. I kind of want to wait till I have what I eat, then do the shot for what I eat. Yeah. I'm kind of butting heads with the doctor. I think my way is better, but I obviously I believe theirs is better and, uh. I just got to realize, you know, do a shot for what I'm going to eat to stick to it. If I need more, I should just do another shot for it. Just the fact that I don't want to do another shot.

Examples of intentionality for those with good treatment include accepting personal responsibility for level of treatment success, making health their number one priority, choosing to eat a healthy diet, and choosing to make diabetes treatment an integrated part of their lives. Participant #8 described how his knowledge of the benefits of good treatment encouraged him to intentionally follow his treatment:

It's just knowing that I'm gonna feel better is a big one. I mean, there's all the long-term risks and knowing what I have to do afterwards is a big help, like if in the morning, uh, I'll be sure to take exactly how much I need and whatever else I might need to do if I have a test because if my blood sugar is off, it could throw off, you know, my processing ability and I wouldn't, I wouldn't be able to do as well, you know. So, I mean, just things like that, knowing all the benefits and all the downsides to not doing it because people, even when I put it off myself, it, I just felt worse.

Textural-Structural Synthesis

The phenomenon of the barriers and facilitators of diabetes treatment as experienced by adolescents revealed itself as an extremely complex web of dynamically interrelated factors. The data analysis helped shed light on this complexity by reducing

and condensing the data into units of meaning, themes, and overarching structures. The following textural-structural synthesis weaves together the composite textural and composite structural descriptions, as well as the universal essences (treatment schemas) of how adolescents experience their diabetes treatment.

Managing diabetes treatment well enough to maintain normal blood sugar levels presents itself as a highly ambiguous and complex phenomenon that functions specific to each adolescent's unique life context. Almost all agree that checking blood sugar regularly, counting carbohydrates accurately, and injecting the correct amounts of insulin at the appropriate times are the basic necessities of diabetes treatment. Unfortunately, this is where universal agreement ends and the extremely complicated nature of managing diabetes treatment begins. There is great variability regarding the voluminous amount of factors influencing diabetes treatment; however, one thing became abundantly clear: *Each adolescent's experience with diabetes must be viewed individually within his or her unique life context to be most accurately understood.*

The emotionality that accompanies diabetes treatment is a broad spectrum of feelings ranging from those of frustration and hopelessness to those of happiness and pride. Within this spectrum of emotionality, larger themes of empathy, confusion, self-esteem, fear, and enjoyment emerged. These themes can encourage, discourage, or have little influence over treatment, based on how the adolescent experiences these themes. All participants experienced their own combination of emotions within these themes associated with their treatment; however, those who experienced more emotions that encouraged treatment managed far better than those who experienced more emotions that discouraged treatment.

Successfully managing diabetes treatment is highly dependent on the success of the adolescent's relationships with family and friends, their medical team, and the school, and on their ability to develop independence. Navigating through successful relationships in these areas often greatly impacts the adolescents' ability to pursue their emerging independence. Those doing well with treatment are often successful with these relationships and do not find their emerging independence compromised. However, those struggling with their treatment often struggle to maintain these relationships and, consequently, caregivers are reluctant to allow greater independence. It is a vicious cycle that, once started, is very difficult to break.

Managing the basic necessities of diabetes treatment is not complicated; rather, it is managing the complexities of life affecting treatment that complicates. To manage diabetes treatment successfully, it must become an integrated and accepted part of life. These concepts, treatment integration and acceptance, were described as processes that usually occur simultaneously over long periods of time. The support of friends and family, healthy relationships, emotions that encourage treatment, maturity, and high levels of self-esteem make possible successful treatment integration and acceptance. Without such a combination of factors, treatment is usually not very successful.

Learning to successfully manage diabetes treatment is also dramatically impacted by cognitive structure and intentional decision making. Factors within the participants' cognitive structure that influence treatment include attitude toward treatment, pessimistic or optimistic worldview, belief system, and coping skills. Intentional decision making refers to purposefully making decisions that will either positively or negatively impact treatment. Each participant described a unique set of factors making up his or her

cognitive structure and intentional decision-making ability. Again, what was important here was understanding how the adolescent's unique life context interacts with these factors to influence treatment. In general, those with successful treatment tended to have a good attitude toward treatment, an optimistic worldview, a healthy belief system, and several healthy coping mechanisms, and they actively participated in treatment, making purposeful decisions that were beneficial. Those doing poorly with treatment simply had much less positive functioning within these factors.

Each of the factors influencing diabetes treatment does not appear that challenging when looked at individually; it is the complex interaction of factors as a whole that casts a fog over successful treatment. To best understand how adolescents experience diabetes treatment, all of the following treatment schemas must be considered as a whole: basics of treatment, emotional, relationship, level of treatment integration and acceptance, cognitive structure, and intentional decision-making ability. In addition, to understand how adolescents experience diabetes treatment, it is essential to recognize how all of these factors interact with each individual adolescent's unique life context.

Final Meeting with Participants

The purpose of the final meeting was to provide the researcher with an opportunity to review the accuracy of his understandings of the phenomenon with the adolescent participants. According to the study's methodology, only the textural-structural synthesis was to be reviewed by participants; however, to provide more detailed results, the participants were also given the eight treatment schemas to review.

The final meetings were originally planned to occur 3 months after the second interview; however, as previously indicated, they occurred between 1½ to 2 years later.

The primary concern related to the delay was that the participants' experience with diabetes treatment may have considerably changed and that they would not be able to relate to the feedback. However, the experience with the final meetings was very much to the contrary. The participants overwhelmingly supported the textural-structural synthesis and the eight treatment schemas saying, for example, "You got it!" "You hit the nail on the head," and "I can see myself in all of these areas." Almost all requested copies of the treatment schemas and suggested that they be published to help increase awareness of how adolescents experience diabetes treatment. One participant recommended that the treatment schemas be developed into a questionnaire that medical teams could use to periodically inquire about all parts of their lives and to identify areas that could be negatively affecting their treatment, rather than talking to the adolescent only about the medical aspects of treatment or the risks of poor treatment. An example that was frequently reported by participants occurred when the medical team would focus on high or low blood sugar numbers rather than on the problems making those number fall outside of the normal range. The eight treatment schemas would allow the medical team to identify and address specific areas that impact blood sugar levels.

CHAPTER V

DISCUSSION

This chapter summarizes the significant findings of this study and the implications for honoring the voices of adolescents, the roles of counseling psychologists, the role of the medical community, and for health care reform. A discussion of these findings from a holistic perspective is important because of the dynamic and complex interaction among many factors. A summary of the most salient findings, discussion of implications and limitations, and future research opportunities are offered to shed light on the complexity and to aid in understanding the factors that influence adolescents' ability to follow their diabetes treatment regimen.

