

**THE LIVED EXPERIENCE OF ADOLESCENT FEMALES WITH DIABETES:  
A PHENOMENOLOGICAL APPROACH**

**Jane Kristin Dickinson, Ph.D.**

**University of Connecticut, 2000**

**Adolescent females with type 1 diabetes are at risk for long-term complications including retinopathy, nephropathy, and neuropathy. Habits formed during this period can positively or negatively influence future health outcomes. It is crucial for diabetes care providers to understand what it is like for adolescent females to live with this disease in order to design and implement effective approaches to the delivery of care and education for this population. The purpose of this study was to gain a better understanding of what it means for adolescent females to live with type 1 diabetes. The following research question was investigated: What is it like for adolescent females to live with type 1 diabetes?**

**Van Manen's phenomenological framework was used to guide the project of inquiry. A purposive sample of 10 adolescent females, ages 16 and 17 years, volunteered to participate in this study. Adolescents, recruited from a diabetes camp, participated in unstructured, one-on-one interviews. Participants' accounts were transcribed and van Manen's wholistic and selective approaches were used to identify and analyze themes.**

**This research revealed five themes, which were presented in the context of a piece of music: Chorus – blending in with the adolescent culture; Solo – standing out and being watched; Trills – weighing the options and choosing a tune; Chords – being tethered to the system and to diabetes; and Dissonance – struggling with conflicts. The findings of the study indicated that there are several conflicts these adolescent females struggle with and choices they are forced to make on a daily basis. These girls are tethered to a disease that will never go away and the health care system that goes with it. Although they find aspects of diabetes difficult to live with, these young women adopt ways to handle their disease within the context of their lives so that it is actually “no big deal”. Fitting in with their peers is often more important than diabetes management for this group of adolescents. By making visible the experience of living with type 1 diabetes for a group of adolescent females, these findings have implications for nursing practice, education, and research.**

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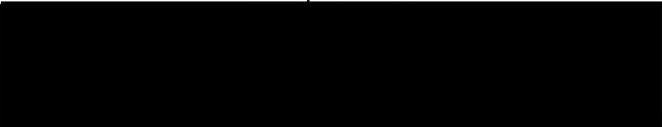
**Doctor of Philosophy Dissertation**

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A PHENOMENOLOGICAL APPROACH**

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## **CHAPTER I**

### **The Focus of the Study**

What is it like for adolescent females to live with type 1 diabetes? Is diabetes a priority or does it take a back seat to peers and adolescent activities? Is it all about numbers, control, and fear of complications or is there more to it than that? What is diabetes all about? The existing research on adolescents with type 1 diabetes indicates that there are currently no answers to these questions. Providers' opinions on this topic are well documented in the literature, however, the perspective of the adolescents, themselves, is largely unknown. The purpose of this research, therefore, was to explore the meaning of living with type 1 diabetes from the adolescent females' point of view.

This chapter introduces the study and its phenomenon of interest: the lived experience of adolescent females with type 1 diabetes. An overview of the research problem, impetus for the study, and significance of the study are discussed. The researcher's assumptions are made explicit.

### **Introduction**

Diabetes Mellitus, a chronic disease in which the body does not properly produce or utilize insulin, is categorized as either type 1 or type 2 diabetes. Approximately 16 million people in the United States have diabetes (ADA, 1996). Most of these people have type 2 diabetes, in which the body produces insulin, but does not use it effectively. High blood glucose levels are the hallmark of both types of diabetes.

Type 1 diabetes (formerly referred to as Insulin-Dependent Diabetes Mellitus or Juvenile-Onset Diabetes) is an autoimmune disorder characterized by an inability to metabolize glucose. Type 1 diabetes accounts for 5-10 % of all cases of diabetes in the

**United States, and most cases are diagnosed before age thirty. Type 1 diabetes is the most commonly diagnosed chronic disease in children. Incidence of type 1 diabetes increases with age until puberty. Peak incidence for girls is 10-12 years, and for boys is 12-14 years (ADA, 1996). People with type 1 diabetes are unable to make enough, if any, endogenous insulin, therefore, insulin must be taken from an outside source. Type 1 diabetes must be managed on a daily basis by taking insulin, following a meal plan, and exercising. Blood glucose monitoring is also an important part of the type 1 diabetes management routine. Failure to manage type 1 diabetes properly leads to long-term complications including retinopathy, nephropathy, neuropathy, and/or heart disease.**

**In recent years the annual cost of diabetes in the United States has exceeded \$100 billion (Rubin, Altman, & Mendelson, 1994). These costs are primarily due to the ravaging complications of diabetes, which frequently affect people with type 1 diabetes:**

- 97% of insulin-users develop retinopathy after 15 years diabetes duration**
- 10-21% of people with diabetes have nephropathy and the risk of end-stage renal disease is 12 times higher in those with type 1 than type 2 diabetes**
- 25-50% of deaths in people over 30 with type 1 diabetes of long duration are caused by heart disease**
- 60-70% of people with type 1 diabetes have neuropathy**
- Overall, complications affect more than 90% of people with type 1 diabetes (ADA, 1996).**

**The Diabetes Control and Complications Trial (DCCT), a nine-year prospective study (1984-1993), indicated that tight control of blood glucose levels in people with type**

1 diabetes, slows the onset and progression of diabetes complications (DCCT Research Group, 1993). The DCCT was a turning point in diabetes management: it brought about changes in both management protocols and outcome expectations. Tight control consists of keeping blood glucose levels as close to the normal (non-diabetes) range, as possible. In order to achieve tight control, people with type 1 diabetes are required to follow intensive diabetes management protocols, including frequent blood glucose monitoring, multiple daily injections of insulin, and strict adherence to exercise and meal planning routines. Despite knowledge of the benefits of intensive diabetes management, however, people with type 1 diabetes still suffer from long-term complications of the disease.

Because adolescence is a difficult time in general, diabetes and its potential complications only compound the challenges faced by this age group. Adolescence, a life stage characterized by a struggle between dependence and independence, is more difficult and dangerous today than it was in the past (Carnegie Council on Adolescent Development, 1995). Many adolescents now face a lack of health insurance coverage (U.S. Department of Commerce, 1994); dietary patterns which can increase their risk for future health problems (Ellis & Torabi, 1994); and increased drug use and teen pregnancy (Resnick et al., 1997). During adolescence, peer relationships and activities outside the home may take precedence over diabetes management. Many adolescents begin a downward spiral of neglecting self-care activities. Others, however, gain knowledge and skills during adolescence that serve as a basis for diabetes self-care and the motivation to continue learning.

Studies have shown that male and female adolescents with type 1 diabetes respond differently to living with diabetes (Hanna & Guthrie, 1999; La Greca, Swales,

Klemp, Madigan, & Skyler, 1995; Thompson, Cummings, Chalmers, Gould, & Newton, 1996). Adolescent females who are left feeling alone and unsupported with regard to their diabetes may lose motivation to take care of themselves. These girls may be at risk for adopting habits which can lead to both short and long-term damage to their physical health. Some adolescent females stop checking their blood glucose levels and take random insulin doses (Dickinson, 1997), while others stop taking insulin altogether. Many do not follow a meal plan. Long-term complications may result from a lack of knowledge about complications and what causes them, apathy toward diabetes management, anger, a belief that nothing bad can happen to them, or a combination of these and other factors.

Complications are occurring at high rates in people with type 1 diabetes, and adolescent females continue to have trouble adhering to diabetes management routines. What motivates adolescent females with type 1 diabetes to learn about the disease and to take care of themselves, therefore, is a question that needs to be answered if we are ultimately to decrease the incidence and progression of these complications. Before embarking on studies concerned with the motives of this population and effective strategies for delivering diabetes care to these patients, however, it is crucial for diabetes care providers to first understand what it is like for adolescent females to live with this disease.

### **Phenomenon of Interest**

The phenomenon of interest for this research was the experience of adolescent females living with type 1 diabetes. The purpose of this study was to gain a better understanding of what it means for adolescent females to live with type 1 diabetes. A

phenomenological approach to this exploration allowed a group of adolescent females to describe their personal experiences with diabetes. Study findings made visible an understanding of what it is like for adolescent females to live with type 1 diabetes and what that experience means. With this understanding, it may be possible to develop more effective approaches to dealing with this population.

### **Impetus for the Study**

The impetus for this study originated from the researcher's personal experience of living with type 1 diabetes and professional experience of working with adolescent females who have type 1 diabetes. The researcher was diagnosed with type 1 diabetes at age seven; therefore, she shares the experience of having been an adolescent female with type 1 diabetes. The researcher has worked closely with adolescent females with type 1 diabetes as a camp nurse and as a diabetes educator for several years. She has directly assisted young women in this age group with diabetes management and education, and has facilitated discussions on living with diabetes. The researcher's professional involvement with adolescent females with type 1 diabetes has revealed that adolescent females often have questions about diabetes management, have incorrect information or beliefs about diabetes, and do not seem to take care of themselves when they are involved with their daily school, social, sports, work, and other activities. Through these experiences the researcher has discovered that although some aspects of living with diabetes may be similar for adolescent females from different generations, times have changed and many aspects of living with diabetes are dissimilar at the dawning of the new century.

### ***Researcher's Perspective***

Van Manen (1990) described the need to explicate assumptions and pre-understandings. This process, sometimes referred to as bracketing (Husserl, 1911/1965), helps to ensure that the researcher interprets the nature of the phenomenon based on the meaning revealed by the participants' personal accounts rather than the researcher's prior knowledge. Prior knowledge can influence a researcher's beliefs about a particular phenomenon. In order to gain a clear understanding of the phenomenon, these beliefs need to be suspended during the course of the study. Van Manen discussed the need to not merely forget or ignore what is known about the topic, because this may cause biases and presuppositions to constantly creep back into the researcher's reflections. It is more effective to become aware of one's perspective of the topic prior to the study, in order to come to terms with assumptions and prior knowledge. By doing so, these presuppositions are suspended so the participants' experience can be illuminated (van Manen, 1990). Before beginning data collection, the researcher reflected on her personal and professional experience with diabetes and adolescent females and made note of her assumptions and pre-understanding related to the phenomenon of inquiry in a research log.

### ***Assumptions and Pre-understandings of the Researcher***

1. **Adolescent females with diabetes have common experiences.**
2. **Adolescent females with diabetes have unique experiences.**
3. **Diabetes is difficult and frustrating for adolescent females.**
4. **Living with diabetes makes adolescent females more responsible and independent.**

5. **Adolescent females with diabetes will share openly their experiences of living with diabetes.**
6. **Current approaches to caring for and teaching adolescent females with diabetes are not effective.**
7. **Adolescent females need an opportunity to talk about what matters to them, i.e., what it means to live with diabetes.**
8. **Knowledge base, level of motivation, and commitment to take care of themselves vary for adolescent females with type 1 diabetes.**
9. **Adolescent females, despite similar experiences in living with diabetes, have unique needs in terms of approaches to teaching about diabetes.**

### **Significance of the Study**

**This study is important for adolescent females with type 1 diabetes and the many people who interact with them, including health care providers, family members, and school personnel. The significance of the study is threefold in that it provides implications for the nursing profession, attention to gender differences in adolescent diabetes, and an opportunity for adolescent females to share their own perspective.**

**First, the findings of this study have implications for advancing nursing practice, education, and research. Very little is currently known about type 1 diabetes from the perspective of people who are living with it. As a result, nursing strategies are being constructed based on assumptions that are unsupported. By providing nurses and other diabetes care professionals with a better understanding of the meaning of living with type 1 diabetes for adolescent females, this study helps bridge a gap in knowledge and provides direction for future inquiry.**

Current approaches to diabetes education, which utilize a compliance, medical or judgment model are not effective with adolescent females. Funnell et al. (1992) have argued for an empowerment approach, as opposed to a demand for behavioral change. They reported that the medical or compliance model does not promote good diabetes management because it is a non-supportive, judging approach (Funnell et al., 1992). Many diabetes care providers assume that adolescents withhold insulin and/or fabricate blood glucose readings (Wehmann, 1985). Making such assumptions without finding out what is truly going on for the adolescent is counterproductive and only serves to anger and/or frustrate the adolescent (Dickinson, 1997). In order to develop appropriate approaches to the care of adolescents with type 1 diabetes, providers need to understand adolescents' responses to diabetes (Brink, 1997). Documenting and interpreting the perspective of adolescent females themselves may allow diabetes care professionals to tailor treatment approaches to adolescent females' needs. These tailored approaches may be more likely to motivate adolescent females to take care of themselves. Greater understanding of the meaning of living with diabetes for adolescent females, therefore, may lead to improved health and well being. The meaning of living with type 1 diabetes can only be richly illuminated using qualitative methods.

Since the conclusion of the DCCT, there is insufficient nursing research which looks at adolescents with type 1 diabetes in the United States. Studies conducted before and during the DCCT (Meldman, 1987; Schwartz, 1991) did not examine the impact of the requirements of intensive diabetes management on adolescents. Studies conducted by nurses since the DCCT were carried out in Finland (Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995) and/or did not explore the whole experience of living with diabetes for

**this group, but only looked at specific aspects of it (Standiford, Turner, Allen, Drozda, & McCain, 1997). Therefore, in order to enhance treatment protocols and approaches to working with adolescent females with type 1 diabetes, qualitative research with United States adolescent females is needed.**

**Phenomenological methods, consistent with nursing as a caring profession, consider the whole person. Gaining an understanding of a person's experience living with a chronic illness such as diabetes is one way to consider the person's whole being. In phenomenological methods, the researcher is the primary instrument used for data collection. This reflects the use of self in nursing practice (Beck, 1994). A relationship develops between the researcher and the study participants during each interview, which allows the researcher to obtain a clearer understanding of the lived experience (Beck, 1994). Only the patient can identify what it means to live with diabetes, however, the nurse can use this understanding to provide better care to the patient. The knowledge gained from this interpretive study may increase nursing's knowledge base of the phenomenon of adolescent females and diabetes, may provide a starting point for developing approaches to teaching adolescent females about diabetes, and may assist in identifying areas for further research. For example, a follow-up study could use phenomenological methods to illuminate the meaning of living with type 1 diabetes for groups of adolescents from different settings.**

**Second, gender differences between female and male adolescents with type 1 diabetes may call for additional considerations in approaches to diabetes care delivery. This study explores the experience of living with type 1 diabetes for adolescent females separately. Such an approach allows adolescent females' unique characteristics and**

experiences to be revealed. Clinical practice interventions, education, and future research, therefore, can be tailored to adolescent females' needs.

Third, this study offered an unusual opportunity to the adolescent female participants. These young women were given a chance to share openly their experience of living with diabetes, which may be something they have rarely, if ever, been able to do. It may have been beneficial for some or all of these girls to have someone actually ask about *them*, perhaps for the first time.

It is clear that something needs to change regarding the approaches currently used in delivering diabetes care to adolescents. It is also clear that adolescent males and females need to be studied separately. None of the existing qualitative research has looked at adolescent females separately, and van Manen's (1990) phenomenological approach, or interpretation, has not been used to explore the meaning of living with type 1 diabetes for this group. We still do not know, therefore, what it means for adolescent females to live with type 1 diabetes. The following research question was investigated in this study: "What is it like for adolescent females to live with type 1 diabetes?" The findings of this study offer valuable insight for nurses in practice, education, and research, which are discussed in greater depth in Chapter V.

### **Summary**

This chapter presented the phenomenon of interest for the study. The research problem, impetus for the study, and significance of the study were discussed. The researcher's assumptions were made explicit.

## **CHAPTER II**

### **Context of the Study**

**This chapter discusses the context of the study. In order to gain a greater understanding of what it means for adolescent females to live with type 1 diabetes, pertinent literature on adolescence and adolescents with diabetes was reviewed.**

**Adolescents have been living with type 1 diabetes since the 1920's, when insulin was first isolated and used in human beings. Prior to that time, children and adolescents with type 1 diabetes did not survive for very long. More than 75 years later, many aspects of diabetes management have changed and some aspects of adolescence have changed as well.**

#### **Adolescence**

**The adolescent culture and issues adolescents face may vary in different locations around the world. In the United States, some aspects of adolescence have remained the same over time, while others have changed. Although the definition of the adolescent age group may differ, this study was based on the following categories of adolescence: 12-14 years (early adolescence); 15-17 years (middle adolescence); and 18-22 years (late adolescence). Some authors have included 10-year-olds (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Carnegie Council on Adolescent Development, 1995) and/or 11-year-olds (Anderson & Laffel, 1997; Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989) in the early adolescent category.**

**Erik Erikson's (1968/1994) theory of adolescent psychosocial development has long been popular in the United States. Erikson's theory, which emphasized the social context of adolescent development, described adolescence as a time of identity crisis.**

Adolescence is a period of turmoil and opportunity, during which young people seek their identity. Adolescence is noted for being a tumultuous period when social and biological changes make life extremely challenging. Adolescents struggle to achieve independence from their parents, yet they are still dependent on parents for support. Adolescents face many challenges including social pressures, family pressures, and physical changes. While anticipating life after high school and managing issues of sexuality and responsibility (Dickinson, 1997), adolescents may not make their health a priority. Health risk behaviors, including smoking, alcohol and other drug use, poor safety, poor nutrition, lack of exercise, and unprotected sex tend to increase during adolescence (Ellis & Torabi, 1994).

Health risk behavior in today's adolescent population is a very real and serious issue. The Carnegie Council on Adolescent Development (1995) compiled a report of statistics they gathered on adolescent risk behaviors and the conclusions they made after reviewing the effects of school, family, and health on adolescents. The Carnegie Council on Adolescent Development refers to adolescence as a "crucially formative phase" (p. 9), which involves biological, physical, behavioral, and social transformations. They reported that adolescents benefit from the continued involvement of parents and families; education and health are closely linked; adolescents benefit from health-promotion programs; social supports are important for adolescent achievement; and the media has a vital role in encouraging adolescents to be constructive and healthy. Focusing on prevention now may decrease future health and social problems for this population. Adolescents are at a cross roads in life: the choices they make and the habits they form will influence the remainder of their lives.