Summary

Identifying what adolescents experience as the barriers and facilitators of their diabetes treatment regimen seemed a fairly straightforward concept at the initial stages of this study. However, after interviewing the first participant, the researcher's conceptualization of the study began to rapidly evolve once it was realized that the influences impacting diabetes treatment are anything but straightforward. In fact, this study's results demonstrated that asking adolescents to report the barriers and facilitators of treatment was far too simplistic of a concept to explain a very complex phenomenon that many physicians, psychologists, and adolescents with diabetes struggle to understand.

After the first interview, it became clear that the adolescents could not simply provide a list of barriers and facilitators of the various aspects of treatment. Instead, many provided explanations of how their lives impacted their treatment, often alluding to concepts that could possibly be considered barriers or facilitators, such as frustration with calculating accurate insulin dosages or levels of self-esteem. Rarely did adolescents identify specific factors as barriers or facilitators. Their descriptions of their experience with diabetes treatment indicated that the results of this study would be very different than initially conceptualized.

The process of data analysis was another indication that the results would be more complicated than a simple list of barriers and facilitators. The transcribed interviews yielded nearly 300 single-spaced (10 font) pages of raw data from which emerged 32 pages of themes. Throughout the data analysis process, searching for clarity became a top priority, eventually resulting in 9 pages of themes organized by category, a textural and structural description for each participant, 8 treatment schemas, composite textural and structural descriptions for the participants as a whole, and a final description of the phenomenon—a textural-structural synthesis.

The textural descriptions provided summaries of what each participant experienced and eventually were integrated to form the composite textural description. This composite description revealed nearly universal agreement among participants in regard to the basic tasks of diabetes treatment, such as checking blood sugar, counting carbohydrates, and calculating accurate insulin dosages. Most participants mentioned varying degrees of frustration in their attempts to keep their blood sugar within the normal range; however, those who managed their treatment well often searched for

solutions, in contrast to those who managed treatment poorly. Other factors, such as diet and physical activity, were often reported as very important to treatment but were not always considered part of treatment and were rarely areas the medical team emphasized. Managing diabetes during special events and in the school environment was consistently reported as very challenging, with little encouragement offered to the participant in these settings.

Another prominent factor was that of the medical team, albeit it was much less influential than the family and likely less influential than most medical teams would like. All participants discussed the impact of the medical team but reported its influence as minimal compared to other factors. One of the most challenging aspects of working with the medical team was a reported lack of empathy in understanding how the adolescents' lives impact their treatment. One positive aspect reported by many was that the medical team did not force their recommendations.

One of the most influential factors discussed by participants was the family. Some reported that family was such an important part of treatment that they might not survive without such support. Although not everyone attributed such importance to the family, all interviewees, even those doing poorly with treatment, reported family as a tremendous influence. Unfortunately, some participants discussed the impact family can have when they do not support treatment. Whether helpful or not, family played a major role for all participants.

Another very influential factor was the emotionality experienced by many adolescents. Emotionality was a factor that truly emerged from the data analysis; it was not part of the original interview protocol. Participants described many emotions, ranging

from anger and frustration to happiness and pride. Other affective-type characteristics reported to significantly impact treatment were level of self-esteem and an apathetic view of treatment.

When the interviews were completed, it was abundantly clear that many factors influenced treatment in addition to the medical tasks required. Many, if not all, of the factors were psychosocial in nature and functioned specific to the unique characteristics of each adolescent's life. These unique characteristics later became one of overarching schemas of the entire study.

The next step in the data analysis was to identify the overarching structures from the nine pages of categorized themes. Once the structures began to emerge, the word *schema* seemed to more appropriately describe what was highlighted, because the overarching structures were representations of how the participants experienced or regarded their treatment. Eight treatment schemas were developed: treatment tasks, affective, relationship, personal uniqueness, treatment integration, acceptance, cognition, and intentionality. The development of these schemas provided the necessary structure to move to the next phase of data analysis.

The next phase was to develop the individual structural descriptions, which provided summaries of how each participant experienced treatment. These were eventually integrated as the composite structural description, which was organized according to the eight treatment schemas, described how the adolescents functioned within each schema, and helped illuminate diabetes treatment for adolescents as an ambiguously complicated entity.

The composite structural description varied from the composite textural description by going beyond simply reporting *what* was experienced to reporting *how* treatment was experienced. For example, in the treatment tasks schema, participants universally reported nearly identical treatment tasks, such as checking blood sugar and calculating insulin dosages; however, participants reported a unique description of how they experienced these tasks. For some, indefinitely maintaining the tasks of treatment was extremely frustrating and often resulted in feelings of hopelessness, while others experienced a sense of pride at their success in maintaining such tasks.

The composite structural description suggested that successfully functioning within all treatment schemas is important for treatment success. Unfortunately, the complexity with which all the factors function within and across schemas also makes the path to successful treatment ambiguous to many adolescents. Viewing treatment through the lens of the treatment schemas illustrates how a complex web of factors can inhibit successful treatment unless the adolescent is functioning well in all schemas. It is also clear, if viewing treatment from a schema perspective, that treatment cannot be discussed simply as *barriers* and *facilitators*, as it is far too complex an issue.

The last step in the data analysis process was to synthesize the composite textural and composite structural descriptions into a final exhaustive description (textural-structural synthesis) of the phenomenon of how adolescents experience diabetes treatment. This description highlighted the influence of the psychosocial context in which diabetes treatment takes place and strongly emphasized the essential importance of understanding how each individual adolescent functions within the eight treatment schemas.

The textural-structural synthesis highlighted and summarized what all participants stressed in various ways: diabetes treatment alone is not that challenging; it is the complex interaction of factors (e.g., basics of treatment, emotional, relationship, level of treatment integration and acceptance, cognitive structure, and intentional decision-making ability) that is difficult to manage. To understand how adolescents experience diabetes treatment, it is essential to recognize how all these factors interact within each individual adolescent's unique life context.

Comparison of Results to Literature Review

The review of the literature yielded six categories of barriers to diabetes treatment adherence: treatment regimen, physician characteristics, patient characteristics, psychological and psychosocial factors, structural factors, and the literature. Some specific examples of barriers from these six categories include the complex treatment regimen, emerging independence of adolescents (Strawhacker, 2001), acceptance of diabetes (Franciosi et al., 2004), low self-efficacy (Logan et al., 2003; Strawhacker, 2001), and physicians ignoring psychological factors and sociocultural factors (Bissel et al., 2004; Rosina et al., 2003). Additionally, the literature does not clearly define the terms *adherence* and *compliance* (Koeningsberg et al., 2004) and problematizes the patients' personality as irresponsible or defiant (Hunt & Arar, 2001).

The findings of this study regarding treatment regimen barriers supported findings from many studies in the literature review, such as the study conducted by Strawhacker (2001). Both the current research study and Strawhacker's research found adolescents' emerging sense of independence particularly difficult and often negatively impacting

treatment, thus functioning as a barrier. Emerging independence is problematic for adolescents with diabetes because it is constrained by the necessity to be dependent on others, particularly the family and medical team. Should an adolescent be diagnosed during adolescence, the abrupt confrontation of emerging independence and the need to be dependent impedes successful treatment. The results of the current study also supported other findings by Strawhacker regarding factors that could hinder treatment adherence, such as adolescents choosing to ignore recommendations of their medical team and manipulating insulin intake, as well as several psychological concepts such as minimization of the illness and poor acceptance.

The review of the literature also yielded six categories of facilitators that were surprisingly similar to the identified barriers: treatment regimen, physician-patient relationship, physician characteristics, patient characteristics, psychological factors, and psychosocial factors. Some specific examples of facilitators from these six categories include individualized treatment plans, permanent lifestyle changes, providing the patient with choices (Koenigsberg et al., 2004), a shared understanding, concordance (Mainous et al., 2004), preventive care (Smith, 2004), and physicians' ability to understand personal history of patients (Bissel et al., 2004; Ditmyer & Telljohann, 2003). Additional examples of facilitators include the physicians' ability to enable their patients (Kerse et al., 2004) and to let patients know what is expected of them (Smith, 2004), as well as the involvement of the family in treatment (Koenigsberg et al., 2004) and community and social support (Van Boemel & Lee, 1999).

The findings from the current study support many of the identified facilitators in the literature. One of the most important findings of this study aligns with the work of

Bissel et al. (2004), which indicated that it is extremely important for physicians to show empathic understanding of the complex life contexts of the adolescents. Bissel et al. also stressed the importance of addressing psychosocial factors to facilitate treatment adherence and to view problems with treatment adherence as a larger, more systemic problem. The current study confirmed those findings by identifying seven out of eight treatment schemas that are psychosocial in nature and that conceptualize problems with treatment adherence from a larger structural perspective. Such a perspective removes placing blame for poor adherence solely on either the adolescent or the physician. A somewhat disconcerting effect of conceptualizing treatment adherence in this way is that the role of the medical team becomes only one factor in influencing treatment adherence.

Many of the findings identified by Koeningsberg et al. (2004) support four overarching structures or treatment schemas identified by this study. First, physicians working with patients, allowing choices in treatment, and utilizing a trial-and-error approach to avoid discouragement are factors illustrated in the Relationship Schema. Second, the medical team's focus on the individual needs of the adolescent in the development of treatment plans represents the Personal Uniqueness Schema. Third, the medical team's focus on permanent lifestyle changes in diet and physical activity supports the Treatment Integration Schema. Lastly, problems with acceptance of diabetes leading to less satisfaction with treatment, directly supports the Acceptance Schema.

This research study is unique because a qualitative, phenomenological method of inquiry was used to investigate the phenomenon of how adolescents experience diabetes treatment—a methodology studying this specific population that was not discovered in other studies in the literature review process. Because this study used a different

methodology to research the topic and yielded some results similar to studies using quantitative methodology, it makes a rigorous contribution to the literature. The rigor of this study was also established through using prolonged engagement, conducting member checks, establishing transferability, and creating an audit trail reviewed by an auditor.

The most prominent result of this study is how the multitude of factors that influence treatment was organized into eight treatment schemas. Previous studies organized factors according to concepts such as psychological and structural but did not provide higher-level categorization as the eight treatment schemas do. This higher level of categorization represents overarching structures that encompass many themes that provide an organization to the numerous factors identified throughout the literature. The eight treatment schemas are: Treatment Tasks, Affective, Relationship, Personal Uniqueness, Treatment Integration, Acceptance, Cognition, and Intentionality. At the final interview, participants overwhelmingly accepted these schemas as a method to explain and understand the factors that influence their treatment. It is hypothesized that members of the medical team could use the eight treatment schemas to identify and target areas of intervention that could ultimately improve treatment. One participant said that these schemas could help providers ask questions pertinent to adolescents' unique life context, rather than just talk about the medical aspects of treatment.

One problem appearing early in the literature review process was that various terms were used to describe problems with treatment adherence, such as *barriers*, *impediments*, and *obstacles*, as well as larger concepts such as *noncompliance* and problems with the *physician-patient relationship*. This study helped to remove some of this ambiguity from the terminology by grouping these terms first into the categories of

barriers and facilitators and then ultimately into the eight treatment schemas. This categorization helps reduce ambiguity by offering a new way to conceptualize the complex interaction of factors that influence treatment adherence. Rather than simply viewing a patient as adherent or non-adherent, this new conceptualization of the diabetes treatment regimen for adolescents allows others to easily determine areas for intervention. It also offers a holistic perspective from which to view treatment adherence and helps eliminate ambiguity of terminology. Furthermore, this conceptualization helps lessen the placing of responsibility of treatment solely on the patient or medical team, and it also emphasizes the importance of psychosocial factors as opposed to a medical-only approach.

Moreover, unlike previous studies, this investigation utilized first-person accounts as the primary data source to uncover and help explain how adolescents experience diabetes treatment. This qualitative understanding sheds light on the complex phenomenon and provides a deeper understanding for those interacting with adolescents with diabetes. This research exposed a firsthand account of the phenomenon of diabetes treatment adherence as experienced by adolescents, which, until now, was not represented in the research.

The literature review suggested that schools can function as facilitators to treatment adherence by becoming an integral part of the multidisciplinary team in planning school-related activities to help incorporate the patient's diabetic treatment regimen (Strawhacker, 2001). However, this was almost never the case as reported by participants in this study. In fact, most participants had a very negative view of their school and stressed how the schools do very little to facilitate treatment.

What eventually came to light in this study was that adolescents do not always understand or have the ability to explain how their complex life context interacts with diabetes treatment. This is consistent with the literature that indicates that patients, parents, and physicians may not understand all the factors that influence treatment adherence and that offers some explanation as to why so many adolescents are hospitalized due to complications from their illness. Helping adolescents to better understand the factors influencing their treatment may therefore lead to improved treatment adherence. Using the eight treatment schemas to provide a framework for broad understanding for the adolescent as well as for the family and medical team may help accomplish this task.