The most critical concerns of adolescence, which are much more prevalent now than in the past, include illicit drug use, teen pregnancy, divorce, violence, greed and materialism, emotional distress, suicidality, and spiritual emptiness (Carnegie Council on Adolescent Development, 1995; Ellis & Torabi, 1994; Resnick et al., 1997; Rodham Clinton, 1996). Ellis & Torabi (1994) also found that adolescents' current dietary patterns put them at risk for future health problems. Adolescent females, in particular, face sexual harassment, rape, and "lookism" (Pipher, 1994). Pipher discussed the fact that although many aspects of the world have changed for adolescent females over time, many others have remained the same. Adolescent females still need "loving parents, decent values, useful information, friends, physical safety, freedom to move about independently, respect for their own uniqueness and encouragement to grow into productive adults" (Pipher, 1994, p. 73).

There are several barriers to health care services for adolescents, which may influence the increase in health risk behaviors in this age group. Health insurance coverage is a major concern for adolescents: one out of every seven adolescents in America is not covered by health insurance, and for those who are insured, it is often not adequate coverage (U.S. Department of Commerce, 1994). Preventive services, developmentally appropriate services, culturally sensitive services, and health care providers who are equipped to work with adolescents are desperately needed. Adolescents with chronic disease are particularly in need of health care that includes anticipatory guidance, education, and counseling (Carnegie Council on Adolescent Development, 1995). The connection of families, schools, and health care providers with adolescents has the potential to reinforce positive health behaviors.

Gillis (1994) suggested that adolescents' definition of health can motivate them to engage in health-promoting lifestyles. Adolescents should be given opportunities to explore health as something they have control of and personal responsibility for. Adolescents should be given opportunities to make independent health-related decisions. Gillis also found that parents have an important role in adolescents' adopting health-promoting lifestyles by modeling healthy lifestyles themselves. Authors of the National Longitudinal Study on Adolescent Health found that parent-family connectedness, school connectedness, and individual characteristics such as self-esteem protect adolescents against every health risk behavior except pregnancy (Resnick et al., 1997).

It is important for adults to intervene, where possible, in order to provide adolescents with a productive and healthy future. The Carnegie Council on Adolescent Development (1995) concluded that certain interventions will benefit adolescents: involve the family; provide a health-promoting environment in schools; teach life sciences and life skills; and promote social support programs. Studies (Carnegie Council on Adolescent Development, 1995; Ellis & Torabi, 1994) have shown that although all adolescents face health and social risks, targeting prevention programs at the early adolescent population (10-14 years) is likely to have a more positive and lasting outcome.

In order to prepare adolescents to be healthy, productive, and successful adults, the following institutions need to work together: schools, health care providers, families, churches, government, businesses, and the media. Before they can help adolescents, however, families and professionals first have to understand adolescents (Carnegie Council on Adolescent Development, 1995).

### Managing Diabetes During Adolescence

Adolescents with type 1 diabetes face the typical tasks of adolescence as well as the many challenges posed by diabetes, including the potential for complications from this disease. This is a critical factor to consider, yet this population is apt to engage in health risk behaviors. With all of the issues being faced during adolescence, it is not surprising that this is a common time for adolescents with type 1 diabetes to be lax or mismanage their disease (Hanna & Guthrie, 1999). Adolescents with type 1 diabetes, however, cannot afford to neglect their disease for any extended period of time. Habits formed during these years can prevent or contribute to future complications. The complications of diabetes including retinopathy, nephropathy, and neuropathy, can ultimately result in blindness, kidney failure, and amputation. Type 1 diabetes also contributes to heart disease, complications of pregnancy, and congenital fetal malformations. Because adolescents have reached the stage in life where they begin to think about the future, these complications can be very real and very frightening to them.

#### *Intensive Diabetes Management*

Although the definition of intensive therapy was ambiguous prior to the DCCT (Hirsch, Farkas-Hirsch, & Skyler, 1990), the concept of intensive management of type 1 diabetes (“intensive therapy” or “intensive treatment”) has been around for many years. The DCCT, a landmark study about type 1 diabetes, examined whether intensive treatment would prevent diabetes complications and/or slow the progression of existing diabetes complications. Intensive treatment was defined as multiple daily injections of insulin or insulin pump therapy, frequent blood glucose monitoring, exercise, and meal planning. The goal of intensive treatment was to achieve and maintain Hemoglobin A1c

**(HbA1C) (a measure of metabolic control) in the normal range (<6.05%) (DCCT Research Group, 1993). Findings of the DCCT indicated that tight control of blood glucose levels in people with type 1 diabetes, delays the onset and/or slows the progression of diabetes complications (DCCT Research Group, 1993).**

**An adolescent subgroup comprised 14 percent of the total DCCT study sample. One hundred ninety-five adolescents between the ages of 13 and 17 years participated in the DCCT. Few adolescent participants were able to consistently achieve and maintain the target HbA1C level, and mean HbA1C levels were higher in adolescents than adults for both treatment groups. Intensive treatment, however, still reduced the risk of complications in this age group. For the adolescent subgroup, this longitudinal study revealed a 53% reduction of risk of developing retinopathy and a 70% reduction of risk of progression of retinopathy for those in the intensive therapy group (DCCT Research Group, 1994).**

**Adverse events of the study included weight gain and hypoglycemia. Adolescent participants in the intensive treatment group had a twofold risk of becoming overweight and 82% of this group experienced severe hypoglycemia (requiring assistance from another person). It was found that severe hypoglycemia did not result in significant impairment of cognitive function for these participants. The investigators recommended the use of intensive therapy for adolescents with type 1 diabetes despite hypoglycemic events and weight gain. The study group also recommended that treatment be directed by a diabetes care team, including a nurse, dietitian, physician, and mental health professional (DCCT Research Group, 1994).**

Several authors have looked at the implications of the DCCT findings for adolescents with type 1 diabetes in “real life” (Brink & Moltz, 1997; DCCT Research Group, 1995; Drash, 1993; Fenton, Clemons, & Francis, 1999; Golden, 1998; Tamborlane, Gatcomb, Held, & Ahern, 1994). Some authors have commented on the fact that the DCCT was not a “real life” scenario (Brink & Moltz, 1997; Drash, 1993), because diabetes care was delivered by a multidisciplinary team of professionals, health care providers were available 24 hours per day, and support was continually provided to participants. Others have noted that DCCT patients were hand-selected and highly motivated (Fenton et al., 1999). Drash (1993) concluded that DCCT-level diabetes management, however, is good for all people with type 1 diabetes, that diabetes care should be delivered by a team, and that behavioral interventions and support are a necessary part of diabetes care. Adolescents who are motivated and have no previous history of hypoglycemia are likely to achieve HbA1C levels closer to the normal level and, therefore, benefit from intensive therapy (Fenton et al., 1999).

A follow-up study, using data gathered during the DCCT, indicated that proportional reductions in HbA1C were accompanied by proportional reductions in the risk of complications. Intensive therapy is the only known way to maximize the decrease in risk of development and/or progression of all diabetes complications. As HbA1C approaches the normal range, the risk of complications continues to decline while the risk of hypoglycemia increases more slowly (DCCT Research Group, 1996a). Before the DCCT, health care providers did not consistently agree with the standards of intensive therapy (Forrest & Orchard, 1997). Since the DCCT, however, intensive diabetes management is being implemented more consistently. Because even modest decreases in

HbA1C can reduce the risk of complications, intensive management is strongly recommended for all adolescents with type 1 diabetes (Brink & Moltz, 1997; DCCT Research Group, 1995; Golden, 1998; Tamborlane et al., 1994).

Further study indicated that patients who followed the intensive treatment guidelines in order to achieve blood glucose levels as close to normal as possible, did not have a decreased quality of life despite the demands of diabetes management and increased frequency of hypoglycemia (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999; DCCT Research Group, 1996b; Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998b). These studies emphasize the importance of achieving metabolic control, or sustaining HbA1C levels as close to the normal range as possible, in order to minimize the chances of long-term complications of diabetes and maximize health. Adolescence is a difficult time to implement intensive management, however, because there are many challenges to achieving and maintaining metabolic control in this age group.

### *Challenges to Managing Diabetes*

Achieving and maintaining metabolic control in the target range can be a challenge for adolescents with type 1 diabetes because of physiological and psychosocial factors (Golden, 1998; Tamborlane et al., 1994). Physiological changes occurring during adolescence make it an especially difficult time to manage diabetes. Some adolescents do everything “right” and still cannot seem to achieve the desired metabolic control. Despite increasing doses of insulin, glucose levels can deteriorate due to insulin resistance caused by the hormonal effects of puberty (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986). This physiological effect, coupled with psychosocial

factors related to adolescence such as dietary indiscretion, rebellion, and emotional lability can lead to poor metabolic control (Amiel et al., 1986) and a compromised health status (Anderson, 1994; Glasgow et al., 1999). Thompson et al. (1996) reported that upon hearing the results of the DCCT many young people with type 1 diabetes want to improve their metabolic control. Adolescents, however, were less likely to perform blood glucose monitoring and females, especially, were more afraid of weight gain.

In order to examine reasons why adolescents with type 1 diabetes refuse to participate in intensive therapy, Tercyak, Johnson, Kirkpatrick, and Silverstein (1998) conducted a study in which adolescents were invited to participate in an intensive therapy program, following DCCT guidelines. Findings indicated that 40% of adolescents refused to participate for the following reasons: increased clinic visits, increased number of injections, increased frequency of blood glucose monitoring, and transportation problems. Brink and Moltz (1997) compiled a list of barriers to implementing DCCT recommendations in children and adolescents: staff resources required (team), cost, intensive home monitoring, training/retraining of health care providers, other medical problems, family/psychosocial problems, and hypoglycemia.

Living with type 1 diabetes as an adolescent can be difficult because of the many ways that diabetes and diabetes management infringe on the typical adolescent lifestyle. The decreased level of structure characteristic of adolescence can be reflected in diabetes management performance. For most adolescents, dietary restrictions or recommendations are the hardest part of the diabetes management routine (Bateman, 1990; Burroughs, Pontious, & Santiago, 1993; Hanna & Guthrie, 1999; Hentinen & Kyngas, 1992; Weissberg-Benchell et al., 1995). Dietary adherence can have a negative

impact on an adolescent's social scene, for it is a time when eating out, fast food, pizza, snacking after school, and other food-related activities are common. These unscheduled, food-related experiences require adjustments (Bateman, 1990) in insulin and most likely additional blood glucose monitoring. Adolescents often feel forced to choose between the demands of adolescence and the requirements of diabetes management. The demands of adolescence are likely to be perceived as more important (Burroughs, Harris, Pontious, & Santiago, 1997). Schlundt et al. (1994) identified the following obstacles to dietary adherence for adolescents with type I diabetes: being tempted to stop trying; negative emotional eating; facing forbidden foods; peer interpersonal conflict; competing priorities; eating at school; social events and holidays; food cravings; snacking when home, alone, or bored; and social pressures.

The use of identification, in the form of a necklace or bracelet is strongly recommended for adolescents, however, this is a sort of "marking" that sets them apart from others (Bateman, 1990). Extra considerations have to be made for travel, driving, school, employment, and contraception and pregnancy (Bateman, 1990). Adolescents live in fear of hypoglycemia (Davidson, Boland, & Grey, 1997): hypoglycemia can be uncomfortable and embarrassing for adolescents, especially when it occurs during sporting or social events. The best way to decrease the incidence of hypoglycemia is to increase the frequency of blood glucose monitoring (Fenton et al., 1999), which is also not ideal for adolescents.

**Hyperglycemia is the result of too little insulin in the blood stream.**  
**Hyperglycemia may result in ketoacidosis, an acute complication of diabetes, which can require hospitalization. Having to miss school and/or other activities because of diabetes**

can be frustrating for adolescents (Bateman, 1990). The increased insulin requirements associated with hormone changes and rapid growth during adolescence (Amiel et al., 1986; Bateman, 1990), can cause hyperglycemia. Another cause of hyperglycemia, that affects a number of adolescents, is the omission of insulin. Having to take insulin can be considered time-consuming and inconvenient for adolescents, which may lead to omission (Bateman, 1990). For others, however, insulin is omitted because adolescents realize that doing so will help them lose weight (Brink & Moltz, 1997). Blood glucose monitoring is another task of diabetes management that can be inconvenient for adolescents. Blood glucose monitoring is currently irreplaceable in accurately assessing the individual's diabetes condition (Wolfsdorf, 1999). Unfortunately, blood glucose monitoring is an invasive procedure that requires time, equipment, and proper technique.

Diabetes is only one part of the context of an adolescent's life, however, the typical problems of adolescence are more dangerous when combined with diabetes (Burroughs et al., 1993; Hanna & Guthrie, 1999). Adolescents live with emotional and social pressures in general and specific to diabetes (Davidson et al., 1997). For example, many adolescents with type 1 diabetes live with the fear of complications and guilt for high blood glucose levels or for anything they have done that strays from the diabetes management plan. Hanson, Henggeler, and Burghen, (1987a) found that stress is directly linked to metabolic control in adolescents with type 1 diabetes: increased stress leads to decreased metabolic control.

Even when people with type 1 diabetes achieve and maintain metabolic control, there can be accompanying problems. For example, a person with diabetes can seem to be doing well when maintaining metabolic control, when actually they are suffering from

depression because diabetes dominates their life (Glasgow et al., 1999). Research has shown that depression is more common in people with diabetes (Close, Davies, Price, & Goodyer, 1986; Glasgow et al., 1999). Close et al. (1986) found that achieving and maintaining tighter metabolic control induced more depression because of the hard work involved, a lack of coping, a lack of personal reward, and a dependence on health care providers.

In a study on quality of life in adolescents with type 1 diabetes, Grey et al. (1998b) found that depression and the degree of upset with coping with diabetes were associated with the impact of diabetes on quality of life. Adolescents who worry more about diabetes are more likely to suffer from depression, to have a harder time coping with diabetes, and tend to use more rebellious coping strategies (Grey et al., 1998b). Although Grey and her colleagues did not find quality of life to be related to metabolic control, other authors have suggested that quality of life can be a predictor of premature mortality (Glasgow et al., 1999).

Many factors during adolescence make this a difficult time to achieve and maintain metabolic control. Adolescents have many tasks to juggle and do not necessarily make diabetes management a priority. Adherence to the diabetes management plan, however, is critical for metabolic control.

Diabetes management is, for the most part, a set of behavioral tasks: it is *self-management*. Diligent self-management and metabolic control go hand in hand. Individual confidence and ability can determine success and adherence to the diabetes management plan. Serious self-management problems, however, typically occur in 13-15 year olds and are very hard to resolve (Glasgow et al., 1999). Adolescents need to

identify with their peers (Wysocki, Hough, Ward, & Green, 1992), and therefore, tend not to adhere to diabetes management plans as well if they feel different from their friends (Hanson, Henggeler, Harris, Burghen, & Moore, 1989). Failure to adhere to the diabetes management plan is a prevalent problem in adolescents with type 1 diabetes, which can lead to negative health outcomes (Palardy, Greening, Ott, Holderby, & Atchison, 1998). The question that many health care professionals and parents have, however, is “how do we get the adolescent to follow the diabetes management plan?” In order to design effective interventions for adolescents with type 1 diabetes, it is crucial to understand the factors that enable them to adhere to the treatment plan (Golin, DiMatteo, & Gelberg, 1996).

A study on compliance in Finnish adolescents with type 1 diabetes revealed that only one-third comply fully with diabetes regimens, about one-half show average compliance, and one-fifth fail to comply (Hentinen & Kyngas, 1992). A follow-up study indicated that adolescents who comply experience a sense of well-being, health, and freedom. Those who partially comply are guided by compulsion, and those who are non-compliant feel that self-care is unnecessary and that their non-compliance gives them freedom (Kyngas & Hentinen, 1995). In a third study, Kyngas, Hentinen, Koivukangas, and Ohinmaa (1996) constructed a model, which revealed that compliance was indicated by self-care behavior, responsibility for treatment, intention to pursue treatment, and collaboration with health care providers. Compliance was greatly determined by motivation, experience with the results of treatment, and having energy and will-power to pursue treatment.

Several authors have found that older adolescents are at higher risk for poor metabolic control due to decreased adherence to treatment regimens (Anderson, 1994; Hanson, Henggeler, & Burghen, 1987b; Weissberg-Benchell et al., 1995; Wysocki et al., 1992). Consistent with suggestions regarding adolescents in general, experts on adolescents with diabetes recommend intervening during early adolescence in order to prevent such difficulties later on (Anderson, 1994; Wysocki et al., 1992). Diabetes management adherence takes commitment and motivation from adolescents with type 1 diabetes and the people who support them in the care of their disease.

### *The Role of Health Care Providers*

The way health care providers interact with adolescents can influence diabetes management adherence and, therefore, metabolic control. Patient-provider communication affects adherence (Glasgow et al., 1999), therefore, an open and honest relationship between patient and provider is essential (Brink & Moltz, 1997). Burroughs, et al. (1993) emphasized that providers must watch and listen carefully to their adolescent patients: they must consider the whole picture.

Adolescents with type 1 diabetes can be viewed as an oppressed group when approaches to diabetes care used by health care providers are paternalistic in nature (Dickinson, 1999), such as when they use judgment and blame. Dickinson (1999) suggests the application of critical social theory to nursing care of this population, in order to help adolescents with type 1 diabetes dialog with health care providers and ultimately take a more active role in their diabetes management.

Studies have indicated that adolescents benefit from health care providers who are realistic about the differences between patient and provider assessments of adherence (Du

**Pasquier-Feiaevsky & Tubiana-Rufi, 1999) and providers who focus on appraisals of adherence to treatment rather than on the risks of nonadherence (Palardy et al., 1998). The health care provider's role is to recommend effective treatment plans, educate the patient, and motivate the patient to follow the treatment plan. Patient participation affects adherence directly and indirectly (Golin et al., 1996). A patient's level of satisfaction with the health care provider, the interaction with the health care provider, and the diabetes management plan can hinge on their level of participation in the health care provider visit (Golin et al., 1996). Research has indicated that patient participation in decision making during visits to health care providers can improve the level of adherence to diabetes self-management (Anderson et al., 1995). Adherence can also be influenced by behavioral interventions which include education, role-playing, relaxation exercises, self-instructions, problem-solving strategies, and homework (Mendez & Belendez, 1997).**

**Diabetes experts recommend that health care providers empower the patient to act in their own self-interest (Funnell et al., 1992) and promote individual flexibility (Brink & Moltz, 1997). Brink and Moltz suggested that health care providers promote increased self-esteem, improved self-care, and sustained adult/parental supervision. They should focus on the patient in order to assess how patients learn, how they are motivated, and what educational/psychological barriers exist. Unfortunately, in the current insurance-dominated system, health care providers are often prohibited from determining individualized approaches to care because of limited resources, time, and reimbursement (B. Anderson, personal communication, Feb., 1998).**

**Although adolescents are typically striving for independence, they still benefit from the support of a health care team in managing their diabetes. The diabetes care**

team recommended by the DCCT study group (1994) may not be realistic or possible, however, the “team” can consist of the adolescent and only one or two health care professionals and still be effective. Positive interactions with health care providers can lead to more positive attitudes about diabetes management. Diabetes education, an important component of diabetes care, can enhance diabetes management and metabolic control.