The literature review revealed only one article that directly discussed factors that facilitate treatment (Koenigsberg et al., 2004). Such a lack of emphasis in the literature provides little insight into what may actually improve treatment adherence. The current study, through a phenomenological method of inquiry, avoided the problem of listing all the difficulties of treatment adherence by providing qualitative descriptions of the phenomenon and the eventual emergence of the eight treatment schemas. This new conceptualization may help shift the focus from problem identification to problem solving and improved treatment.

This study also highlights the value and important contribution qualitative research can bring to the topic of adolescent treatment adherence. Because the literature review identified very few qualitative studies in the area of diabetic treatment adherence and not one qualitative study regarding adolescent treatment, qualitative methodology may be useful in identifying salient factors in complicated phenomenon such as diabetes

treatment adherence (Marshall & Rossman, 1995). The most salient factors in this study were identified and then conceptualized as the eight treatment schemas, a new contribution to the literature.

Implications of the Research

Honoring the Voices of Adolescents

Honoring the voices of adolescents diagnosed with diabetes is likely the most important implication of this research, as it could ultimately aid in their improved treatment and overall health. This conclusion was reached because of the tremendous desire adolescents placed on wanting to be understood based on how their unique life context impacts their diabetes treatment. Honoring their voices simply means conveying, through empathic understanding, that their individual experience with diabetes treatment is understood. According to the participants, if the medical team understood each adolescent in this way, they would be better equipped to make treatment recommendations that are a closer fit within the adolescent's unique life context. As a result, the relationship between the adolescent and medical team would improve and a shared perspective of treatment would be strengthened. All of these factors emerge simply by honoring the adolescents' voices and lend increased support to improved treatment.

Counseling Psychologists

The findings of this research are also pertinent to the field of counseling psychology because they illuminated the factors influencing the diabetes treatment regimen for adolescents as almost exclusively psychosocial in nature. Because of this, the role of counseling psychologists in the treatment of adolescents with diabetes can be viewed as a valuable resource in several ways. Counseling psychologists could serve as members of the “medical team” and function as consultants, providing information about the dynamic interaction of psychosocial factors in treatment. Counseling psychologists could also become an integrated part of the medical team and function as behavior interventionists to help improve treatment adherence. This would likely be accomplished by observing the adolescents’ functioning across the eight treatment schemas, highlighting areas of strength and targeting areas of identified weakness.

Functioning successfully as a behavior interventionist in a traditional diabetes clinic may be difficult for counseling psychologists due to visits with patients occurring only once every 3 months. For the adolescents who struggle the most, counseling psychologists could provide traditional weekly counseling services in addition to clinic visits. This would allow the counseling psychologist to build rapport, demonstrate to the adolescent how to develop a healthy relationship with a professional, develop a strength-based model for improvement, and focus on behavior change. In addition, any mental health diagnosis could be treated simultaneously. This service, in collaboration with medical care, would likely be of great benefit to the medical team who simply does not have the time to address the abundance of psychosocial factors during clinic visits.

As stated previously, the medical team's role in influencing treatment is only one factor among many. As this study and others (Franciosi et al., 2004) show, factors such as low levels of education and lower levels of psychological adaptation to diabetes tend to discourage treatment. These factors, along with the heavy psychosocial emphasis, are not usually within the scope of the medical team and may require intervention from other sources, such as counseling psychologists, in order to improve treatment.

The Medical Team

The findings of this study are also pertinent to the medical field by stressing the extreme importance of acknowledging psychosocial factors and showing empathic understanding of how each adolescent's unique life context impacts diabetes. The medical team also must understand that acknowledging the adolescent's experience does not mean agreeing with poor treatment choices. It may be impossible to increase the frequency of clinic visits, but it is reasonable to increase the amount of time spent discussing psychosocial factors.

The field of counseling psychology has identified a good relationship between patient and provider as a necessary factor in successful treatment, along with presenting a structured form of treatment (Fischer et al., 1998). Considering that many of the factors influencing diabetes treatment adherence are psychosocial in nature, the same is likely true for medical teams and their adolescent patients. Thus, medical teams could use the findings of this study to develop a unified and structured approach to treating adolescents with diabetes.

Because the role of family is extremely important to diabetes treatment and even considered part of treatment by some of this study's participants, the medical team could encourage increased family participation. This might occur by inviting the family to clinic visits and encouraging active family involvement with treatment on a regular basis. Counseling psychologists could be helpful in increasing the medical team's ability to include family in treatment by introducing concepts such as shaping, developing short-term behavior and/or treatment targets, and working to develop equal partnerships between the medical team, adolescent, and family in searching for the best treatment solutions.

The medical team may wish to eliminate the contradiction sent to adolescents about the seriousness of diabetes. Many physicians suggest that diabetes should not be referred to as a *chronic illness*, but rather a *condition*. A contradiction is created when the medical team talks about a condition and then recommends fairly strict treatment guidelines befitting a chronic illness. Use of the term *condition* may send the message to adolescents that their illness is not serious and, therefore, treatment recommendations do not need to be taken seriously. Logan et al. (2003) lend support to using the term *chronic illness* rather than *condition* when discussing diabetes with adolescents, because it helps adolescents understand the seriousness of their diagnosis and provides encouragement to follow their treatment.

Health Care Reform

This research comes at an opportune time as our nation struggles with health care reform. The implications of this study on health care reform lie in the area of treating the

unique needs of each individual patient. The results make clear the desire adolescents have to be viewed as whole persons whose treatment is impacted by a complex array of factors. This means allowing the medical team to design treatment that best fits each adolescent. The primary obstacle appears to be lack of time and, to a lesser extent, expertise to address the many psychosocial factors. Improved insurance coverage allowing medical teams increased time with patients and covering the costs of utilizing counseling psychologists could go a long way to improving diabetes treatment for many adolescents. Such a response to diabetes treatment would illustrate a preventative, rather than reactionary, approach and could ultimately be very cost-effective by eliminating some of the extreme costs of hospital stays and serious health complications that arise due to poor treatment.

Limitations of the Study

Limitations of this study include adolescent self-report, generalization issues, and lack of parent and physician perspectives. Adolescent self-report in qualitative interviews may function as a limitation for this study due to the likelihood that adolescents in general may not have a strong grasp on the factors influencing treatment adherence. However, the purpose of this study was not to identify if adolescents accurately understand the influences on treatment adherence, but rather to identify how adolescents experience treatment adherence.

The results of this study will not generalize to other populations and are valid only for the selected participants from the selected research site. In qualitative studies, generalization is not given the same importance as in quantitative studies. Generalization

in qualitative studies is often referred to as transferability (Lincoln & Guba, 1985). In qualitative studies, according to Lincoln and Guba, the researcher is responsible only for setting a working hypothesis with a description of the time and context in which the data were gathered, which will allow for consideration of transferability. A complete description of transferability can be found in the Defining and Attaining Rigor section of Chapter III.

Future Research Opportunities

Maintaining a diabetes treatment regimen to the extent of keeping blood sugar and A1C levels within the normal ranges and avoiding serious health problems has illuminated itself as highly psychosocial in context. The psychological aspects impacting treatment often became apparent during this study and in the literature review but were not the focus of this study; rather, treatment adherence was the topic of the research. Because of this lack of research focus, psychological aspects in the literature regarding treatment adherence are often referred to in nondescript terms. The sociological aspects of treatment are numerous but have often suffered a similar fate in that they are seldom the topic being researched. Future research could help distinguish these factors and ultimately investigate how specific psychosocial factors impact treatment.

Designing a follow-up study that dovetails with these findings could have considerable research implications. This study was holistic in nature, attempting to illuminate as many factors as possible that influence adolescents' diabetes treatment. Exploring the specific factors and complex interaction of factors found within the eight

treatment schemas has the potential to add additional layers of understanding to the phenomenon.

In order to keep the scope of this study manageable, caregivers' and medical teams' experiences were not assessed. Replicating the same methodology as this study, researchers could explore caregivers' and medical teams' experiences to provide a broader description of the phenomenon and to add further credibility to the design. These additional experiences would provide a total of three sets of qualitative data that could be used to develop an overarching description of the phenomenon. Such research could be extremely valuable and possibly facilitate a shared belief among adolescents, parents, and physicians regarding the adolescent's treatment.

Adding cross-cultural and sociocultural components to this research would also bring greater credibility to the results. All participants for this study were from a fairly homogenous group; all were from the Midwest, of middle- to lower-income levels, and of similar cultural backgrounds. The racial background was also not very diverse, with eight Caucasian participants and one African-American participant. Future research may incorporate factors to better represent cross-cultural and sociocultural components such as religion, language, cultural influences, differing role expectations, conflicts in values, race, and gender.

Another area of research that deserves additional exploration is understanding how having to manage a life-long illness impacts adolescents' diabetes treatment. One participant in this study mentioned that it was difficult to treat an illness that would never go away. Further exploration of this concern among the adolescent population could be useful, as adolescence is a time of increasing awareness of mortality.

Because there is considerable confusion within the literature regarding the factors that influence the diabetes treatment regimen, a clear understanding is difficult. Future research and literature review could help reduce this confusion by working to identify universally accepted terminology. In addition, terms such as *adherence*, *compliance*, and *barriers and facilitators* used within the literature have added to the confusion. These terms could be clarified by future research that is designed to offer deeper qualitative descriptions that these terms have previously failed to capture.

Additional qualitative studies using adolescents' first-person accounts to describe their experience with the diabetes treatment regimen is an area of research that is very much needed. Further research from this methodological perspective could aid in transferability of results. Also, qualitative studies focusing on specific themes or factors generated by this study could provide additional salient factors that typically could not be identified using quantitative methods.

Personal and Professional Reflections

The results of this study have already begun to impact my work as a counseling psychologist by highlighting the importance of understanding the complex life context in which my clients experience their lives. This concept is not new to the field of counseling psychology; however, the results of this study taught me the importance of weaving my clients' life context throughout the process of treatment. By doing this, I acknowledge the personal uniqueness of each client and provide treatment specifically tailored to function best within his or her life context. Understanding counseling clients using a treatment

schema perspective is an area of interest and possible research that I plan to pursue in the future.

The prolonged process of conducting this study provided a wonderful opportunity to help me better understand how adolescents experience diabetes treatment. Personally, the most enlightening result was the development of the eight treatment schemas, because they provided me with a method to organize the many factors influencing diabetes treatment and the ability to identify areas that could cause adolescents to struggle with their treatment. Because of the participants' overwhelmingly positive reaction to the treatment schemas, along with my personal interest in the topic, publishing an article discussing the treatment schemas is a goal for the near future.

My experience observing students in an academic environment for 2 weeks and checking my blood sugar for a week helped me personally understand the world in which adolescents with diabetes must interact. This experience helped me become sensitive to the issues they face on a daily basis. One of the most helpful aspects of this experience was learning the importance of empathic understanding that was often stressed by participants. Even though I had to check my blood sugar for only 1 week, I did not always check it as recommended for many of the same reasons reported by the participants. Having caregivers and the medical team display empathic understanding would let me know that they understand my experience and realize that it is challenging to always follow the recommended treatment.

This study was conducted to illuminate adolescents' experience with the factors that influence their diabetes treatment regimen and to expose the essence of the phenomenon. In general, the results highlighted that the factors are primarily psychosocial

in nature, are complex and dynamically interrelated, and must be viewed within each individual adolescent's unique life context to be best understood. More specifically, the eight treatment schemas provide an overarching structure by which to understand the complexity of the phenomenon and which previously was not available. Hopefully, this research continues the trend in reframing the idea of adolescent treatment adherence from a problem-focused approach to a solution-focused approach and to a more holistic concept of understanding. The results have potentially far-reaching implications for counseling psychologists, other mental health providers, medical professionals, caregivers, school professionals, and adolescents with diabetes for improved understanding of the phenomenon and ultimately improved treatment.

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Appendix A

Invitation to Participate in a Research Project

Invitation to Participate in a Research Project

The following is a script that a nurse will read to the adolescent patients and the patient's caregivers at their regularly scheduled appointments in the diabetes clinic.

We are conducting a research project here in the clinic that will attempt to identify some of the factors that influence diabetes treatment adherence from adolescents' perspective. It would involve the adolescent meeting with the researcher to discuss those factors. Would you like to discuss the project with the researcher?

If the adolescent and caregiver answer *yes* to the preceding question then the researcher will read the following script to adolescent and caregiver.

Your child has been invited to participate in a research project designed to help identify the factors that influence diabetes treatment adherence from adolescents' perspective. Our hope is to highlight what adolescents' view as the factors influencing treatment adherence in order to provide the information to the medical and psychological community. Participation will involve caregivers and adolescents completing background questionnaires and the adolescent two face-to-face interviews and a final meeting at the clinic. The information collected on the background questionnaire will be used to help select a diverse sample and it is possible that not everyone who volunteers will be interviewed. Caregivers are required to be at the same location but in a separate room while the adolescent and researcher interview. The two face-to-face interviews will last between 60 and 90 minutes but duration is variable. The first and second interviews will take place approximately one week apart. The final meeting will occur three months after the second interview and will allow the researcher to review the accuracy of his understandings of your child's perspectives and to gather what he feels is necessary after considering what was learned from the interviews as a group. Your participation in this project will have no impact on the services you receive in this clinic. All information gathered from the interviews will be kept confidential. If you agree to participate in this project please read and sign the consent/assent forms.