### *Diabetes Education*

Diabetes education is a mainstay of health care for adolescents with type 1 diabetes (Schwartz, 1991; Wolfsdorf, 1999). In order to manage diabetes successfully, adolescents must be equipped with the problem-solving skills necessary to maintain near-normal blood glucose levels in the context of the adolescent lifestyle (Wolfsdorf, 1999). Research has indicated that problem-solving based learning methods help adolescents with type 1 diabetes to make more appropriate decisions regarding dietary adherence (Pichert et al., 1994).

Brink and Moltz (1997) discussed the importance of diabetes education for adolescents and recommended that diabetes education be age-appropriate with a focus on motivation of patients and families. Diabetes management must be taught using both a proactive and reactive approach. The way diabetes education is delivered may have an impact on habits formed by adolescents with type 1 diabetes. Dickinson (1998) found that very few studies have been conducted since the DCCT, which use teaching interventions to improve metabolic control in adolescents with type 1 diabetes. A meta-analysis, which examined the effect of diabetes education interventions on adolescents, revealed that the number of studies being conducted on the effect of diabetes education

interventions on metabolic control in adolescents was insufficient to see any trends (Dickinson, 1998). The author concluded that such studies may not be conducted for several reasons: insufficient funding, difficulty recruiting participants, and lack of insurance reimbursement in the long run. The author also acknowledged that additional studies may exist but have not been published, or may not contain the appropriate data required to be included in a meta-analysis (Dickinson, 1998).

Several experts agree that knowledge or education is not enough for adolescents with type 1 diabetes to achieve metabolic control (Burroughs et al., 1993; Glasgow et al., 1999; Hanson et al., 1987b; Wysocki et al., 1992). Many factors have an impact on adolescent diabetes self-management. Some adolescents with type 1 diabetes report an increase in daily hassles due to the tasks of diabetes management. Diabetes also leads to increased incidences of emotional and behavioral problems (Fonagy, Moran, Lindsay, Kurtz, & Brown, 1987; Glasgow et al., 1999). Eating disorders are a prevalent issue during adolescence, and they are significantly more common in adolescents with type 1 diabetes due to the required emphasis on food in diabetes management, desire for autonomy from parents, and a need for peer approval (Neumark-Sztainer et al., 1996).

Many diabetes professionals have emphasized the importance of a behavioral component in diabetes education (Davidson et al., 1997; Glasgow et al., 1999). Davidson and her colleagues (1997) hypothesized that behavior modification interventions specifically promoting the use of more effective coping skills, may help adolescents with type 1 diabetes. They used a behavior training program in conjunction with education to improve coping and ultimately diabetes outcomes (Davidson et al., 1997). Adolescents with type 1 diabetes struggle with adapting to daily management, identity,

independence/dependence, peer issues, and social competence. Coping skills training was implemented to address these challenges. The intervention included social problem solving, communication skills training (social skills training and assertiveness training), cognitive behavior modification, and conflict resolution (Davidson et al., 1997). Results from this study revealed that intensive therapy by itself improves metabolic control, however, the addition of coping skills training significantly enhances metabolic control. The authors concluded that coping skills training allows adolescents with type 1 diabetes to manage their lives in the context of diabetes (Grey, et al., 1998a).

As these studies indicate, education, alone, is not enough for adolescents with type 1 diabetes. These young people need health care interventions which incorporate an understanding of the whole person. In addition to diabetes education, an important component of diabetes management is the involvement of parents.

### *The Role of Parents*

Another recommendation for adolescents with type 1 diabetes, which parallels the conclusions of the Carnegie Council on Adolescent Development (1995), is the need for parental involvement (Anderson, 1994). In the 1980's, researchers realized that rather than separating completely from parents and the family, adolescents actually need to stay connected with parents in order to achieve more positive health outcomes (Anderson et al., 1989; Follansbee, 1989; Hanson et al., 1987a; Hanson et al., 1989). Hanson et al. (1989) found that family flexibility and positive relations are beneficial to metabolic control in adolescents with type 1 diabetes. Shared responsibility between parents and teens is also associated with increased metabolic control (Follansbee, 1989).

Since the conclusion of the DCCT, the recommendation for continued parental involvement during adolescence still exists and may be even more urgent (Anderson, 1994; Anderson et al., 1997; Anderson, Brackett, Ho, & Laffel, 1999; Brink & Moltz, 1997; Hanson, DeGuire, Schinkel, & Kolterman, 1995). In the past, one of the tasks of adolescence was described as a conflict between independence and dependence (Smiley, 1988). More recently, however, Anderson (1994) has suggested that adolescents need to establish interdependence, and, therefore, healthy interpersonal relationships with their parents. Adolescence is a period of transition and reorganization in which interdependence between adolescents and parents can lead to better communication and more positive health outcomes. Staying connected with parents during this stage decreases adolescents' vulnerability to peer pressure, as opposed to separating from parents at this age, which can lead to increased health-compromising behavior (Anderson, 1994).

Several studies (Anderson et al., 1997; Anderson et al., 1999; Grey et al., 1998b; Hanson et al., 1995) have indicated that parental involvement in adolescent type 1 diabetes management is associated with increased adherence and metabolic control, and decreased family conflict. Parental use of negative behaviors to promote adherence tends to lead to decreased metabolic control, whereas positive or supportive behaviors lead to better metabolic control (Burroughs, et al., 1993). Grey et al. (1998b) noted that the challenge is in finding an effective degree of parental involvement that is comfortable for both adolescents and parents, and does not risk negative outcomes resulting from over or under involvement.

Although adolescents typically separate from their parents at this age, staying connected with parents is valuable for adolescents with type 1 diabetes. Parents play a role in supervising, supporting, and/or advising adolescents, which can improve metabolic control during this difficult stage. Health care providers need to take responsibility for encouraging parental involvement in diabetes management (Brink & Moltz, 1997; Wolfsdorf, 1999).

### *Differences Between Females and Males*

Gender differences between female and male adolescents with type 1 diabetes may call for additional considerations in approaches to diabetes care delivery. Adolescence, especially for females, is marked by an increased awareness of body image and concern for weight and general appearance. Diabetes, a disease that has meal planning as a major focus, lends itself to additional issues around food and eating. It is well documented that eating disorders occur with frequency in this population (Bubb & Pontious, 1991; Cohn, Cirillo, Wingard, Austin, & Roffers, 1997; Neumark-Sztainer et al., 1996). The deliberate withholding of insulin in order to control weight is considered by some to be a form of eating disorder (Brink, 1997). Brink reported that overall poorer glycemic control, increased incidence of diabetic ketoacidosis, and insulin omission are characteristic of adolescent females with type 1 diabetes. The imposed structure of diabetes management and frustrations with achieving tight control may be more than adolescent females, who are juggling so many issues already, can handle.

Girls have a higher tendency to mismanage their diabetes than boys, during adolescence (Hanna & Guthrie, 1999). La Greca et al. (1995) evaluated gender differences in metabolic control for adolescents with type 1 diabetes and found that girls

have worse metabolic control and more symptoms of depression and anxiety than boys. The authors suggested that taking an interest in the patient and their current life situation apart from diabetes, may help health care professionals be alert to depressive symptoms (La Greca et al., 1995). In adolescent females, poor metabolic control can lead to delayed pubertal maturation and menstrual irregularities (Charron-Prochownik & Arslanian, 1997). In addition to the typical worries of adolescence and diabetes, adolescent females also have concerns about the effects of diabetes on planning for and having children in the future (Charron-Prochownik & Arslanian, 1997).

Although adolescent girls are more likely to want to improve metabolic control than boys (Thompson et al., 1996), adolescent females experience more diabetes-related hospitalizations than males (Cohn et al., 1997). Research has shown that male and female adolescents respond differently to living with type 1 diabetes (Brink, 1997; Cohn et al., 1997; La Greca et al., 1995), however, studies that look at them separately are not in the literature. Adolescent females and males need to be studied separately, using qualitative methods, in particular, in order to gain a more in-depth understanding of their experiences.

Volumes of quantitative studies regarding glycemic control in adolescents with type 1 diabetes have not changed the fact that this is a difficult life stage with the potential of leading to long-term complications. While these studies are vital to examine the effects of various approaches to care, the statistics indicate that many of these approaches have not worked. The results of one study suggested the need to further investigate with qualitative methodologies (La Greca et al., 1995).

### *The Adolescent's Perspective*

Qualitative research, which focuses on the individual's perspective, is well-suited to studying what it means for adolescent females to live with type 1 diabetes. Few qualitative studies, however, have been conducted on this topic. Because of the changes in diabetes management practices since the conclusion of the DCCT, there is an even greater need to explore adolescent females' experience of living with type 1 diabetes. Five studies have explored aspects of the experience of living with type 1 diabetes for adolescents, using qualitative methods (Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995; Meldman, 1987; Standiford et al., 1997; Wdowik, Kendall, & Harris, 1997).

In 1987, Meldman published the results of her qualitative study, which explored the experience of adolescents with type 1 diabetes. The author conducted a descriptive study with 12 adolescents with type 1 diabetes (ages 15 to 18 years). Meldman reported that adolescents with type 1 diabetes were ambivalent about self-management. Themes revealed through the interview data were categorized as psychosocial, developmental, or clinical, and all of the themes displayed this ambivalence. Participants in Meldman's study reported having conflicts with other people about such issues as overprotection and dependence. Meldman concluded that by appreciating the ambivalence adolescents feel toward diabetes management, health care providers can enhance their understanding of adolescents' experience of living with type 1 diabetes. Meldman recommended that health care providers give adolescents the opportunity to discuss their problems and feelings in order to foster independence and a collaborative relationship between patient and provider.

**Kyngas and Barlow (1995) used grounded theory to examine the personal meaning of diabetes for adolescents in Finland. Fifty-one Finnish adolescents with type 1 diabetes (ages 13 to 17 years) were asked to talk about what diabetes means to them and what kind of impact diabetes has on their lives. The findings indicated that these adolescents had negative responses to living with diabetes. Two themes, control and fear, emerged as the personal meaning of diabetes. The study also revealed that type 1 diabetes controls, or limits, their freedom and independence. Diabetes was described as a disruption to the balance of life. The authors concluded that these results can raise awareness of the challenges experienced by adolescents with type 1 diabetes. It was suggested that health care providers consider adolescents' need to have confidence in their ability to perform self-care. The authors recommended that health care providers provide support to adolescents with type 1 diabetes, in order for them to achieve confidence (Kyngas & Barlow, 1995).**

**Kyngas & Hentinen (1995) used grounded theory to examine the meaning of compliance with self-care for a group of 51 adolescents with type 1 diabetes in Finland. The authors reported four categories of behavior patterns: good compliance, imposed compliance, conscious non-compliance, and non-compliance, which depict differences in the meaning of compliance, and factors that promote compliance among these adolescents. The authors found that adolescents need to feel that compliance is achievable within their lifestyle, and that self-care is meaningful in attaining their goals. Compliance for these adolescents was related to their self-care and the type of adaptation (positive or negative) they had to the disease. The authors recommended that anticipating**

how patients cope with self-care is important because it may influence the choice of treatment plans for them (Kyngas & Hentinen, 1995).

Standiford et al. (1997) studied 60 children and adolescents (ages 10 to 17 years) to explore personal illness models (cognitive representations of individuals' illnesses) of diabetes. Participants were asked to describe their responses to living with diabetes, specifically regarding their beliefs about diabetes, diabetes management, control, and problems. Results of the study indicated that this group of adolescents wanted health care providers to offer strategies for managing diabetes in order to prevent future complications; family and friends were viewed as supportive; and fears included hypoglycemia and long-term complications. The authors suggested that understanding how adolescents with type 1 diabetes view their disease may assist health care providers in tailoring diabetes interventions to individual needs (Standiford et al., 1997).

Using focus groups and interviews, Wdowik and her colleagues (1997) identified factors that affect adolescents' ability to engage in appropriate diabetes self-management behaviors. Findings of the study included barriers to successful diabetes management: time management, stress, hypoglycemia, dietary constraints, and inadequate finances; and psychosocial issues that affected successful management: inconveniences of diabetes management, motivators to managing diabetes, and social support issues. The authors concluded that some adolescents may report having better metabolic control than they actually have. The authors suggested using their findings and future studies to assist in developing diabetes programs including health care, education, and support components for adolescents (Wdowik et al., 1997).

Existing studies have used quantitative and qualitative methods to identify or describe aspects of type 1 diabetes for adolescents. We know that adherence to a diabetes management routine is vital for positive health outcomes in adolescents with type 1 diabetes and that these young people face several physiological and psychosocial barriers to metabolic control. We also know that health care providers and parents play an important role in diabetes education and management for adolescents. We do not, however, have a grasp of what it means for adolescents to live with this disease on a daily basis. We know that adolescent females and males are different in their responses to living with diabetes; however, no one has studied them separately. It is clear that in order to gain a more thorough and current understanding of adolescents' experience of living with type 1 diabetes, qualitative methods are needed. Qualitative studies to date were either conducted prior to the DCCT, included participants from other cultures, or did not fully address the experience of living with diabetes. Although much is known about the phenomenon of adolescent diabetes, what is not known is what it means for adolescent females to live with type 1 diabetes day in and day out.

Continuing to examine diabetes in adolescents the same way it has been studied historically encourages a narrow vision, and very little advancement of understanding. Conversely, studies that make visible what it means for adolescent females' to live with diabetes on a daily basis may provide the insight needed to develop innovative approaches to care. An interpretive phenomenological approach is one way to illuminate that meaning. In the context of what is currently known about diabetes management and metabolic control in type 1 diabetes, a fuller understanding of this phenomenon may

**provide the foundation for more effective approaches to diabetes care and potentially a decreased incidence of complications for these young women.**

### **Summary**

**This chapter presented the context of the study. The current adolescent culture in the United States was discussed, and a review of the current literature on adolescence and type 1 diabetes was provided. Aspects of managing diabetes during adolescence were made explicit, including intensive management and challenges to managing diabetes; the role of health care providers and diabetes education; the role of parents; the differences between males and females; and the adolescent's perspective.**

## **CHAPTER III**

### **Method of Inquiry**

**This chapter presents an overview of the method of inquiry used for this study. Phenomenology as a philosophical perspective and a research methodology is discussed, as well as van Manen's phenomenological framework. Recruitment and protection of study participants, participant profile, and data collection procedures are presented. Data analysis and evaluative review are also explained.**

#### **Phenomenology as a Philosophical Perspective**

**Phenomenology was chosen as the philosophical context of this study because of its focus on understanding experience from an individual's perspective. Human experience is meaningful to the individual and can only be revealed through the individual's personal perspective. It cannot be quantified or objectified if it is to be truly revealed. Phenomenology, therefore, shifts attention from the reality of the world to the meaning of reality for individuals.**

**Phenomenology is not a singular or unified approach. Spiegelberg (1971) suggested approaching phenomenology as a "movement" because of the diverse points of view held by philosophers within phenomenology. Phenomenology has never been static but has continued to change and evolve since Husserl's time. A major variance in phenomenological approaches is rooted in the ideological differences between Husserl (1911/1965) and Heidegger (1953/1996).**

**The use of phenomenology in the context of this study originated with Edmund Husserl. Husserl (1911/1965) considered phenomena to be the things of which one can be aware, or anything of which one is conscious. Husserl (1911/1965) saw**

phenomenology as inseparable from philosophy. Philosophy is a questioning of the basis of the world, which, according to Husserl (1931), is rooted in phenomenology. This “eidetic phenomenology” aims at establishing (or describing) knowledge of essences (Husserl, 1931). Essence is the structure and meaning of an empirical phenomenon, or experience (Husserl, 1931).

Husserl (1911/1965) considered intentionality to be a characteristic of phenomenology. Consciousness is considered intentional, because it is always directed toward something, therefore, there is an undeniable relationship between the conscious mind and that which it is conscious of (Husserl, 1911/1965). Consciousness is a person’s inseparable connection to the world. The intentional structure of experience reflects each person’s way of being in his/her world. Phenomenological reduction is the device which allows a person’s consciousness to be made visible. This reduction shapes the researcher’s interest in the phenomenon, suspends prior beliefs and knowledge about the phenomenon, and directs one to the essence of the phenomenon (Husserl, 1911/1965).

Husserl’s phenomenology is a philosophical perspective, which considers knowledge to be constituted by meanings. Those meanings are defined by the specific reality for the person. Humans’ understanding of the world is based on how they experience it, act upon it, and interact with it. The lived experience gives meaning to the world. Another aspect of Husserl’s (1911/1965) phenomenology is intersubjectivity. Eidetic, or essential, meaning of an experience is fundamental to that experience, regardless of who has the experience. Different people have different perspectives of shared events. Lived experience is subjective because individuals have different realities. Intersubjectivity, however, exists when a group of people shares a common world

(Schutz, 1932/1967). Every experience, to which a person gives meaning, relates to an experience of another person, because they exist in the same world.

Similar to Husserl, Heidegger (1953/1996) described phenomenology as a philosophical perspective which considers knowledge as being constituted by meanings. Turning back to the things themselves provides entry into the meaning of experiences. Those meanings are defined by the specific reality for the person. Heidegger's work, however, differed from Husserl after that point. Heidegger refined Husserl's phenomenology and blended it with existentialism to constitute what is known as existential phenomenology. Heidegger's phenomenology focused on the meaning of being. Existential phenomenology uses interpretation, as opposed to description, to capture the meaning of being.