Appendix B

Background Questionnaire: Caregiver Form

Background Questionnaire: Caregiver Form

If you would like your adolescent to be considered for this study, and have signed the consent form, you will be agreeing to allow them to participate in two face-to-face interviews and a final meeting regarding the factors influencing adolescent diabetic treatment adherence.

Caregiver Names: _____

Address: _____

Phone: _____

e-mail: _____

Adolescent's name: _____

Demographic Information - Adolescent

Age _____ Race _____
Sex _____ Grade _____

Number of years diagnosed with Diabetes _____

Insulin Dependent: Yes / No

1. From your perspective, how well does your adolescent follow his/her recommended diabetes treatment regimen? Circle one of the following:

Above Average Average Below Average

Please provide any other comments regarding your adolescent's treatment regimen.

Appendix C

Background Questionnaire: Adolescent Form

Background Questionnaire: Adolescent Form

If you would like to be considered for this study, and your caregiver has signed the consent form and you have signed the assent form, you will be agreeing to participate in two face-to-face interviews and a final meeting regarding the factors influencing adolescent diabetic treatment adherence.

Caregiver Names: _____

Address: _____

Phone: _____

e-mail: _____

Adolescent's name: _____

Demographic Information - Adolescent

Age _____ Race _____
 Sex _____ Grade _____

Number of years diagnosed with Diabetes _____

Insulin Dependent: Yes / No

1. From your perspective, how well do you follow the recommended diabetes treatment regimen? Circle one of the following:

Above Average Average Below Average

Please provide any other comments regarding your treatment regimen.

Appendix D
Caregiver Consent Form

Caregiver Consent Form

Western Michigan University
Department of Counselor Education and Counseling Psychology
Principal Investigator: Norman Kiracofe, Ph.D.
Student Investigator: Roger W. Apple, M.A.
MSU/KCMS Faculty Advisor: Martin Draznin, M.D.

Your child has been invited to participate in a research project entitled "*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*". The purpose of the study is to identify, from the adolescents' perspective diagnosed with diabetes, the factors that influence following their treatment regimen. Our hope is to highlight what adolescents' view as the factors influencing treatment adherence in order to provide the information to the medical and psychological community. Your adolescent's participation will involve two face-to-face interviews and a final meeting at the clinic. Caregivers are required to be at the same location but in a separate room while the adolescent and researcher interview. The reason for this is to remove any influence the caregiver might have over the adolescent during the interview. The two face-to-face interviews will last between 60 and 90 minutes but duration is variable. The first and second interviews will take place approximately one week apart. The final meeting will occur three months after the second interview and will allow the researcher to review the accuracy of his understandings of your child's perspectives and to gather what he feels is necessary after considering what was learned from the interviews as a group. Your participation in this project will have no impact on the services you receive in this clinic. All information gathered from the interviews will be kept confidential. This project is being conducted to fulfill *Roger W. Apple's* dissertation requirement under the direction of Norman Kiracofe, Ph.D.

Your child will be free at any time -- even during the interviews -- to choose not to participate in this study. Although there may be no immediate benefits to your child for participating, there may eventually be benefits to the medical community in terms of understanding how adolescents perceive the factors affecting their treatment adherence. With this information the adolescents and physicians could be more likely to create a healthier working relationship. This information could also help reduce the stress that often occurs between patients and physicians in term of treatment adherence. Benefits may include 1)providing a setting for adolescents to tell their story about treatment adherence might be a benefit, 2)the adolescents may learn something about their own process of treatment adherence, 3)a void in the literature regarding *adolescent perceptions* of treatment adherence will be filled, 4)providing valuable information to the medical community which hopefully will lead to a better understanding of diabetic adolescent treatment adherence, 5)providing a basis for improved physician /patient relationship, 6)possibly lead to improved health for adolescents with diabetes, and 7)illustrate the value and usefulness of counseling psychology in medical settings.

All information from the interviews will remain confidential. That means that your child's name will be omitted from all notes and transcriptions and a code number will be attached. All digital recordings will be identified with a code number instead of the participants' names. After the transcripts are collected the digital recordings will be destroyed. The principal investigator will keep a separate master list with the names of the children and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. After the transcripts are cleaned of all identifying information the original transcripts will be kept in a locked location in the principal investigator's (Norman H. Kiracofe, Ph.D.) office at Western Michigan University. The co-investigator (Roger W. Apple, MA) will keep a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants will be given a copy of their transcripts and asked to review for confidential information. Any confidential information identified by the participants will also be removed. All other forms will be retained for at least three years in a locked file cabinet in the principal investigator's office. No names will be used if the results are published or reported at a professional meeting. Contextual information such as age, race, level of adherence to treatment will also remain confidential. Much of this information will be gathered on the background questionnaires and may be discussed during the interviews. Much of this information will not be directly reported in the results. When this information is reported in the results it will be reported as composite information and not individually.

There is little or no risk to your child in participating in this study other than possibly recalling distressing memories associated with medical compliance or complications with their diabetes. Should any adolescent participant become upset during an interview to the extent that they are unable to continue the interview will be stopped and the caregiver will be asked to come to the interview room. At that point it will be up to the caregiver and adolescent to decide whether or not to continue. As in all research, there may be unforeseen risks to your child such as an accidental injury. However, the likelihood of any injury during interviews is extremely unlikely. Should any injury occur, appropriate emergency measures will be taken; however, no compensation or treatment will be made available to you or your child except as otherwise specified in this permission form.

You may withdraw your child from this study at any time without any negative effect on services to your child provided through the Michigan State University Medical Clinics. If you have any questions or concerns about this study, you may contact either **Roger W. Apple** at (1-269-598-8897), **Norman Kiracofe, Ph.D.** at (1-269-387-5115) or **Crystal Richman (MSU/KCMS Clinical Research Coordinator)** at (337-6012). You may also contact the Chair, Human Subjects Institutional Review Board at (387-8293) or the Vice President for Research (387-9298) if questions or problems arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study If the stamped date is older than one year.

Your signature below indicates that you, as caregiver or guardian, can and do give your permission for _____ (*child's name*) to participate in two individual interviews, a final meeting, and for the results to be part of the described dissertation.

Caregiver Signature

Date

Permission
Obtained by:

Initials of researcher

Date

Appendix E

Informed Assent from Adolescent to Participate

Informed Assent from Adolescent to Participate
 Western Michigan University
 Department of Counselor Education and Counseling Psychology
 Principal Investigator: Norman Kiracofe, Ph.D.
 Student Investigator: Roger W. Apple, M.A.
 MSU/KCMS Faculty Advisor: Martin Draznin, M.D.

You are invited to participate in a research project entitled "*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*". The purpose of the study is to identify the factors that influence your treatment regimen. Your participation will involve two face-to-face interviews and a final meeting at the clinic. The interviews will last between 60 and 90 minutes and will take place about one week apart. The final meeting will occur about three months later and will give you a chance to discuss the findings with the researcher. Participating in this project will not affect the services you receive in this clinic and you can choose to not participate at any point during the study.

If you choose to participate the results will not be given to your caregivers or your physician. After this project is complete anyone will have access to the results including your caregivers and physician. Your name will not be used on any of the results. The researchers will use a code number instead. The researchers will keep a list of names and code numbers that will be destroyed once the study is complete.

If you have any questions or concerns about this study, you may contact either **Roger W. Apple** at (1-269-598-8897), **Norman Kiracofe, Ph.D.** at (1-269-387-5115) or **Crystal Richman (MSU/KCMS Clinical Research Coordinator)** at (337-6012). You may also contact the Chair, Human Subjects Institutional Review Board at (387-8293) or the Vice President for Research (387-9298) if questions or problems arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

Your signature below indicates that you agree to participate in two interviews and to have the results published in the dissertation.

 Print name here

 Sign name here

 Today's Date

Assent

Obtained by:

 Initials of researcher

 Date

Appendix F

Caregiver Consent for Digital Recording

Caregiver Consent for Digital Recording

Thank you for agreeing to participate in the research study "*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen.*" The primary method of data collection will be interviews. Each interview will be digitally recorded. After each interview the digital recordings will be transcribed and the recordings will be destroyed. The principal investigator will keep a separate master list with the names of the children and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. After the transcripts are cleaned of all identifying information the original transcripts will be kept in a locked location in the principal investigator's (Norman H. Kiracofe, Ph.D.) office at Western Michigan University. The co-investigator (Roger W. Apple, MA) will keep a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants will be given a copy of their transcripts and asked to review for confidential information. Any confidential information identified by the participants will also be removed. All other forms will be retained for at least three years in a locked file cabinet in the principal investigator's office. No names will be used if the results are published or reported at a professional meeting.

If you have any questions or concerns about this study, you may contact either **Roger W. Apple** at (1-269-598-8897), **Norman Kiracofe, Ph.D.** at (1-269-387-5115) or **Crystal Richman (MSU/KCMS Clinical Research Coordinator)** at (337-6012). You may also contact the Chair, Human Subjects Institutional Review Board at (387-8293) or the Vice President for Research (387-9298) if questions or problems arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

Your signature below indicates that you agree to the digital recording of each interview and to have the study results published in the dissertation.

Caregiver Signature

Date

Permission
Obtained by:

Initials of researcher

Date

Appendix G

Informed Assent from Adolescent for Digital Recording

Informed Assent from Adolescent for Digital Recording

Thank you for agreeing to participate in the research study "*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*". The primary method of data collection will be interviews. Each interview will be digitally recorded. After each interview the digital recordings will be transcribed and the recordings will be destroyed. The principal investigator will keep a separate master list with the names of the adolescents and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. After the transcripts are cleaned of all identifying information the original transcripts will be kept in a locked location in the principal investigator's (Norman H. Kiracofe, Ph.D.) office at Western Michigan University. The co-investigator (Roger W. Apple, MA) will keep a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants will be given a copy of their transcripts and asked to review for confidential information. Any confidential information identified by the participants will also be removed. All other forms will be retained for at least three years in a locked file cabinet in the principal investigator's office. No names will be used if the results are published or reported at a professional meeting.

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This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

Your signature below indicates that you agree to the audio-tapping of each interview and to have the study results published in the dissertation.

Print name here

Sign name here

Today's Date

Assent
Obtained by:

Initials of researcher

Date

Appendix H
Interview Protocol

Interview Protocol
Modified July 25, 2007

Project Title: Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen

- * Briefly explain project to participant.
- * Remind participants that all information will remain confidential.

Grand Tour Question

Briefly tell me about all parts of your diabetes treatment. In other words, what is your doctor, nurses, and the entire medical team recommending you do to manage your diabetes and stay healthy?

Main Questions

1. Who are the members of your health care team?
 - a. What do they do to help you follow your treatment?
 - b. What do they do that make following your treatment difficult?
2. What is the recommended normal range for your blood sugar level?
 - a. How often do you check your blood sugar?
 - b. What helps you maintain your recommended blood sugar level?
 - c. What makes maintaining the recommended blood sugar level difficult?
 - d. What about hypoglycemia/hyperglycemia (i.e. blood sugar levels dropping to low or rising too high?)
3. What is the recommended A1C level?
 - a. What helps you maintain the recommended A1C level?
 - b. What makes maintaining the recommended A1C level difficult?

4. Tell me about your meal plan.
 - a. What helps you follow your meal plan as indicated by your health care team?
 - b. What makes following your meal plan difficult?
5. How much daily physical activity does your health care team recommend?
 - a. What helps you get the recommended daily amount of physical activity?
 - b. What makes getting this amount of daily physical activity difficult?
6. Insulin
 - a. What encourages you to take your insulin as prescribed by your health care team?
 - b. What makes taking your insulin as prescribed by your health care team difficult?
7. Tell me about special events such as birthday parties, playing sports, staying overnight with friends, holidays, and taking your medication at school.
 - a. What encourages you to follow your treatment as recommended by your health care team during these special events?
 - b. What makes following your treatment as recommended by your health care team difficult during these special events?

8. Family (immediate and extended)
 - a. What do they do to help you follow your treatment?
 - b. What do they do that make following your treatment difficult?
 9. School
 - a. What about school helps you follow your treatment?
 - b. What about school makes following your treatment difficult?
 10. Tell me about how your diabetes treatment affects your freedom to do what you want and go where you want. (Note to researcher: sense of independence)
 11. Tell me about any feelings of embarrassment of your diabetes or not wanting people to find out you have diabetes.
 - a. What about these feelings motivate you to follow your treatment?
 - b. What about these feelings make following your treatment difficult?
- * Review the main points.
 - * Ask participants if they have any questions.
 - * Remind participants that all information will remain confidential.
 - * Thank each person for participating in the interview.

Appendix I

Caregiver Consent Form of Adolescents 18-19 Years of Age

Caregiver Consent Form of Adolescents 18-19 Years of Age
 Western Michigan University
 Department of Counselor Education and Counseling Psychology
 Principal Investigator: Norman Kiracofe, Ph.D.
 Student Investigator: Roger W. Apple, M.A.
 MSU/KCMS Faculty Advisor: Martin Draznin, M.D.