Heidegger was concerned with "being-in-the-world". According to Heidegger (1953/1996), the relationship of a person to the world is the starting point for and most important aspect of studying people. The question of being comes before the question of knowing because a person is a self-interpreting being. Although the world exists prior to people, the world constitutes and is constituted by people. Interpretive phenomenology is the search for understanding of people's experiences of being in the world (Heidegger, 1953/1996).

Both of these phenomenological ideologies are concerned with meaning. While Husserl's (1911/1965) philosophy was based on the question of *what we know*, Heidegger (1953/1996) was interested in the *meaning of being*. This difference in philosophical perspective, epistemology vs. ontology, was what separated the two

schools of thought, and therefore, the two types of phenomenological research methodologies.

*Van Manen's Philosophical Approach to Phenomenology*

Van Manen's phenomenology originated from the Dutch approach, which combines aspects of both eidetic and existential phenomenology (Cohen & Omery, 1994). Van Manen (1990) calls phenomenology a "theory of the unique" and a "reflective discipline" (p.7), which always begins in the lifeworld. It is difficult to define van Manen's philosophy of phenomenology because, as he says, one can only understand phenomenology by "actively doing it" (p.8). He describes phenomenology as a philosophy of individuals, studied against the background of pursuing an understanding of the whole.

For van Manen (1990), human beings are self-interpreting. Human beings attach meaning to their experiences in the world. Van Manen states that human science is rational, because it assumes that human experience can be understood, although the actual experience is always more complex than its description. Van Manen combines parts of both Husserl's and Heidegger's work in his approach. For example, van Manen describes phenomenology as the study of the world as people experience it (Husserl, 1911/1965). He also describes phenomenology as thoughtfulness; a mindful wondering about what it means to be (Heidegger, 1953/1996).

According to van Manen (1990), phenomenology brings people in more direct contact with the world. It is the study of existential meanings. Like Husserl (1911/1965), van Manen believes that consciousness gives human beings access to the world: consciousness is an awareness of and response to the environment. However, for van

**Manen, meaning is found in the intersubjective, which refers to the researcher's ability to portray an accurate interpretation of the meaning of the phenomenon to the reader.**

### **Phenomenology as a Research Methodology**

**Phenomenology is the study of lived experience; the study of what it means to be human. Two distinctive approaches to phenomenological research include descriptive and interpretive phenomenology. Descriptive phenomenology, based on the work of Husserl (1911/1965) seeks to make vivid the essence of the phenomenon being studied. Heidegger (1953/1996) introduced interpretive phenomenology. Interpretive phenomenology is the search for an understanding of people's experience of being in the world. Husserl (1911/1965) emphasized turning back to the "things themselves" in order to describe the essence of human experience. Heidegger (1953/1996) emphasized understanding through interpretation.**

**In descriptive phenomenology, the researcher brackets his/her presuppositions and knowledge about the phenomenon, reflects on participants' accounts of their experience, and describes the essential structures of the phenomenon. In order to see phenomena clearly, Husserl (1911/1965) supports the use of bracketing as a way of setting aside the researcher's presuppositions including assumptions, beliefs, and prior knowledge about the phenomenon. Husserl (1911/1965) promoted bracketing, or phenomenological reduction, as a way to open up the full range of conscious experience. The task is to set aside, or bracket, what is known about the phenomenon, in order to elucidate the essence of the phenomenon. While presuppositions and theories limit experience to those things that are known, suspending such prior beliefs allows the phenomenologist to truly attend to the individual's experience.**

Heidegger's (1953/1996) phenomenology, on the other hand, does not promote the use of bracketing because interpretation occurs in context. According to existential phenomenology, it is not possible to bracket because people are self-interpreting beings who cannot step out of their contexts. Interpretation takes place in the context of the everyday experience of the researcher and participants. Interpretation goes beyond description and uncovers hidden meaning. Using experience in the everyday world as a starting point, interpretation enables a more in depth understanding of a specific phenomenon (Heidegger, 1953/1996).

*Van Manen's Methodological Approach to Phenomenology*

Van Manen's (1990) method of phenomenology is a combination of descriptive and interpretive phenomenology. Van Manen portrays phenomenology as describing a phenomenon and allowing it to show itself through interpretation. Phenomenological research, the study of essences, aims at unveiling the meaning of a lived experience, which is not overtly visible. Phenomenology seeks to discover both what a phenomenon means and how it is experienced. Although van Manen believes that a complete phenomenological reduction is impossible, he promotes the use of bracketing in his phenomenological approach. Van Manen recommends making presuppositions about the phenomenon explicit prior to beginning the study, in order to suspend them or hold them in abeyance during the study. For van Manen, phenomenology is an attempt to explicate the meaning of an experience through an interpretive description, although the researcher bears in mind that the lived experience is always more complex than the explicated meaning can reveal.

Van Manen's phenomenological method was deemed appropriate for this study because of the need for an interpretation, not just a description, of the lived experience of adolescent females with type 1 diabetes. The researcher's strong personal interest in and professional experience with the phenomenon also fit well with van Manen's method. Van Manen's method was used, therefore, to illuminate the meaning of the experience of living with type 1 diabetes for adolescent females.

### **Van Manen's Phenomenological Approach Applied**

Using van Manen's (1990) phenomenological method, the following phenomenological question was examined: What is it like for adolescent females to live with type 1 diabetes? The researcher employed van Manen's six activities which assist in the pursuit of human science research: turning to a phenomenon which seriously interests us and commits us to the world; investigating experience as we live it rather than as we conceptualize it; reflecting on the essential themes which characterize the phenomenon; describing the phenomenon through the art of writing and rewriting; maintaining a strong and oriented pedagogical relation to the phenomenon; and balancing the research context by considering parts and whole.

#### *Turning to a phenomenon which seriously interests us and commits us to the world*

The impetus for the study was the researcher's personal experience of living with type 1 diabetes and professional experience of working with adolescent females who have type 1 diabetes. Having been an adolescent female with type 1 diabetes and having worked closely with many of these young women, the researcher developed a strong interest in this population. The researcher's personal and professional experience, therefore, established her commitment to the phenomenon of interest. The extant

literature on adolescents with type 1 diabetes is limited to data that describe particular aspects of the phenomenon. The need for a deeper understanding of the whole experience, therefore, also committed the researcher to the phenomenon of interest.

*Investigating experience as we live it rather than as we conceptualize it*

The study investigated a group of adolescent females' experience with type 1 diabetes as *they* lived it and *not* as either the researcher or any others conceptualize it. This was made possible by making presuppositions explicit and through personal interviews with the participants. Van Manen (1990) discusses the problem of "knowing too much" about the phenomenon being studied (p.46). The researcher's pre-understanding and beliefs about the phenomenon can actually influence the interpretation by causing him/her to jump to conclusions without considering the perspective of the study participants. Van Manen recommends the use of bracketing in order to avoid allowing these presuppositions to conceal the character of the study, which is the participants' responses. Prior to beginning the study, the researcher reflected upon and made visible her presuppositions related to the phenomenon, biases and beliefs, theoretical knowledge, and understanding. These presuppositions were recorded in a research log, in order to make them explicit.

*Reflecting on the essential themes which characterize the phenomenon*

Phenomenological methods are used in order to better understand the meaning of an aspect of human experience. The meaning of a situation needs to be discovered through the experience of that situation for those who are living it (van Manen, 1990). In this case, the meaning of living with type 1 diabetes was revealed through listening to and reflecting on the experience of living with type 1 diabetes as described by a group of

adolescent females. A personal, unstructured interview was conducted with each participant, in which she shared her experience. These narratives were audio taped and transcribed, creating a text. These texts portray the significance of individuals' experiences (van Manen, 1990). Analysis of the texts required the researcher's thoughtful reflection, which enabled the themes in the data to be made visible.

*Describing the phenomenon through the art of writing and rewriting*

The purpose of phenomenological research is to apply "language and thoughtfulness" in order to present the phenomenon as it shows itself (van Manen, 1990, p.33). According to van Manen, language is the only way to shed light on experience. The language of the participants' interview narratives reveals themes which can be considered units of meaning. The art of being sensitive to the participants' experiences allows the researcher to make visible the essence of the phenomenon. It is through writing and rewriting that the description and interpretation of the phenomenon comes alive. The phenomenological reflection employed in this interpretive study enabled the researcher to discover meaning of the lived experience, which can, in turn, be communicated to outsiders.

*Maintaining a strong and oriented pedagogical relation to the phenomenon*

The researcher's professional experience with adolescent females with type 1 diabetes fueled her commitment to the phenomenon of interest in this study. Knowledge of the need for more effective approaches to nursing care of this population gave her a strong and oriented relationship to the phenomenon. Effective nursing interactions with adolescent females who have type 1 diabetes are important for positive health outcomes in this population. This study was conducted in order to provide nurses with a clearer

understanding of the meaning of living with type 1 diabetes for adolescent females. The researcher was personally engaged in this study because of her deep desire to improve the lives of adolescent females with type 1 diabetes.

*Balancing the research context by considering parts and whole*

The researcher considered parts and whole of the participants' experience as she reflected on the interview data. By reflecting on smaller parts, the whole experience took on new meaning. In this study, the researcher looked at the parts of these adolescent females' stories, which gave her a better grasp of their experience of living with type 1 diabetes. Through the process of reflection, the themes revealed from the data became the instrument by which the researcher achieved understanding of the phenomenon (van Manen, 1990). The themes are the vehicle for presenting the meaning so that others can grasp it as well.

**Protection and Recruitment of Study Participants**

Approval for the study was obtained from the research committee at the sponsoring organization of the diabetes camp where participants were recruited (see Appendix A) and the University of Connecticut Committee on the Use of Human Subjects in Research (see Appendix B). Written support for the study was also obtained from the Executive Director of the camp's sponsoring organization (see Appendix C) and the Medical Director of the camp (see Appendix D).

Participants were recruited from a group of adolescent females who were participating in the Counselor-In-Training (CIT) program at a diabetes camp in New England. The following criteria were required for inclusion the study: age 15 to 17 years, English speaking, and diagnosed with type 1 diabetes. No attempts were made to exclude

participants on the basis of race, religion, cultural or educational background, or socio-economic status.

A letter explaining the study was sent to the parents/guardians of the CITs (see Appendix E). A second letter, explaining the study and inviting the CITs to participate in the study was sent to the CITs (see Appendix F). These letters were mailed two weeks prior to the CITs' arrival at camp.

Informed consent (see Appendix G) was obtained from parents before any participants took part in the study. On the first day (Opening Day) of the camp session, the researcher met with each participant and her parents/guardians. Parents and participants were informed that confidentiality would be maintained throughout the study. They were assured that names would not be attached to any publication or presentation of the study findings. At that time the study was explained in further detail, questions were answered, and consent forms were signed. Participants signed the consent form in addition to their parents/guardians, indicating that they volunteered to take part in the study.

### **Study Participants**

The study sample consisted of a purposive sample of 10 Caucasian adolescent females with type 1 diabetes. Participants were between the ages of 16 and 17 years and had been living with type 1 diabetes for 5 to 12 years. Table 1 provides characteristics of the study participants (see Appendix H).

## **Study Setting**

**This study was conducted at a diabetes camp in New England. The researcher's past and current involvement in the camp, as a consultant, facilitated the recruitment of participants at this location. The camp is a residential summer camp for girls ages 6 to 17 years with type 1 diabetes, which is operated by a non-profit organization, dedicated to providing educational programs for children with diabetes and their families. Camp attendees represent the United States and several foreign countries. The camp accepts campers on a first-come, first-served basis, regardless of race or (family's) financial status. Financial assistance is available for those campers whose families are otherwise unable to pay the camp fee.**

**The camp's Counselor-In-Training (CIT) program is designed to train adolescent females (15-17 years) to become camp counselors. The program curriculum addresses the areas of leadership, diabetes education, self-esteem/self-confidence building, child development, and camp operation. CITs are never solely responsible for the care of campers. They are transitioning between camper and staff status and are in a constant learning environment.**

**At the time of the study the researcher was employed, on a consulting basis, by the sponsoring organization. The researcher, however, never worked directly with the potential participants of the study, and CITs were not aware of the researcher's consulting role at the camp. Her role during the camp season consisted of providing diabetes education for the staff and consulting on diabetes-related and staff management issues throughout the summer. The researcher's only direct involvement with the participants of the study during the camp season was to conduct her research. The researcher agreed**

to share the study findings with the sponsoring organization and members of the camp staff.

### **Data Collection Procedures**

Data collection consisted of face-to-face, unstructured interviews. The Director of the CIT program arranged interview times, which were held on the first two days of the camp session. Interviews were conducted before the diabetes education component of the CIT program began, so that participants would not have any additional educational “preparation” for the interviews. Diabetes education sessions sometimes take the format of open discussions where the CITs talk about different experiences they have in living with diabetes. Interviews were conducted prior to these sessions because exposure to such sessions before the study interviews had the potential to affect participants’ responses during their interviews.

The interviews were conducted in a quiet and comfortable room, and the door was closed for privacy. A sign was hung on the outside of the door, indicating that the interview was taking place. Each participant was informed that the interview would be audio taped using two tape recorders. The researcher explained that the participants would be given the second tape to keep when the study was completed. A card with the research question written on it (What is it like for you to live with diabetes?) was placed in front of the participant during the interview. Before beginning the interview, the researcher explained to each participant that there were no “right” or “wrong” answers and that nothing they said would affect their CIT status.

At the start of each interview, the participant was asked to describe her experience of living with type 1 diabetes. The researcher began by asking the broad question, “What

is it like for you to live with diabetes?" The researcher asked each participant to discuss what it is like to live with diabetes in all aspects of her life, including school, home, sports, social, work, or other activities. Additional open-ended questions were asked, as needed, to clarify responses given by the participants.

The adolescent females who participated in the study shared openly during the interviews. Phenomenological interviews lasted from 15 to 35 minutes. Most of the interviews lasted 20 to 25 minutes. One participant admitted feeling nervous before beginning the interview, however, all 10 adolescents participated without any apparent problems. The interview tapes were reviewed several times and the interviews were transcribed.

### **Data Analysis**

Van Manen's (1990) phenomenological method provided a guide for analyzing the data in this study. According to van Manen:

...human science research is a form of writing. Creating a phenomenological text is the object of the research project. ...The phenomenological method consists of the ability, or rather the art of being sensitive – sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak (p.111).

Using an interpretive phenomenological method, the findings of the study articulate the experience of living with type 1 diabetes for these adolescent females.

The purpose of analyzing the data of a phenomenon is to seek meaning, or determine the essence of the experience (van Manen, 1990). Van Manen defines phenomenological themes as structures of experience. Themes are derived from

statements extracted from the data. The themes identified each capture part of the essence of the experience being studied. Isolating themes is a way to simplify or organize the data in phenomenological research. Van Manen suggests various approaches to isolating thematic statements from the data. The researcher used van Manen's wholistic and selective approaches to analyze the data:

- The 10 interview transcripts were read and re-read several times in their entirety, using the wholistic approach to obtain an overall sense of the data. The wholistic approach allowed the researcher to attend to the whole meaning of each participant's account.
- The interview transcripts were read again and statements/phrases which stood out as meaningful were highlighted. The selective approach was used to highlight statements which seemed particularly revealing about the experience of living with type 1 diabetes.
- Thematic phrases were developed from the highlighted statements.
- Careful reflection on the data revealed themes in the text. Themes are commonalities revealed within and across the data, which illuminated the meaning of the phenomenon.
- The researcher continually checked the fit of themes with the original data, by re-reading the transcripts.

Because phenomenological research seeks to illuminate meaning in human experience, phenomenological reflection is employed as a way to help unfold meanings embedded in the text and uncover the meaning of the phenomenon (van Manen, 1990). The researcher reflected on the individual responses of participants, the whole of each

participant's experience, and similarities and differences between participants, in order to arrive at themes which most appropriately and accurately characterize the phenomenon.

In order to generate deeper insights and understanding about the phenomenon of inquiry, van Manen (1990) recommends the use of collaborative discussions or "hermeneutic conversations" (p. 100). The researcher discussed the themes revealed in this study with an expert in adolescent diabetes. This expert is a nurse practitioner who provides diabetes care to children and adolescents with type 1 diabetes in both the outpatient and inpatient setting. This nurse has also worked at diabetes camps for several years. During these informal conversations, the researcher and this nurse discussed the themes' orientation to the phenomenon and checked the fit of the themes with the data.

Van Manen (1990) also recommends the use of additional sources to obtain thematic descriptions. The researcher looked at entries that children and adolescents with type 1 diabetes made in journals at the camp. During each camp session, campers and staff are asked to write their reflections on experiences with camp, diabetes, or life in general in these journals, which remain at the camp. This technique gave the researcher additional insight regarding the experience of living with type 1 diabetes. For example, several entries correlated with the feeling of loneliness that emerged from the interview data. These campers wrote about how good it felt to be around other people with type 1 diabetes; because it was the first time they realized they are not alone. The themes were presented using a music analogy, which illuminated the study findings. The researcher also used lines from existing poems and songs to illustrate the themes revealed in the study data.

## **Evaluation Standards for the Project of Inquiry**

In order to promote rigor and merit, this study was guided by Burns' (1989) Standards for Qualitative Research: descriptive vividness, methodological congruence, analytical preciseness, theoretical connectedness, and heuristic relevance.

### ***Descriptive Vividness***

Descriptive vividness refers to the description of the study and the findings of the study. The presentation of the study findings should make the experience come alive for the reader. As van Manen (1990) explained:

Creating a phenomenological text is the object of the research process. If the description is phenomenologically powerful, then it acquires a certain transparency, so to speak; it permits us to "see" the deeper significance, or meaning structures, of the lived experience it describes. A description is a powerful one if it reawakens our basic experience of the phenomenon it describes, and in such a manner that we experience the more foundational grounds of the experience (pp.111, 122).

Descriptive vividness is demonstrated by the phenomenological writing of the study findings. The researcher's findings are written so that the reader will "see" the meaning of the phenomenon.