Your child has been invited to participate in a research project entitled “*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*”. The purpose of the study is to identify, from the adolescents’ perspective diagnosed with diabetes, the factors that influence following their treatment regimen. Our hope is to highlight what adolescents’ view as the factors influencing treatment adherence in order to provide the information to the medical and psychological community. Your participation will involve completing a background questionnaire. There will be questions inquiring as to age, ability to follow the treatment regimen as prescribed, number of years since first diagnosed with diabetes, gender, race, and cultural background. This information will help provide an information rich sample of not only adolescents, who have few problems adhering to their treatment regimen, but also those who moderately adhere, and those who have significant problems with adherence. Such a sample will help to more accurately identify the barriers and facilitators of treatment adherence as perceived by adolescents.

Your participation in this project will have no impact on the services your child receives in this clinic. All information gathered from the background questionnaires will be kept confidential. Completed background questionnaires will be kept in a locked location in the principal investigators office for a minimum of three years and then destroyed. This project is being conducted to fulfill *Roger W. Apple’s* dissertation requirement under the direction of Norman Kiracofe, Ph.D.

If you have any questions or concerns about this study, you may contact either ***Roger W. Apple*** at (1-269-598-8897), ***Norman Kiracofe, Ph.D.*** at (1-269-387-5115) or ***Crystal Richman (MSU/KCMS Clinical Research Coordinator)*** at (337-6012). You may also contact the Chair, Human Subjects Institutional Review Board at (387-8293) or the Vice President for Research (387-9298) if questions or problems arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

Your signature below indicates that you agree to complete a background questionnaire and are aware that the information will be used in the study and the results published in the dissertation.

Caregiver Signature

Date

Permission
Obtained by:

Initials of researcher

Date

Appendix J

Informed Consent Form: Adolescents 18-19 Years of Age

Informed Consent Form: Adolescents 18-19 Years of Age
 Western Michigan University
 Department of Counselor Education and Counseling Psychology
 Principal Investigator: Norman Kiracofe, Ph.D.
 Student Investigator: Roger W. Apple, M.A.
 MSU/KCMS Faculty Advisor: Martin Draznin, M.D.

You are invited to participate in a research project entitled “*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*”. The purpose of the study is to identify the factors that influence your treatment regimen. Your participation will involve two face-to-face interviews and a final meeting at the clinic. The interviews will last between 60 and 90 minutes and will take place about one week apart. The final meeting will occur about three months later and will give you a chance to discuss the findings with the researcher. Participating in this project will not affect the services you receive in this clinic and you can choose to not participate at any point during the study.

All information gathered from the interviews will be kept confidential. If you choose to participate the results will not be given to your caregivers or your physician. After this project is complete anyone will have access to the results including your caregivers and physician. Your name will not be used on any of the results. The researchers will use a code number instead. The researchers will keep a list of names and code numbers that will be destroyed once the study is complete. This project is being conducted to fulfill *Roger W. Apple's* dissertation requirement under the direction of Norman Kiracofe, Ph.D.

Information such as age, race, level of adherence to treatment will also remain confidential. Much of this information will be gathered on the background questionnaires and may be discussed during the interviews. Much of this information will not be directly reported in the results. When this information is reported in the results it will be reported as composite information and not individually.

The original transcripts will be kept in a locked location in the principal investigator's (Norman H. Kiracofe, Ph.D.) office at Western Michigan University. The co-investigator (Roger W. Apple, MA) will keep a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants will be given a copy of their transcripts and asked to review for confidential information. Any confidential information identified by the participants will also be removed.

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This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

Your signature below indicates that you agree to participate in two interviews and a final meeting and to have the results published in the dissertation.

Sign name here

Date _____

Consent
Obtained by:

Initials of researcher

Date _____

Appendix K

Informed Consent Form: Adolescents 18-19 Years of Age for Digital Recording

Informed Consent Form: Adolescents 18-19 Years of Age for Digital Recording

Thank you for agreeing to participate in the research study "*Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen*". The primary method of data collection will be interviews. Each interview will be digitally recorded. After each interview the digital recordings will be transcribed and the recordings will be destroyed. The principal investigator will keep a separate master list with the names of the children and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. After the transcripts are cleaned of all identifying information the original transcripts will be kept in a locked location in the principal investigator's (Norman H. Kiracofe, Ph.D.) office at Western Michigan University. The co-investigator (Roger W. Apple, MA) will keep a copy of the transcripts in his home and on NVIVO computer files accessible only to himself. Participants will be given a copy of their transcripts and asked to review for confidential information. Any confidential information identified by the participants will also be removed. All other forms will be retained for at least three years in a locked file cabinet in the principal investigator's office. No names will be used if the results are published or reported at a professional meeting.

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Sign name here

Date

Assent

Obtained by:

Initials of researcher

Date

Appendix L


Human Subjects Institutional Review Board Letter of Approval



Human Subjects Institutional Review Board

Date: March 27, 2007

To: Norman Kiracofe, Principal Investigator
Roger Apple, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair 

Re: HSIRB Project Number: 07-03-24

This letter will serve as confirmation that your research project entitled "Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: March 27, 2008

Appendix M

Michigan State University/Kalamazoo Center for Medical Studies
Letter of Approval



MICHIGAN STATE UNIVERSITY
KALAMAZOO CENTER FOR
MEDICAL STUDIES

March 21, 2007

▼
A PARTNERSHIP OF
BORCESS MEDICAL CENTER
BRONSON METHODIST HOSPITAL
MICHIGAN STATE UNIVERSITY
▼

Mr. Roger Apple
MSU/KCMS
Pediatrics

Dear Mr. Apple:

This letter confirms final approval of your proposal "Adolescent Perceptions of the Barriers and Facilitators Influencing their Diabetes Treatment Regimen" from MSU/KCMS Human Resource, Accounting, and Information Technology Departments and the CEO. You may proceed with your project.

As communicated in the preliminary approval letter from the Research Committee, we will need the IRB initial and ongoing annual approvals for your project. When your project is complete, please notify the IRB, the Research Department and Accounting if a sub-account was set up for any funding. A copy of the research protocol closure report to the IRB and their approval letter should be forwarded to the Research Department.

Thank you for keeping us informed on the progress of your project.

Sincerely,

Luis H. Toledo, MD, PhD
Director of Research

▼
1000 OAKLAND DRIVE
KALAMAZOO, MICHIGAN 49008
(269) 337-4400
Fax (269) 337-4234