### ***Methodological Congruence***

Methodological congruence refers to attention to rigor in documentation, procedural rigor, ethical rigor, and auditability (Burns, 1989). Methodological congruence is evidenced by the description of the study procedures. The researcher described van Manen's (1990) phenomenological approach and how it was applied to

**data analysis. The researcher paid careful attention to documenting the study methods so that the study could be repeated. Being able to recount the steps taken during the study gives the researcher accountability for the work performed. It is difficult to articulate the research methods in phenomenology because they rely heavily on the researcher's own reflection and intuition. The researcher kept a research log throughout the study, which provided a place to make notes such as experiences during data collection and observations of non-verbal responses during interviews. A sample entry in the researcher's log follows: "non-verbal...HK made facial/vocal expression to indicate she likes attention she receives when friends/others watch her 'do diabetes'." The researcher referred back to the log in order to help reflect on themes.**

**The researcher attended to ethical rigor by following standards for human rights protection set by the Committee on the Use of Human Subjects in Research at the University of Connecticut and the research committee at the camp's sponsoring organization.**

### ***Analytical Preciseness***

**Because qualitative research involves the transformation of data across several levels of abstraction, analytical preciseness "requires that the researcher make intense efforts to identify and to record the decision-making processes through which transformations were made" (Burns, 1989, p.50). Analytical preciseness is seen in the researcher's recording of reflections on the data in the research log. The researcher collaborated with two other nurses who are experts in phenomenological methods, to ensure that themes were logical and reflective of the meaning embedded in participants' experiential accounts. The researcher also collaborated with a nurse who is an expert in**

the care of adolescents with diabetes, to discuss themes that were revealed from the data. An additional source, journal entries, was also used to check congruence with the data. The nurse expert's experience with adolescent females with type 1 diabetes and the journal entries reinforced themes revealed in the study data.

### *Theoretical Connectedness*

Theoretical connectedness refers to the connection between the findings of the study and what was previously known about the phenomenon. This standard is evidenced in the discussion of the study findings. The findings of the study are compared and contrasted to what is already known about this topic. Theoretical connectedness was also addressed by the researcher's checking the fit of themes with the original data, in order to ensure that the experience of these adolescents was appropriately portrayed in the findings.

### *Heuristic Relevance*

Heuristic relevance refers to the relevance of the findings to nursing practice, education, and research. This can also be seen in the discussion of study findings. The findings contribute to nursing's extant body of knowledge by addressing an important, yet understudied dimension of clinical practice.

### **Summary**

This chapter presented phenomenology as a philosophical perspective and as a method of inquiry. Van Manen's approach to phenomenological research was discussed. Protection and recruitment of study participants, participant profile, study setting, and data collection procedures were presented. Data analysis and evaluation standards for the study were also explained.

## **CHAPTER IV**

### **Findings of the Study**

**This chapter presents the findings of the study, using the metaphor of a musical composition to explicate the experience of living with type 1 diabetes for a group of adolescent females. The aim of the study was make visible a comprehensive understanding of what it means for adolescent females to live with type 1 diabetes and what that experience is like. Analysis of the participants' accounts revealed that five themes captured the nature of this experience: Chorus – blending in with the adolescent culture; Solo – standing out and being watched; Trills – weighing the options and choosing a tune; Chords – being tethered to the system and to diabetes; and Dissonance – struggling with conflicts. These themes will be further illuminated in the findings to follow.**

#### **Introduction**

**The personal accounts of the study participants came alive for the researcher in much the same way as a piece of music. There were many parallels between the narratives of these young women and the nature of a work of music. For example, the basic elements that make up a piece of music, rhythm, melody, timbre, harmony, and form (Bacharach & Pearce, 1977), reflect this experience. Rhythm, which refers to the organizing and timing of the music, is found in the everyday experiences of these adolescents. Just as sounds are arranged in patterns to create the framework of music, so is the framework of their lives created. Rhythm is what causes music to move (Hoffman, 1997). A melody is a musical profile that moves from note to note. A melody is a tune that can be sung or played on an instrument. Some melodies are straightforward and**

others have no clear beginning or end (Hoffman, 1997). A “melody” is created and plays throughout the lives of these girls.

Timbre refers to the “tone color” of a piece of music. Timbre is the quality that gives the music its individual character (Hoffman, 1997). Each individual adolescent female has qualities or a “timbre” that is her own. Harmony, which is built from a melody, is the sound of more than one note at a time. Harmonic quality varies according to the combination of notes being played or sung (Bacharach & Pearce, 1977). The relationships in the adolescents’ lives produce “harmony”. Form is the means by which the other four elements are put together to create a piece of music. Form gives beauty to any work of art – it is the structure of the music (Bacharach & Pearce, 1977). All of these characteristics of the adolescent females’ experience combine and result in the “form” or structure of their lives.

A canon is a specific type of musical composition consisting of two or more parts that fit together to create an interesting sound. A canon can be simple and straightforward or very complex, and it can continue indefinitely (Hoffman, 1997). For the adolescent females who participated in this study, the experience of living with type 1 diabetes resembles a canon: it is continuous, has no beginning or ending and is never actually completed.

The experience of living with diabetes, for these young women, also corresponded to several different components of a piece of music: chorus, solo, trills, chords, and dissonance. A chorus is an organized group of singers. According to Bacharach and Pearce (1977), choral singing cultivates musicianship because it shows a person’s ability to create music as part of a group. Choral singers work together using

the whole musical score and not just their own parts. Being able to produce the proper sound using these techniques is a great achievement (Bacharach & Pearce, 1977). Like members of a chorus, these adolescent females are a part of the adolescent culture and the activities that go along with it.

A solo, on the other hand, is a part in a piece of music that is played or sung by one performer. A soloist may or may not be accompanied by other voices or instruments. Similar to performing a solo part, the young women in this study perform the daily tasks of diabetes management on their own. Trill comes from the Italian word, *tremolare*, and means, “to quiver”. A trill is a rapid alternation between two different notes. In the works of particular composers including Mozart and Beethoven, trills commonly follow an extended solo section (Hoffman, 1997). The various choices these girls have to make regarding diabetes management and how it fits into their lifestyles resemble the trills in a piece of music.

Hoffman (1997) defines a chord as three or more distinct notes played or sung together to produce harmony. A chord progression is a variety of chords played in a particular order which works effectively with the melody and builds the piece of music (Hoffman, 1997). The relationships that the adolescents have with parents, teachers, health care providers, and others are like chords. Just as musicians have no choice in the chords present in a piece of music, these adolescent females are forced into these relationships.

Dissonance is the result of two or more musical notes, played or sung simultaneously, which produces a harsh or disagreeable sound (Hoffman, 1997).

Hoffman also calls this “an effect of clashing or unease” (p.17). On the other hand,

Bacharach and Pearce (1977) claim that dissonance can be “exciting and full of tension” (p.77). Dissonance can even be heard as a logical step between two consonances (sounds that fit together and make sense) (Bacharach & Pearce, 1977). Like dissonant sounds in a musical composition, the participants deal with daily conflicts regarding their disease. Some conflicts are easier than others to resolve, but all of them influence the sound of these girls’ life music.

In a musical work, the same sounds may be heard at different times, in repetition, or only once. Similarly, the themes revealed in this study appear throughout the adolescents’ experiences. The different aspects of living with type 1 diabetes, reported by these girls, fit into their lives at various times, just as different instruments may play the same high or low notes at varied points in the music.

#### **Chorus – blending in with the adolescent culture.**

In a piece of music, the chorus is a mixed group of vocal parts that are performed together. These parts are written so they are interwoven to create a sound together. The members of a chorus work together for the same goal: to present the music as it is supposed to sound. Like members of the chorus, these adolescent females are actively engaged in the usual activities of adolescence. They become so involved in the adolescent experience that diabetes is not necessarily an issue:

*It's just an extra thing. I tend to think of it as not that big a deal and I just go on... .. my life comes first – that's important.*

For this group of adolescent females, diabetes does not define who they are. They are “normal” teen-age girls who enjoy the same activities as other kids their age. They want to be just like everyone else in their age group.

*I play sports and I'm a life-guard... I just bring orange juice with me or something to drink – it's no big deal. I really don't think it makes a difference, honestly, I don't – as long as you're playing to your best ability...*

Living with diabetes, therefore, means still being able to fit in with the crowd or “chorus”. Reflecting on how diabetes affects her socially, one adolescent said:

*I mean I don't really think of it as like – it's a disease, but I'm not like, 'oh my God, I have a disease' you know, I'm just – it's just like something that I can deal with. I don't consider myself different from anybody.*

Another participant explained that diabetes is something that can go with her, regardless of what she is doing:

*I definitely have choices, because I can do whatever I want. I just have to take the diabetes with me.*

For these adolescent females, being a teen-ager and being part of the adolescent culture come before being an adolescent with diabetes, therefore, diabetes is not uppermost in their minds. Diabetes is simply part of who they are and there is no way to change that fact. These girls do not let diabetes prevent them from living and enjoying life as adolescents. They go out with friends and eat the same types of food their friends eat. Some participate in sports, others hold paying jobs, and a few do both.

*It's normal – I just do what everyone else does. If I'm low I'll just have something. I mean, it's normal.*

The title of the song, “Cry Freedom” (Grey, Tinsley, & Griesar, 1996, track 10) (see Appendix I), illuminates in part what the experience means to these girls as they seek freedom from diabetes and freedom to be like other adolescents. The first line of the chorus says, “Hands and feet are all alike”. Many of the participants in this study reported feeling just like other kids their age, despite having diabetes. In this case, “hands and feet” are literally the outward appearances of their bodies, as well as the styles of clothing they wear, the music they listen to, the places they go, and the activities they participate in. Their “hands and feet” are like everyone else’s because diabetes does not interfere with those aspects of their lives. Diabetes is a silent disease, which does not show on the outside. That allows these adolescents to fit in and to be like their peers at least in terms of these outward appearances. One participant explained:

*I usually don't feel that different. I usually just feel like everyone else... I feel pretty normal like everyone else.*

And another adolescent said:

*I take control of my diabetes, but I do it like – if I have to take my shot I go to the bathroom and I'll keep it to myself. I feel normal, like I don't feel like I have anything wrong with me.*

Like members of a chorus whose voices blend to create the desired sound, being a “normal” adolescent and fitting in are what counts as important for these girls.

Adolescence is a time when bonding with peers is a priority and living with type 1 diabetes does not hinder this process. As much as they want to be part of the crowd, these young women are also required, by the nature of their disease, to be soloists. At

times they feel as diabetes makes them stand out from the crowd, even if no one notices or says anything.

**Solo – standing out and being watched.**

A solo part is played or sung by one person. A solo performer is on one's own. For this reason, the soloist must know their part and be comfortable with performing it. Most of the participants in this study described aspects of living with diabetes as having to do it on their own: it is their own thing.

*...It's just something different from other people that I have to do during the day...*

Just as a soloist has to learn an extra part, for the adolescent females in this study, living with diabetes means having to learn an extra role. Being the soloist can be lonely, frustrating, and scary. Living with diabetes involves an extra stress in life; an extra thing to do. And it seems as if no one else has to do it. There are times when it feels like they are all alone in the world and no one truly understands what they are going through.

*...sometimes I wish I could just like have somebody that has diabetes to talk to about it because they would actually know what I'm going through.*

Whereas on the outside their “hands and feet are all alike”, in actuality diabetes separates them from everyone else. Another line in the song, “Cry Freedom” (Grey, et al., 1996, track 10), says, “”But gold between divide us”. For these girls, the gold that divides them and makes them different from their peers is the fact that they have diabetes.

A soloist has the responsibility of performing part of the music alone and without any support. Soloists focus on getting the notes and rhythm right, knowing the words, and adding to the music as a whole. It requires a lot of work to prepare and perform a

solo, just as it takes a lot of work to manage diabetes. These young women have to monitor blood glucose levels, watch food intake, adjust insulin doses, and manage diabetes within their life as a whole. One participant, who wears an insulin pump, described her experience:

*...I have to do so many things for it and most of the population doesn't do those things...like an extra class...it's just an extra thing to do...so I don't die.*

Some of these girls shared how frustrating it is to have to stop in the middle of an activity and check their blood glucose level or eat a snack. One participant explained:

*...when I'm at a school dance or I'm out to the movies I always have to check the time and make sure like I have snacks with me.*

Even when they do not think about diabetes, it is still there and it never goes away. They know they still have the solo act:

*I don't even think about it but it's just like there and it affects me...*

Like performing a solo, living with type 1 diabetes means getting extra attention. These young women, however, do not necessarily want this attention. They are embarrassed by having people ask questions, watch them eat, take insulin, or prick their fingers. Some of these girls think it is annoying when other people mistakenly think they are using illicit drugs. They do not like when other people, especially friends and friends' parents, make a big deal of their diabetes. One adolescent explained:

*I don't like the attention for something that I have no control over. I didn't choose to get it, so it's not like something that I want attention for.*

Many of these girls discussed how they were forced, by diabetes, to be more independent and responsible at a younger age than their peers. The demands of diabetes management make this a fact of life for these adolescents. One participant explained:

*...it makes me feel like I have more responsibility than everyone else and it kind of makes me feel like more of an adult faster...*

And another said:

*I think it made me more responsible at least – like earlier. ...it just made me grow up, mature sooner so that I could deal with it and take care of it by myself...*

Living with diabetes means having more responsibility and, therefore, having to be more responsible. Living with diabetes means being responsible for their health and knowing the consequences of not taking on that responsibility. It means having to be responsible even when they may not necessarily want to be responsible. No one else will ever again take care of their diabetes solely for them. They will never know life without the burden of this role. They will always be a little “older” and a little “wiser” than their peers because of their experience with diabetes. Like the lines in the poem below portray, the girls in this study can never return to a life without responsibility.

**Who has known heights and depths shall not again**

**Know peace –**

**...He shall not speak the common tongue again (Whiteside, 1936, p.610).**

A soloist, who has been set apart by their solo performance, can return to singing with the chorus, however, that person will always be known as the soloist – someone who has gone above and beyond the ordinary music parts and someone who is different from the others. Adolescent females with type 1 diabetes can still participate in the adolescent

culture and fit in with the crowd, but they will always be set apart as someone different, even if only in their own minds.

In addition to having solo parts, adolescent females with type 1 diabetes have to make choices that others do not have to worry about. The decisions they make or options they choose can influence their part in the chorus, their solo performance, and their future.

### **Trills – weighing the options and choosing a tune.**

A trill is an alternation, or wavering, between two notes in a piece of music. In a trill, neither note is settled on until the trill is finished, at which point one note is chosen and the music continues. Like trills, the adolescent females in this study waver on choices regarding diabetes. They often go back and forth on which choice to make and, depending on the situation, the decision may vary. The way the subsequent music sounds depends on that choice. Some decisions lead to positive social outcomes and the potential for negative health outcomes. Although the tune sounds good at the time, often when the event is over, the tune changes. On the other hand, healthy decisions that may cause negative social outcomes can lead to an unpleasant tune as well. It is hard for adolescents to realize that the music that will be playing in their future is ultimately more important than what they are hearing right now.

The two biggest choices reported by the participants in this study are deciding whether or not to follow the diabetes management plan and deciding whether or not to tell other people about their diabetes. These adolescent females go back and forth on both issues. Living with diabetes means consciously choosing to take care of oneself, or not to take care of oneself.

*...I'd get myself strawberry milkshakes and that was a bad idea. ...and then I'd take my blood and it'd be like 420... ...it was just dumb... That really messed a lot of things up.*

Some participants reported that sometimes they take care of their diabetes, and other times they do not. Typically, it is not on the forefront of their thoughts, but choosing not to take care of diabetes can lead to serious health consequences. One participant explained how diabetes is not always her first priority:

*I tend to put it on the back burner – I take care of it and stuff, but it's not what I'm always thinking about.*

Another participant talked about how being an adolescent female and having type 1 diabetes means sometimes having to choose between doing the right thing with one's friends or with one's body. It can be very difficult to choose between something like eating ice cream with friends and skipping ice cream to keep the blood glucose level in range. Often the adolescents choose to do what friends are doing. Unfortunately, even when it feels good to go out with friends and eat what and when they are eating, there is a downside:

*...sometimes I don't think before I eat something sweet...and then I'm like, 'Oh no, my A1C's going to be awful'...I'm like, 'Oh, I shouldn't have done that...'*

One participant explained how choosing to take care of her diabetes can also backfire:

*Sometimes I can sort of be like, 'I think my blood sugar is low so why don't we eat now?' and they're usually like, 'oh, ok' – so lots of times they will, but I can tell it's not what they really want to do.*

Robert Frost's (1969) poem, "The Road Not Taken", describes how the choice a person makes can make a difference in the outcome. These girls have a choice to make regarding which path they will follow: the path of diabetes management and positive health outcomes, or the path of diabetes mismanagement and potential health problems. Their decision of which path to follow will make a difference immediately and has the potential to make a difference for their future as well. Most of these young women discussed being aware of the dangers of mismanaging their diabetes, but that sometimes they still choose that path.

*I know I shouldn't have the ice cream or a real Coke if I'm not low...*

*...sometimes I splurge and I end up being 450 and would be like, 'oh, why did I do that? I feel really awful.'*

The "trill" or going back and forth on whether or not to take care of their diabetes first or follow the crowd is a difficult choice for these adolescent females. Being an adolescent female with type 1 diabetes, for these young women, means choosing to live life as a teen-ager and somehow fitting diabetes into that lifestyle.

Whether or not to communicate with others about diabetes, how much to tell them and when, is another set of choices for the participants in this study. All of these girls understand the importance of informing others about their diabetes, although they do not all do so consistently. Whereas one participant does not tell anyone outside of her immediate family and health care team that she has diabetes, the others do not feel it necessarily needs to be a secret.

*I pretty much feel comfortable talking about diabetes with anybody...*

For the same participant who does not tell anyone about her diabetes, the thrill can end on a different note than for the ones who tell. The resulting music can have a different sound. For this participant, there is always the threat of danger, for instance, an emergency to which no one will know how to respond. This adolescent described a typical situation when she put off taking care of her diabetes in order to avoid telling her friends:

*...it has happened, ...I need to take my shot or something and I don't have the chance to and I just waited – I wouldn't tell them – I just waited. ...I've had times when my blood sugar was really high because of that...*

This adolescent can be lucky sometimes, but the risk is always there. It is the nature of adolescents to keep things to themselves in order to fit in and be like everyone else; however, doing so can be dangerous for these girls.

Unlike the one adolescent, for the remaining participants, telling others about diabetes means making people aware of their needs, and decreasing the chances of getting into trouble. People who are informed are also more likely to support adolescents in performing diabetes management tasks when necessary. Living with type 1 diabetes, for these girls, means having to decide *when* to tell people about diabetes. Sometimes it is not the first thing they disclose about themselves, for instance on a date or when meeting new friends. At other times, however, it is important to inform people such as school nurses, teachers, and coaches, so they would know what to do in an emergency. One participant talked about the frustration of feeling like she has to tell people even when she does not want to:

*...sometimes I don't want to tell them and I'm like, 'I have to.'*

Another adolescent had a suggestion for handling the constant barrage of questions about diabetes:

*It gets very annoying. It's just constant – everybody asks. You should just tattoo it on my forehead so they can just read it...*

Although it can be annoying at times, the majority of the study participants admitted that telling others about diabetes is important.

These girls waver on whether or not to tell people about diabetes, particularly when there is a chance they will pass judgment or discriminate against the adolescent. However, some of these adolescent females reported that people who are not informed about diabetes tend to have incorrect ideas about it. These people often liken diabetes to AIDS and/or think that these girls are using illicit drugs when they are taking insulin. Communicating with others about diabetes, therefore, is a way to teach people what type 1 diabetes is really about.

*I like talk to them because, I mean, a lot of people don't know what it is and kind of, I don't know, just like to get it out there more...*

Living with type 1 diabetes, for these girls, means weighing the options of the different choices they face. These adolescent females have to live with the consequences of those choices. Like the trills in a piece of music, these girls go back and forth on these choices and through the decisions they make, or the “notes” they end up on, they determine the “tune” their life plays. These choices or “trills” appear on a day to day and often moment to moment basis, and, therefore, have a large influence on both the music in these girls’ lives and the meaning that living with diabetes holds for them.

Given their desire to fit in, their struggle with being different, and the constant choices they face, it is not surprising that these adolescent females sometimes make unhealthy choices. These girls, however, live with the reality that certain choices may lead to dreadful health outcomes. Although they face options constantly each day, they do not have a choice about having diabetes. Not only are these young women connected to the disease, but to health care providers, parents, teachers, school nurses, coaches, and other adults as well.

### **Chords – being tethered to the system and to diabetes.**

A chord is a combination of tones or notes which are played or sung together and blend harmoniously. The tones in a chord are connected and cannot be loosened as long as that chord is played or sung. This connection forces the performers to work together. The sound of chords may be pleasant or not pleasant depending on the tones involved. Some chords add to the beauty of a piece of music, while others detract from it. By nature of living with type 1 diabetes, these females are tethered to other people. In other words, they are fastened to them and restrained in how far they can stray and for how long. Like the notes in a chord, the players in an adolescent's diabetes management "team" must work together. These people include parents, teachers, school nurses, coaches, and health care providers. Sometimes their efforts are positive, but other times they are negative.

*Sometimes they try to make suggestions, but usually – I don't know – it's not in the best way that they do it...*

All of the participants in this study discussed how, in various aspects of their lives, they are tethered to the “system”. For them, the system is parents who are over involved or hyper vigilant;

*...my mom, she's been really like rough on me about what I eat... She has totally cut out anything with sugar.*

teachers and coaches who look out for them in ways they do not for other students;

*They ask me if I need anything – they would tell me, 'there's stuff in my bag.'*  
*Some coaches actually go out and get stuff.*

school nurses who call their parents when their blood glucose is low or high;

*...the nurses at school are really overanxious. Like if I'm ever low...or if I'm like above two-something, they'll call home.*

and regulations that require them to check their blood glucose outside of the classroom.

*You're not allowed to test in class...how hard it is to eat our snacks and do our stuff in class...*

The “system” is also the health care providers they have to meet with every three months, and the tasks they have to perform for diabetes management. These various relationships or “chords” can be helpful, supportive, and positive or they can be frustrating and negative.

Most of these young women reported their frustration with having their parents ask them questions, nag them about what to eat and what not to eat, and remind them to check their blood glucose and take extra food. One adolescent gets particularly annoyed when her parents make a big deal out of her diabetes in public places like restaurants. Another reported feeling that her parents' demands are unreasonable:

*...sometimes they demand too much of you because it's like it's going to happen that you're going to have really low blood sugars or high ones...*

Teachers and coaches are usually accepting of these adolescents' diabetes needs, however, some of the girls have had bad experiences with teachers who questioned them about eating snacks or leaving class to check their blood glucose. Living with type 1 diabetes means dealing with the extra attention, whether that is concern or doubt, from authority figures such as teachers and coaches. Some girls have coaches who pack extra food for them and others are allowed to do their own thing.

Many of the participants talked about having increased interactions with school nurses including having to go to the school nurse's office to check blood glucose levels or to treat low blood glucose. One adolescent explained that it can be very upsetting when the school nurse does not involve the adolescent in diabetes decisions:

*...they'll want to talk to my parents – they won't talk to me about it or anything but they'll only talk to them and almost like, 'talk to me about it if you're having a problem with it because I know what my blood sugar was...'*

Although it is helpful to have the support and assistance of adults, these forced connections or “chords” for these young women sometimes get so frustrating that the solo part looks inviting.

All of the young women in this study discussed their visits to health care providers. Most participants reported that they see diabetes specialists, while two see pediatricians for their diabetes care. Several negative aspects of health care provider visits emerged. They find it frustrating to have to miss activities for appointments; it is degrading to have to carry urine samples to the health care provider's office; and it is

inconvenient to have to wait in the office for a health care provider to arrive, only to have them rush through the visit and leave.

*It's just gross. You have to carry your pee in a paper bag. It's kind of weird – twisted.*

Some participants have positive relationships with their diabetes providers. They talked about characteristics of health care providers that they find beneficial. Health care providers are helpful when they make suggestions about insulin doses or food choices. Most of the adolescent females appreciate when their health care providers relax and interact socially with them in the office. One participant discussed how she appreciates the approach her health care provider uses:

*She talks to me. I mean, she talks to all my family, but she makes the connection with me and asks me what's going on instead of my parents.*

While adolescents' teachers, coaches, school nurses, and parents play important roles that change with time, being tethered to the system and to the disease never goes away. They can never escape the demands of diabetes management.

Many of the participants mentioned having their HbA1C checked at routine diabetes visits. Some of them talked about how they worry that their number will be “high” or “bad” and that their health care providers will be upset with them. Thoughts about HbA1C often lead to worry and guilt for these young women. One participant admitted that she does not feel any different regardless of her HbA1C number. She defines it as good or bad according to feedback from health care providers:

*...my A1C is high and stuff so that's kind of bad...I feel like it's bad because the doctors say it's bad...*

Having to visit health care providers every three months, being subjected to invasive procedures such as blood draws and/or unappealing procedures such as urine collection, and having numbers evaluated and/or judged, means being tethered to a system that is filled with frustrations. These adolescents do not have the option to break free from this system. When health care providers interact positively with these adolescents, however, the connection is beneficial to them and they do not seem to mind it as much. Living with type 1 diabetes, for the participants in this study, means being bound to a system of adults who are more involved, more concerned, and more protective with them than with other adolescents. It means being connected to a health care system of providers, procedures, and treatments. It means not having a choice regarding these connections or “chords”. At a time when autonomy and identity are important goals, these adolescent females are tethered to several mandatory relationships.

Throughout the various parts of the music in these adolescent females’ lives notes that do not blend harmoniously result in “dissonance” or conflicts. The struggle between joining the chorus or performing the solo, being forced to make choices, and being tethered to the system and to the disease, along with other conflicts, affects the tune that plays out in these girls’ lives.

#### **Dissonance – struggling with conflicts.**

Dissonance is a discordant sound resulting from the combination of tones that do not seem to fit together. Dissonance is difficult and somewhat annoying to listen to or perform because of the sound it makes. Dissonance calls for a resolution, where at least one of the dissonant tones is transferred to a harmonious one, which results in a more acceptable sound. For the adolescent females in this study, living with type 1 diabetes

involves many conflicts, which resemble the dissonant sounds in music. These conflicts are difficult and annoying to handle. Unfortunately, there is often no clear resolution for the conflicts with which these girls live.

The choice of whether or not to take care of their diabetes is a “trill” for these adolescents. If a trill is played fast enough that the two notes blend, dissonance results. This choice, therefore, is also a conflict for these girls: the struggle of knowing that diabetes management needs to be a priority, yet not wanting to and/or not making it a priority. A couple of participants mentioned that when they do not *do* diabetes they feel as if they do not *have* diabetes. They both realize, however, the potential consequences of this behavior.

*...if I didn't do the blood tests and the shots I'd be like, 'hey, I don't have diabetes.' But that just kind of got shot down within a couple days I was in the hospital just lying there.*

All of the adolescent females in this study reported that living with diabetes means struggling with conflicts. Although all of the participants said that diabetes is no big deal, they also identified many aspects of diabetes that are hard to live with on a daily basis. It means carrying bulky supplies and equipment around at all times and having to be prepared for any situation. Supplies are expensive. The combination of diabetes as no big deal and diabetes as a hassle creates a dissonant sound or conflict. The conflict is the intersection of the chorus and solo parts, because the two cannot be performed simultaneously by the same person.

Despite their attempts to fit in, diabetes gets in the way of a normal adolescent lifestyle, especially when these girls have to stop what they are doing and attend to

diabetes management, or when their blood glucose level is low. Low blood glucose is especially frustrating because it can affect their mood, their performance in school, work, or sports, or can interrupt an activity. High blood glucose can also cause mood swings, headaches, fatigue, and nausea. These can, in turn, have an impact on relationships, school, work, and sports activities, and level of motivation.

*...when I was high I felt really tired and I just didn't feel like doing anything...*

It's a pain to have to think about food all the time: what is being served and when, how much is ok to eat and how it will affect the blood glucose level, how much insulin to take, etc.

In Robert Frost's (1969) poem, "The Investment", he describes an old house on a farm. Like buying a house, effectively managing diabetes is an investment in one's future. These girls have to invest their time and effort in managing diabetes in order to reap the benefits of good health later in life. Despite being bogged down in the work of farming, the husband and wife who own the house have painted it and often play the piano loudly inside:

Not to sink under being man and wife,

But get some color and music out of life (p.263-264).

These last two lines of the poem parallel the experience reported by all of the study participants. These girls balance the frustrations, hassles, and inconveniences of diabetes by making it no big deal. In order not to "sink" under the strain of it, they take diabetes in stride; they do what they have to do and get on with life as adolescent females. The "dissonance" of diabetes, including finger sticks, injections, responsibility, high and low blood glucose levels, and health care provider appointments, finds its resolution in a

certain degree of acceptance and adjustment. When the music continues, therefore, it is more pleasant and enjoyable. Diabetes management, for many of these girls, is such a routine part of their lives, that they almost do not notice it at times, as one girl described:

*“...like brushing your teeth – it’s like an everyday thing.”*

The threat of complications is very real and frightening for the girls in this study. Some of them are motivated to take better care of themselves when they think or hear about complications, however, most of them would rather not think about complications and do not think about them most of the time.

*I don’t handle my diabetes thinking about the complications down the road.*

Many of these girls acknowledged that being an adolescent often comes before managing diabetes. One participant explained that with all the things she has to do, diabetes does not always receive the most attention:

*I always pay attention to it, but – I don’t know – maybe it just needs to be a little bit extra sometimes. It’s hard to do that when you only have so much time and so much energy to do so much.*

Whether or not they think about complications or make diabetes a priority, however, these young women are still tethered to this disease.

The thought of the future, for these girls, is a conflict because it holds the possibility of both good and bad things. The uncertainty of these young women’s future is a dissonant sound. Some of the participants talked about the future in terms of going on an insulin pump and advances in technology that will make it easier to manage diabetes. Others talked about their fear of developing complications. One participant explained her thoughts on pregnancy:

*If you're going to have a kid you have to plan everything out before you even start trying because you know, you have to make sure your blood sugars are perfect like absolutely perfect and I'm like, 'that's not me.'*

Many of the study participants discussed the challenge they have with their parents. They get very frustrated with their parents for nagging and being over involved with their diabetes management, yet they know they need their parents' input, support, and suggestions and that their parents are only involved because they care. Having parents involved with diabetes management decisions and tasks means these adolescents cannot be as independent as they want to be. It often feels for some of these adolescents, that sometimes their parents give them trust, independence, and responsibility and other times they take it away. One participant gets angry and spiteful at times:

*...my mom's like, 'You shouldn't have done that,' or 'Watch what you're eating' ...It makes me want to go like eat more in front of her face.'*

At the same time, however, all of these girls appreciate when their parents make suggestions and that they care enough to be concerned.

Some participants discussed the conflict of whether to let friends into their world of diabetes. Friends are an invaluable part of the adolescent experience, and all of the study participants talked about how much they appreciate when their friends are caring and supportive about their diabetes. They feel comforted knowing that friends are interested in learning about diabetes. Friends show their interest and concern by asking questions and offering to help. On the other hand, some participants reported times when it seems that friends forget about their diabetes, because they do insensitive things like

offering candy or not eating at the appropriate times. One adolescent told about her friends' response to her diabetes:

*I know they care but they don't feel like listening to it, like they don't really want to hear about it...*

Some of these girls get irritated when friends think they know enough about diabetes to explain it to other people, or when friends question them about food they are eating.

These conflicts create dissonance for the adolescent females in this study.

Struggling with conflicts, although frustrating, becomes a way of life for them and they somehow find a way to deal with it because they have to. The ways these girls manage diabetes within their lives or manage their lives despite having diabetes is the resolution which allows their life's music to continue.

### **Summary**

The experience of living with type 1 diabetes, for the adolescent females who participated in this study, is like a piece of music. The tune plays throughout their lives, constantly changing and evolving as they engage in activities, juggle responsibilities, make decisions, handle relationships, and struggle with conflicts. The music of these adolescents' experience is made up of chorus parts, solo parts, trills, chords, and dissonance. These different parts come and go throughout their experiences and sometimes overlap. The adolescent females, themselves, are the composers of their own musical composition and they must conduct the piece as it is played in their lives. It is only each adolescent female who can ultimately take responsibility for the tune that will play in her future, and the sound that is made now will have a great influence on that

**future tune. This chapter presented the findings of the study. Themes revealed in the study data, were discussed within the context of a piece of music.**

## **CHAPTER V**

### **Discussion of Findings and Implications for Nursing**

**This chapter presents a discussion of the findings of the study. What is currently known about adolescents and type 1 diabetes is discussed within the context of what was found in this study. The researcher's reflections on the project of inquiry are included. Implications for nursing practice, education, and research are presented. Limitations of the study are explained.**

#### **Discussion of Findings**

**The findings of this phenomenological study contribute to the body of knowledge for diabetes in general and provide a more comprehensive understanding of what it is like for adolescent females to live with type 1 diabetes on a daily basis. Research has indicated that adolescents with type 1 diabetes need to intensively manage their disease in order to reduce the risk of long-term complications (DCCT Research Group, 1994; 1995). This study revealed, however, that being part of the adolescent culture can hinder diabetes management for this group of adolescent females. Diabetes management often takes a back seat to adolescent activities.**

**Research has indicated that adolescents are generally more likely to engage in health risk behaviors (Ellis & Torabi, 1994). Supportive to this notion was the finding that the adolescents in this study do not always make diabetes management a priority, which is a health risk for these girls. Although the study participants did not discuss specific health risk behaviors, adolescent females with type 1 diabetes may take risks such as using drugs and alcohol, having unprotected sex, or not wearing a seat belt.**

**These behaviors have potential implications for health in general, but also could directly and negatively affect diabetes for these young women.**

**Claims that quality of life is maintained despite the demands and challenges of intensive diabetes management (Boland et al., 1999; DCCT Research Group, 1996a; Grey et al., 1998b) should be questioned in light of this study's finding that most participants mentioned several hassles, inconveniences, and frustrations with living with type 1 diabetes. These characteristics of the participants' experience living with diabetes, therefore, could very well affect these girls' quality of life.**

**This study supported and elaborated on the previous finding that adolescents with type 1 diabetes can be fearful of, uncomfortable with, and embarrassed by hypoglycemia (Davidson et al., 1997). This study also revealed that these adolescent females find it frustrating when low blood glucose levels cause mood swings. One participant explained how people tend to connect her mood to her blood glucose level:**

*...if I'm acting weird, then they'll automatically assume – they'll start asking me like, 'E, is your – are you low? Are you high?' and that really, really annoys me because I won't be and I'll just be like, 'No! I'm just in a silly mood – I'm having fun, just don't – why can't you accept this is me and not because I'm low or something?'*

**Several authors have discussed the influence of patient-provider relationships on diabetes management adherence and resulting metabolic control (Brink & Moltz, 1997; Burroughs et al., 1993; Glasgow et al., 1999). Existing studies have indicated that providers who interact positively and allow patients to participate in decision-making are beneficial to adolescents with type 1 diabetes (Paiardy et al., 1998; Anderson et al.,**

1995). This study revealed that this group of adolescent females prefers health care providers who are calm and relaxed. Some of them reported that they like when health care providers notice trends in blood glucose levels and make suggestions for management changes when necessary. Most of the participants appreciate having health care providers who spend time with them, talk to them, and connect with them.

Whereas research has indicated that adolescents benefit from parental involvement in diabetes management (Anderson et al., 1997; Anderson et al., 1999; Grey et al., 1998b; Hanson et al., 1995), this study revealed that parental involvement is a conflict for these young women. All of the study participants reported that one or both of their parents are involved in their diabetes management on some level. Many of these girls discussed their frustrations with parents' nagging, taking away trust, or being over involved in diabetes management. Many, however, admitted knowing their parents' involvement is motivated by concern and care. A few participants suggested their parents know too much about diabetes management. Only one talked about how she appreciates when her parents look at her blood glucose levels and make suggestions. The participants whose parents are least involved, however, discussed their struggles with achieving and maintaining metabolic control.

Meldman's (1987) qualitative study, which described adolescents' experience with type 1 diabetes, was conducted using procedures similar to the current study. Meldman's finding that adolescents are ambivalent toward self-management was supported by this study. All of the participants in this study mentioned at least one, if not many, aspects of the diabetes management plan that they do not follow. Whereas Meldman named her study participants' response "ambivalence", the response of the

young women in this study was called a “conflict”. Meldman also reported conflicts that adolescents experience. Overprotection and dependence, two conflicts reported by Meldman, were also prevalent in this study. This study revealed several additional conflicts for the adolescent female participants, including parental involvement, letting friends in, and adjusting to living with diabetes.

Kyngas and Barlow (1995) found that adolescents respond negatively to living with type 1 diabetes. Most participants in this study discussed ways that diabetes can be a hassle, however, the overall depiction of diabetes was not a negative one, as Kyngas and Barlow’s study revealed. All of these young women, instead, found ways to handle diabetes so that they could describe it as “no big deal”.

Unlike the other qualitative studies conducted with adolescents with type 1 diabetes, which focused on specific aspects of their experience (Kyngas & Hentinen, 1995; Standiford et al., 1997; Wdowik et al., 1997), this study explored adolescent females’ whole experience of living with type 1 diabetes. Kyngas and Hentinen (1995) identified categories of compliance and how compliance fits into the adolescents’ lifestyle. This study, on the other hand, revealed conflicts for the adolescent female participants, which can influence their degree of adherence to the diabetes management plan. Standiford et al. (1997) and Wdowik et al. (1997) identified characteristics of adolescents’ experience living with type 1 diabetes. This study described similar findings, for example, fear of long-term complications and inconveniences of diabetes management. This study also revealed a deeper understanding of the meaning these experiences hold for the adolescent females with type 1 diabetes.

Although there is much agreement between the findings of this study and previous research, some of the current findings raise questions about prior research. One of the most important findings of this study is that these young women feel that living with diabetes is no big deal and they want others, including parents, friends, teachers, and school nurses, to treat it that way as well. They feel that diabetes is their own thing, and although they appreciate suggestions, they want to be in charge of managing it. These girls are aware of the risk of complications and they know what they need to do to manage their disease, but sometimes they just want to be adolescent females. These findings indicate that approaches to diabetes care and education need to be tailored to this age and gender group. The answers are not as easy as simple recommendations such as “get the parents more involved”.

#### *Reflections on the Project of Inquiry*

The study findings revealed both similarities and differences with the researcher’s initial assumptions regarding the phenomenon of interest. Consistent with the assumption that adolescent females with diabetes have common experiences, several aspects of these adolescent females’ experience of living with type 1 diabetes were similar. For example, most participants reported that their mothers are more involved with diabetes than their fathers.

The researcher expected adolescent females with diabetes to have unique experiences, however, more participants shared common experiences. A few participants reported experiences related to diabetes that were unique, for instance, one participant does not tell anyone other than close family members that she has diabetes. Prior to the study, the researcher believed that diabetes is difficult and frustrating for adolescent

females. Although participants described diabetes as a pain, a hassle, inconvenient, and an extra stress, contrary to this assumption, they all reported that diabetes is not a big deal. Most of them described diabetes as part of their daily routine, thus, something they have gotten used to.

The findings of the study supported the researcher's assumption that living with diabetes makes adolescent females more responsible and independent. All participants reported being more independent and having more responsibility than their peers, because of diabetes. These characteristics of the diabetes experience, however, were sometimes positive and sometimes negative. The researcher assumed that adolescent females with diabetes would share openly their experiences of living with diabetes. It is impossible to know whether or not these young women shared everything about their experience. Although all 10 participants seemed to speak openly, some shared more information than others. The researcher was surprised that participants did not talk more about specific ways their actions and interactions affect their diabetes management.

The study findings changed the researcher's perspective that current approaches to caring for and teaching adolescent females with diabetes are not effective. As the researcher expected, some of the study participants discussed their frustrations with health care providers' interactions. They reported health care providers' rushing through visits and not providing assistance or information. On the other hand, several participants felt that their health care providers are very helpful and supportive when they notice patterns in blood glucose levels and make suggestions for management changes.

Some participants confirmed the researcher's bias that adolescent females need an opportunity to talk about what matters to them, i.e., what it means to live with diabetes.

**These girls mentioned that they would like to have someone they could really talk to about diabetes. Knowing other adolescent females with diabetes helps because they understand what it is all about.**

**The study data clearly supported the researcher's belief that knowledge base, level of motivation, and commitment to take care of themselves vary for adolescent females with diabetes. These adolescent females reported varying degrees of knowledge about diabetes, and motivation and commitment to managing their disease. These girls also reported that levels of knowledge, motivation, and commitment have changed during their adolescent experience. For example, learning about complications has improved self-care for some participants.**

**The study findings reframed the researcher's view that adolescent females, despite similar experiences in living with diabetes, have unique needs in terms of approaches to teaching about diabetes. The study participants who discussed health care provider interactions consistently reported wanting health care providers to furnish information and support in a relaxed and sociable atmosphere.**

#### ***Limitations of the Study***

**Findings of the study represent the perspectives of the 10 participants and cannot be generalized to all adolescent females with type 1 diabetes. A limitation of the study is the fact that all 10 adolescent females who participated in this study are white. As a result, adolescent females from various ethnic backgrounds in the United States, were not represented. Because not every adolescent female with type 1 diabetes has the opportunity to attend diabetes camp, the fact that participants were recruited at a diabetes camp is a limiting factor as well. Diabetes camp is expensive and may not be affordable**

to a general population of adolescent females. As a result, adolescent females who do not attend diabetes camp for financial or other reasons were not represented in this study. It is also impossible to know if participants' experience of living with type 1 diabetes was influenced by their camp experience.

An additional limitation of the study was the brevity of interviews. Adolescents can be a difficult age group to interview because they may not speak as openly as adults. For this reason, the researcher suggests making the adolescent participants as comfortable as possible with the interview setting and assuring them that there are no negative consequences of anything they may say.

### **Implications for Nursing**

This study, which provided a greater understanding and discovery of the meaning of living with type 1 diabetes for adolescent females, has many and various implications for nursing. Nurses and other health care providers can use this understanding to improve their interactions with adolescent females who have type 1 diabetes. An understanding of what the experience of living with type 1 diabetes is like and what it means, for adolescent females, may help health care providers to dispel prior assumptions about this phenomenon. Such an understanding may enhance health care providers' ability to listen to these young women and use what the adolescents say to improve their practice.

### ***Nursing Practice***

The findings of this study have implications for nursing practice. The adolescent female participants identified characteristics of health care providers that they find positive and negative. Nurses play an important role in the experience of living with type

**1 diabetes for adolescent females, therefore, an understanding of the adolescent female's perspective has potential to enhance the way nurses care for this population. Adolescent females interact with nurses in school, at health care facilities, at camp, and sometimes at home. Nurses have an opportunity to support, advise, and educate these young women. The findings of this study indicate that these girls find it helpful when health care providers assist them with their diabetes management, however, it is important that this is done in a friendly and relaxed manner. Nurses need to approach adolescent females with type 1 diabetes in an open, caring way and they need to be very knowledgeable about all aspects of diabetes management. Nurses should ask adolescent females about their experience – their successes and their frustrations – in order to gain a better understanding of how to tailor diabetes education to their individual needs.**

**Nurses need to connect with the adolescent females by directing questions and information to them. At the same time, however, nurses play a vital role in making sure parents are involved in diabetes management. Parents must receive the same information and instructions as the adolescent, although it may help to do so in separate rooms, so adolescents feel comfortable being completely open and honest. Nurses need to help adolescents and parents understand the importance of maintaining parental involvement in diabetes management. This requires an assessment of the level of parental involvement necessary for different families, as it can vary. Families in which parental involvement causes friction, rebellion, or decreased self-care on the part of the adolescent, may require additional nursing intervention and/or a different type or level of parental involvement. The findings of this study revealed that parental involvement is a conflict for these girls, therefore, it is an area for nurses to address carefully.**

Nurses can help adolescent females with type 1 diabetes by offering to inform school nurses, teachers, and coaches about diabetes in general and their specific needs. Nurses should be sensitive to each adolescent's desire to make this information public, while advising them about the advantages of communicating with school faculty. Nurses are also in a position to teach adolescent females ways they can take better care of themselves. These girls need to be educated on safety issues including seat belts, drug and alcohol use, and safe sex, and how lack of attention to these issues can affect their health, diabetes, and future.

Diabetes education is another important aspect of nursing care of adolescent females with type 1 diabetes. Some of the study participants talked about how little they gain from hearing the same information repeated over and over again at health care visits. Again, nurses need to assess the individual experience of the adolescent female, find out what she needs to know, and how she best learns. Asking about the whole picture is likely to elicit a more helpful response than merely asking what an adolescent wants or needs to know. For example, "What kinds of things do you have trouble explaining to other people about diabetes?" instead of, "What don't you know about diabetes?" Nurses can help adolescents see trends in their blood glucose levels and show them how to make adjustments to correct any problems. Nurses can use these teaching/learning opportunities to encourage adolescent females to check and document their blood glucose levels more regularly.

Some study participants talked about their fear of complications and others said they do not want to hear about complications. Most reported that they do not think about complications very often. Nurses can help adolescent females with type 1 diabetes by

teaching them how to best care for themselves in order to avoid complications. By focusing on positive aspects of diabetes management and not negative consequences of complications, nurses can provide adolescent females with the knowledge and tools to promote healthy outcomes. Nurses can also share the findings of this study with their patients, in order to help the adolescent females get in touch with their own experience and perhaps realize that they are not alone. Nurses can initiate contact between adolescent females who indicate they would like to talk to someone who has type 1 diabetes.

### *Nursing Education*

The findings of this study have implications for nursing education. Nurses provide education on many different levels. Nursing faculty can impart the findings of this study to their students, and nurse clinicians can share this information with other nurses through inservices, grand rounds, or other presentations. It is important to teach and encourage the use of good listening and assessment skills in the care of adolescent females with diabetes. Adolescent females with type 1 diabetes require both physical and psychosocial assessment. Clinical and classroom instructors can integrate the study findings into their teaching curriculum. For example, students will benefit from knowing that this group of adolescent females preferred a calm, relaxed, and interactive approach from health care providers.

Nursing interventions, such as listening to individuals' perspectives, should also be disseminated through nursing education. Educators can teach nurses to involve parents in the care of adolescent females with type 1 diabetes. Nurses should be taught to

**find ways to determine what level and type of parental involvement works best for individual patients.**

**These findings should also be shared with school nurses, teachers, and coaches; health care providers; and community groups. Information can be presented at local or national conferences for organizations including the American Diabetes Association, the American Association of Diabetes Educators, the American Dietetics Association, the Association of School Nurses, and the Association of Camp Nurses. Professionals and lay people can receive this information through live presentations or written publications. However it is delivered, though, education is the only way the study findings will get incorporated into practice.**

### ***Nursing Research***

**The findings of this study have implications for future nursing research. This study has indicated that by using interpretive methods to explore the phenomenon of living with type 1 diabetes for adolescent females, a better understanding of the meaning can be unveiled. Van Manen's (1990) phenomenological framework was particularly fruitful in guiding the project of inquiry. As a result, the findings of this study can be used as a foundation for building future nursing research.**

**Van Manen's (1990) framework can be used in several follow-up studies. In order to gain a greater understanding of the meaning of living with type 1 diabetes for adolescent males, and in order to examine differences between males and females, the same study should be conducted with a group of adolescent males in a diabetes camp setting. In addition, groups of adolescent females and males could be studied (separately)**

in different settings, such as out patient health care facilities, private offices, schools, and support groups.

Others have recommended intervening with younger adolescents in order to prevent future problems (Anderson, 1994; Wysocki et al., 1992). A follow-up study, using van Manen's (1990) approach should be conducted with early adolescents from various settings. A better understanding of what it means to live with type 1 diabetes as an early adolescent may have different implications for nursing practice, education, and research. In addition, using the same methods to study late adolescents with type 1 diabetes may shed light on nursing practices that could begin in early adolescence to prevent problems that occur later on. Follow-up studies, using van Manen's framework, should include samples of participants from inner cities and various socioeconomic and cultural backgrounds.

Alternative research methods including ethnography, grounded theory, and action research, can also be employed to study samples of adolescents with type 1 diabetes. The close observation involved in ethnography may reveal aspects of the adolescent diabetes experience that would not surface during an interview. Although the intent of this research was not to build theory, it furthers the base of nursing knowledge and can be helpful to those who will create theory. These findings can be a stepping off point for middle range theory, in particular. Follow-up studies using grounded theory methods may assist in the development of such nursing theory.

Action research could illuminate nursing practice innovations through the input of the adolescents, themselves. The participants in action research are seen as "partners and stakeholders in studies that are responsive to their interests and concerns" (Powers &

Knapp, 1995, p.1). As a result, these participants are likely to suggest effective nursing interventions for their age or gender group. Future phenomenological studies could also employ focus groups as a way to encourage adolescents to be share their experiences. The use of action research or focus groups is likely to make adolescents feel more comfortable with sharing their experiences and/or suggestions openly, because they participate in groups with their peers.

Quantitative studies will need to be conducted in order to measure the effect of new nursing interventions which may arise from these study findings. A group of diabetes experts who met to discuss diabetes research, have recommended that studies emphasize behavioral strategies, using outcomes such as self-efficacy, depression, anxiety, well-being, and psychosocial functioning to measure outcomes (Fain, Nettles, Funnell, & Charron-Prochownik, 1999). An example, therefore, of a potential quantitative study, is one that examines the effect of a nursing intervention (for instance, assertiveness training) on self-efficacy and HbA1C. Such a study would examine whether the intervention improved participants' level of self-efficacy, metabolic control, neither, or both. Finally, additional qualitative studies could explore the experience of adolescent females who have received new nursing interventions.

The experience of living with type 1 diabetes from adolescents' perspective has been understudied in the United States since the conclusion of the DCCT. Additional studies are needed in order to provide the most appropriate and effective care to these young people. Findings from such studies have the potential to facilitate positive health outcomes for this group as well.

## **Summary**

**This chapter discussed the findings of the study in the context of what was previously known about adolescents and diabetes. Reflections on the project of inquiry were presented and implications for nursing practice, education, and research were explicated. Limitations of the study were also included.**

**Van Manen's (1990) framework was used in this phenomenological study. Ten adolescent females were interviewed in order to explore individual perspectives of living with type 1 diabetes. This study provided a rich understanding of what it means for these adolescent females to live with type 1 diabetes and what this experience is like. The findings revealed that while these adolescent females want to be part of the adolescent culture, they often feel alone. They waver on whether or not to take care of themselves and they deal with a life-long tethering to the health care system and the disease. They struggle with many conflicts, including whether or not to make diabetes management a priority and whether or not to tell others about it. As these themes play out in their lives, the adolescent females' experience unfolds like a piece of music. In conclusion, living with diabetes is not as simple and straight forward as sometimes implied and perhaps preferred by professionals. As such, health care providers need to consider the whole person and the meaning diabetes has for them. To do anything less, is to treat the individual as an object, which defies the essence of professional nursing practice.**

**The words in the song, "Cry Freedom" (Grey, et al., 1996, track 10), continue, "the future is no place to place your better days". These young women cannot afford to wait: they must act *now* to manage their disease in ways that will assure them healthy and**

**positive futures. Health care providers, therefore, must adopt approaches to caring for these adolescents that will assist them in achieving this critical goal.**

## Appendix A

### Letter of Approval from Sponsoring Organization



Programs:  
Clara Barton Camp  
Barton Adventure Camp  
Barton Family Weekends  
Barton Wacky Weekends  
Barton Conference Center  
Clara Barton Birthplace

February 1, 1999

To Whom it May Concern:

President  
Philip Good  
Vice President  
H.C. "Lari" Goodwin  
Treasurer  
Norman J. Richardson  
Clark  
Richard Houlahan

Trustees  
Robert D. Babcock, Jr.  
Janet H. Bowering  
Michael D. Brockelman  
Martha Clark  
Robert J. Fesko  
Mark Fuller  
Donald L. Hall  
Mary D. Kikoyne  
David P. Kowal  
Carol B. Lawrence  
Gordon Miller  
David Silverman  
Tricia Hughes-Skulsky  
Eloise Wellington

Trustee Emeritus  
Beatrice B. Carpenter  
Executive Director  
Shelley D. Yeager

Jane K. Dickinson is hereby granted permission to conduct her doctoral research study, *The Lived Experience of Adolescent Females with Insulin-Dependent Diabetes Mellitus: A Phenomenological Approach*, at the Clara Barton Camp. Clara Barton Camp, a program of The Barton Center for Diabetes Education, is an eight-week resident summer camp for girls with diabetes.

The research committee has read Jane's proposal and agrees with the importance of this study. It is understood that Jane will conduct interviews with the sixteen-year-old Counselors-In-Training (CITs), upon obtaining written consent of parents and participants. The interviews will take place on camp property, during the summer camp season, and will not interfere in any way with the camp program.

Sincerely,

[Redacted Signature]  
Shelley D. Yeager, MA, LCSW  
Executive Director

[Redacted Signature]  
Gaylen McCann, OTR/L  
Camp Administrator

**The Barton Center for  
Diabetes Education, Inc.  
is a nonprofit organization  
dedicated to the education  
and support of young  
people with diabetes  
and their families.**

[Redacted]

[Redacted]

## Appendix B

### Notice of Approval from University of Connecticut Committee on the Use of Human Subjects in Research

*The Experience of Adolescent Females with Type 1 Diabetes*

Jane K. Dickinson, RN, MSN, CDE  
Principal Investigator

#### INFORMED CONSENT

The purpose of this study is to gain an understanding of what it is like for adolescent females to live with diabetes. By sharing this understanding with diabetes professionals and other health care providers, more effective approaches to diabetes education may be achieved in the future.

The study will take place at the Clara Barton Camp (CBC) during the month my daughter is a Counselor-In-Training (CIT).

For this study, Jane K. Dickinson will interview my daughter. Jane will ask my daughter what it is like for her to live with diabetes.

My daughter can refuse to answer any questions in the interview. I understand that my daughter or I can withdraw permission for participation at any point during the study. This decision will not affect my daughter's CIT status.

~~I have been informed that my daughter's remarks will be confidential and will not affect her CIT status.~~

I understand that overall results of the study will be shared with my daughter and me, published in a national health care journal, and presented at a national health care conference. My daughter will not be identified by name.

I understand that if I have questions about the study I can contact Jane K. Dickinson by phone [redacted] or email [redacted] at any time.

By signing below, I give permission for \_\_\_\_\_ to participate in the study, *The Experience of Adolescent Females with Type 1 Diabetes*.

\_\_\_\_\_  
Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date



**Appendix C**  
**Letter of Support**



*Programs:*

**Clara Barton Camp**  
**Barton Adventure Camp**  
**Barton Family Weekends**  
**Barton Wacky Weekends**  
**Barton Conference Center**  
**Clara Barton Birthplace**

February 1, 1999

To Whom it May Concern:

*President*  
Philip Good  
*Vice President*  
H.C. "Lan" Goodwin  
*Treasurer*  
Norman J. Richardson  
*Clerk*  
Richard Houlahan  
*Trustees*  
Robert D. Babcock, Jr.  
Janet H. Bowering  
Michael D. Brockelman  
Martha Clark  
Robert J. Fesko  
Mark Fuller  
Donald L. Hall  
Mary D. Kilcoyne  
David P. Kowal  
Carol B. Lawrence  
Gordon Miller  
David Silverman  
Tricia Hughes-Skulsky  
Elise Wellington  
*Trustee Emeritus*  
Beatrice B. Carpenter  
*Executive Director*  
Shelley D. Yeager

I am writing in support of Jane K. Dickinson's doctoral research study entitled, *The Lived Experience of Adolescent Females with Insulin-Dependent Diabetes Mellitus: A Phenomenological Approach*.

Adolescent females with IDDM represent a population with more challenges than most age groups. The mysteries of why so many of these girls struggle with diabetes management have remained unsolved for years. It seems as if most studies to date have concentrated on younger children, adults, or have only looked at specific factors which researchers determine have an effect on individuals with diabetes. Jane's study, using interviews, will address this problem by getting the adolescent females' perspective. This study has potential to uncover answers to the questions diabetes professionals have pondered for years.

I am very excited to hear Jane's results, and wholeheartedly endorse her study.

Sincerely,

  
Shelley D. Yeager, MA, LCSW  
Executive Director  
The Barton Center for Diabetes Education

***The Barton Center for  
Diabetes Education, Inc.  
is a nonprofit organization  
dedicated to the education  
and support of young  
people with diabetes  
and their families.***





## Appendix D

### Letter of Support



*Programs:*

Clara Barton Camp  
Barton Adventure Camp  
Barton Family Weekends  
Barton Wacky Weekends  
Barton Conference Center  
Clara Barton Birthplace

February 6, 1999

To Whom it May Concern:

*President*  
Philip Good  
*Vice President*  
H.C. "Lan" Goshorn  
*Treasurer*  
Norman F. Richardson  
*Clerk*  
Richard Hubbard

*Trustees*  
Robert D. Babcock, Jr.  
Janet H. Bowering  
Michael D. Brockelman  
Martha Clark  
Robert J. Fesko  
Mark Fuller  
Donald L. Hall  
Mary D. Killoyne  
David P. Kowal  
Carol B. Lawrence  
Gordon Miller  
David Silverman  
Trent Hughes-Skubsky  
Elouse Wellington

*Trustee Emeritus*  
Beatrice B. Carpenter  
*Executive Director*  
Shelley D. Yenger

Jane K. Dickinson's doctoral research study is long overdue! As a Pediatric Endocrinologist and the Medical Director for The Barton Center, I have been working with adolescent females with Insulin-Dependent Diabetes Mellitus for several years. Although it's easy to see trends in diabetes management issues, reasons for them can not always be pinpointed.

Unfortunately, in this age of managed care, doctors do not have time to interview patients as Jane plans to do in her study. It will be very interesting to hear what Jane finds through studying this group. I strongly support her in this work and wish her every success.



Craig A. Alter, MD  
Pediatric Endocrinologist  
University of Massachusetts Medical Center  
Medical Director  
The Barton Center for Diabetes Education

***The Barton Center for  
Diabetes Education, Inc.  
is a nonprofit organization  
dedicated to the education  
and support of young  
people with diabetes  
and their families.***



**Appendix E**  
**Letter to Parents**

*Jane K. Dickinson, RN, MSN, CDE*

[REDACTED]

[REDACTED]

June 10, 1999

Dear Parent(s) of 1999 Counselors-In-Training:

Your daughter has reached a CBC milestone – CIT! I have no doubt that she will have a wonderful month at camp, learn lots, and make a difference in the lives of many younger campers. She also has an opportunity to impact other teen-agers with type I diabetes.

As part of my PhD in Nursing program at the University of Connecticut, I will be conducting my dissertation research at CBC this summer. I am planning to study what it's like for adolescent girls to live with type I diabetes by asking them. By giving them a chance to talk about their own experience of living with diabetes, I hope to provide insight for health care providers and other diabetes professionals. Ultimately, I would like to see effective teaching approaches come out of understanding the individual perspectives of those living with diabetes.

I will be available on Opening Sunday to answer any questions you may have about the study. Should your daughter decide to participate, her responses will be confidential and will in no way affect her CIT status. Declining to participate will also not affect her CIT status in any way. If you would like to contact me before that time, I can be reached by phone at [REDACTED] or e-mail, [REDACTED].

I look forward to seeing you this summer!

Sincerely,

[REDACTED]

Jane K. Dickinson, RN, MSN, CDE

**Appendix F**  
**Recruitment Letter**

*Jane K. Dickinson, RN, MSN, CDE*

[REDACTED]

[REDACTED]

June 10, 1999

Dear 1999 Counselor-In-Training:

Hello! I hope you are getting excited for this summer at CBC, because it's going to be new and different, more work, more fun, and more fulfilling than any summer you've experienced yet! As a CIT, you have the chance to make a difference in the lives of younger campers. This year, you will also have an exciting new opportunity.

I am working on my PhD at the University of Connecticut, and will be doing research for my dissertation this summer. I am planning to study what it's like for adolescent females to live with diabetes. It's your turn to talk! I will be interviewing the CITs to find out your experience living with diabetes. There are absolutely no right or wrong answers and the information gathered is confidential. Whatever you say will not affect any part of your camp program.

Your participation in this study is completely voluntary and you have the right to refuse to participate at any time. If you choose not to participate, your decision will in no way affect your status as a CIT. If you choose to participate in the study, you will make a difference in the lives of other teen-agers who live with diabetes. You will also help health care professionals understand your experience.

I will be available on Opening Sunday to answer any questions you may have about the study. If you would like to contact me before that time, I can be reached by phone at [REDACTED] or email [REDACTED]

I look forward to seeing you this summer!

[REDACTED]

*Jane K. Dickinson, RN, MSN, CDE*

**Appendix G**  
**Informed Consent**

*The Experience of Adolescent Females with Type 1 Diabetes*

Jane K. Dickinson, RN, MSN, CDE  
Principal Investigator

INFORMED CONSENT

The purpose of this study is to gain an understanding of what it is like for adolescent females to live with diabetes. By sharing this understanding with diabetes professionals and other health care providers, more effective approaches to diabetes education may be achieved in the future.

The study will take place at the Clara Barton Camp (CBC) during the month my daughter is a Counselor-In-Training (CIT).

For this study, Jane K. Dickinson will interview my daughter. Jane will ask my daughter what it is like for her to live with diabetes.

My daughter can refuse to answer any questions in the interview. I understand that my daughter or I can withdraw permission for participation at any point during the study. This decision will not affect my daughter's CIT status.

I understand that overall results of the study will be shared with my daughter and me, published in a national health care journal, and presented at a national health care conference. My daughter will not be identified by name.

I understand that if I have questions about the study I can contact Jane K. Dickinson by phone (██████████) or email (██████████) at any time.

By signing below, I give permission for \_\_\_\_\_ to participate in the study, *The Experience of Adolescent Females with Type 1 Diabetes*.

\_\_\_\_\_  
Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

## Appendix H

### Characteristics of the Study Participants

**Table 1**

**Characteristics of the Study Participants**

	N	%
<b>Age (years)</b>		
16	9	90
17	1	10
<b>Grade</b>		
11 <sup>th</sup>	7	70
12 <sup>th</sup>	3	30
<b>Race</b>		
White	10	100
<b>Duration of diabetes (years)</b>		
5	2	20
6	1	10
7	1	10
9	2	20
10	2	20
11	1	10
12	1	10
<b>Years attending diabetes camp</b>		
5	3	30
6	2	20
7	2	20
9	1	10
10	1	10
11	1	10
<b>Diabetes-related hospitalizations (other than diagnosis)</b>		
0	6	60
1	2	20
2	1	10
>2	1	10

## Appendix I

### “Cry Freedom” song lyrics

How can I turn away  
Brother/Sister go dancing  
    through my head  
Human as to human  
The future is no place  
To place your better days

Cry freedom, cry  
From a crowd 10,000 wide  
Hope laid upon hope  
That this crowd will not subside  
Let this flag burn to dust  
And a new a fair design be raised  
While we wait head in hands,  
    hands in prayer  
And fall into a dreamless sleep again  
And we wave our hands

Hands and feet are all alike  
But gold between divide us  
Hands and feet are all alike  
But fear between divide us  
All slip away

There was a window and by it stood  
A mirror in which  
    he could see himself  
He thought of something  
Something he had never had but  
    hoped would come along  
Cry freedom, cry  
From deep inside  
Where we are all confined  
While we wave hands in fire  
Wave our hands

Hands and feet are all alike  
But gold between divide us  
Hands and feet are all alike  
But fear between divide us,

Slip away  
In this room stood a little child  
And in this room this little child  
    she would remain  
Until someone might decide  
To dance this little child  
    across the hall  
Into a cold, dark, space  
Where she might never trace her  
    way across this crooked mile  
Across this crooked page  
Cry freedom, cry  
From deep inside where  
    we are all confined  
Till we wave our hands

How can I turn away  
Brother/Sister go dancing  
    through my head  
Human as to human  
The future is no place  
To place your better days

Hands and feet are all alike  
But gold between divide us  
Hands and feet are all alike  
But fear between divide us  
Hands and feet are all alike  
Hear what I say  
Hear what I say  
Oh, so be it

How can I turn away  
Brother/Sister go dancing  
    through my head  
Human as to human  
The future is no place  
To place your better days

## References

- Amiel, S.A., Sherwin, R.S., Simonson, D.C., Lauritano, A.A., & Tamborlane, W.V. (1986). Impaired insulin action in puberty: A contributing factor to poor glycemic control in adolescents with diabetes. *The New England Journal of Medicine*, *315*(4), 215-219.
- Anderson, B.J. (1994). Childhood and adolescent psychological development in relation to diabetes. In C.J. Kelnar (Ed.), *Childhood and Adolescent Diabetes* (pp. 107-119). London: Chapman & Hall.
- Anderson, B.J., Brackett, J., Ho, J., & Laffel, L.M.B. (1999). An office-based intervention to maintain parent-adolescent teamwork in diabetes management. *Diabetes Care*, *22*(5), 713-721.
- Anderson, B.J., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *The Journal of Pediatrics*, *130*(2), 257-265.
- Anderson, B.J., & Laffel, L.M.B. (1997). Behavioral and psychosocial research with school-aged children with type 1 diabetes. *Diabetes Spectrum*, *10*(4), 277-281.
- Anderson, B.J., Wolf, F.M., Burkhart, M.T., Cornell, R.G., & Bacon, G.E. (1989). Effects of a peer-group intervention on metabolic control in adolescents with IDDM. *Diabetes Care*, *12*(3), 179-183.
- Anderson, R.M., Funnell, M.M., Butler, P.M., Arnold, M.S., Fitzgerald, J.T., & Feste, C. C. (1995). Patient empowerment. *Diabetes Care*, *18*(7), 943-949.
- Bacharach, A.L. & Pearce, J.R. (Eds.). (1977). *The musical companion*. NY: Harcourt Brace Jovanovich.

- Bateman, J. (1990). An extra source of conflict? Diabetes in adolescence. *Professional Nurse*, 5(6), 290-292,294,296.
- Beck, C.T. (1994). Phenomenology: Its use in nursing research. *International Journal of Nursing Studies*, 31(6), 499-510.
- Boland, E.A., Grey, M., Oesterle, A., Fredrickson, L., & Tamborlane, W.V. (1999). Continuous subcutaneous insulin infusion. *Diabetes Care*, 22(11), 1779-1784.
- Brink, S. (1997). So what's the difference between teenage boys and girls, anyway? *Diabetes Care*, 20(11), 1638-1639.
- Brink, S.J., & Moltz, K. (1997). The message of the DCCT for children and adolescents. *Diabetes Spectrum*, 10(4), 259-267.
- Bubb, J.A. & Pontious, S.L. (1991). Weight loss from inappropriate insulin manipulation: An eating disorder variant in an adolescent with Insulin-Dependent Diabetes Mellitus. *The Diabetes Educator*, 17(1), 29-32.
- Burns, N. (1989). Standards for qualitative research. *Nursing Science Quarterly*, 2(1), 44-52.
- Burroughs, T.E., Harris, M.A., Pontious, S.L., & Santiago, J.V. (1997). Research on social support in adolescents with IDDM: A critical review. *The Diabetes Educator*, 23(4), 438-448.
- Burroughs, T.E., Pontious, S.L., & Santiago, J.V. (1993). The relationship among six psychosocial domains, age, health care adherence, and metabolic control in adolescents with IDDM. *The Diabetes Educator* 19(5), 396-402.
- Carnegie Council on Adolescent Development (1995). *Great transitions: Preparing adolescents for a new century*. NY: Carnegie Corporation.

Charron-Prochownik, D., & Arslanian, S. (1997). Women with diabetes – the adolescent years: A case study and review. *Diabetes Spectrum, 10*(3), 180-184.

Close, H., Davies, A.G., Price, D.A., & Goodyer, I.M. (1986). Emotional difficulties in diabetes mellitus. *Archives of Disease in Childhood, 61*, 337-340.

Cohen, M.Z. & Omery, A. (1994). Schools of phenomenology: Implications for research. In J. Morse (Ed.), *Critical issues in qualitative research* (pp. 136-156).

Thousand Oaks, CA: Sage.

Cohn, B.A., Cirillo, P.M., Wingard, D.L., Austin, D.F., & Roffers, S.D. (1997). Gender differences in hospitalizations for IDDM among adolescents in California, 1991. *Diabetes Care, 20*(11), 1677-1682.

Davidson, M., Boland, E.A., & Grey, M. (1997). Teaching teens to cope: Coping skills training for adolescents with insulin-dependent diabetes mellitus. *Journal of the Society for Pediatric Nurses, 2*(2), 65-72.

*Diabetes 1996 Vital Statistics.* (1996). Alexandria, VA: American Diabetes Association.

Diabetes Control and Complications Trial Research Group (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *The New England Journal of Medicine, 329*(14), 978-986.

Diabetes Control and Complications Trial Research Group (1994). Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. *The Journal of Pediatrics, 125*(2), 177-188.

**Diabetes Control and Complications Trial Research Group (1995).** The relationship of glycemic exposure (HbA1C) to the risk of development and progression of retinopathy in the Diabetes Control and Complications Trial. *Diabetes*, *44*, 968-983.

**Diabetes Control and Complications Trial Research Group (1996a).** Influence of intensive diabetes treatment on quality-of-life outcomes in the Diabetes Control and Complications Trial. *Diabetes Care*, *19*(3), 195-203.

**Diabetes Control and Complications Trial Research Group (1996b).** The absence of a glycemic threshold for the development of long-term complications: The perspective of the Diabetes Control and Complications Trial. *Diabetes*, *45*, 1289-1298.

**Dickinson, J.K. (1997).** *Diabetes from an adolescent perspective: A case study.* Unpublished manuscript, University of Connecticut at Storrs.

**Dickinson, J.K. (1998).** *A meta-analysis of the effects of innovative teaching interventions on metabolic control in adolescents with insulin-dependent diabetes mellitus.* Unpublished manuscript, University of Connecticut at Storrs.

**Dickinson, J.K. (1999).** A critical social theory approach to nursing care of adolescents with diabetes. *Issues in Comprehensive Pediatric Nursing*, *22*(4), 143-152.

**Drash, A.L., (1993).** The child, the adolescent, and the Diabetes Control and Complications Trial. *Diabetes Care*, *16*(11), 1515-1516.

**Du Pasquier-Fediaevsky, L., & Tubiana-Rufi, N. (1999).** Discordance between physician and adolescent assessments of adherence to treatment. *Diabetes Care*, *22*(9), 1445-1449.

**Ellis, N.T. & Torabi, M.R. (1994).** Prevalence of adolescent health risk behaviors: School health implications. *Journal of School Nursing*, *10*(4), 25-33.

- Erikson, E. (1994). *Identity: Youth and crisis*. NY: W.W. Norton & Company.  
(Original work published in 1968).
- Fain, J.A., Nettles, A., Funnell, M.M., & Charron-Prochownik, D. (1999). Diabetes patient education research: An integrative literature review. *The Diabetes Educator*, 25(6), 7-15.
- Fenton, C.L., Clemons, P.M., & Francis, G.L. (1999). How do the results of the Diabetes Control and Complications Trial relate to the practice of pediatrics: Who should have intensive management? *Pediatric Annals*, 28(9), 600-604.
- Follansbee, D.S. (1989). Assuming responsibility for diabetes management: What age? What price? *The Diabetes Educator*, 15(4), 347-352.
- Fonagy, P., Moran, G.S., Lindsay, M.K.M., Kurtz, A.B., & Brown, R. (1987). Psychological adjustment and diabetic control. *Archives of Disease in Childhood*, 62, 1009-1013.
- Forrest, K. Y-Z, & Orchard, T.J. (1997). Have diabetes care behaviors changed since the DCCT? *Practical Diabetology*, March, 6-8.
- Frost, R. (1969). The investment. In (E.C. Lathem, Ed.). *The Poetry of Robert Frost* (pp.263-264). NY: Henry Holt & Company.
- Frost, R. (1969). The road not taken. In (E.C. Lathem, Ed.). *The Poetry of Robert Frost* (p.105). NY: Henry Holt & Company.
- Funnell, M.M., Anderson, R.M., Arnold, M.S., Barr, P.A., Donnelly, M., Johnson, P.D., Taylor-Moon, D., & White, N.H. (1992). Empowerment: An idea whose time has come in diabetes education. *Beta Release*, 16(2), 54-58.

Gillis, A.J., (1994). Determinants of health-promoting lifestyles in adolescent females. *Canadian Journal of Nursing Research, 26*(2), 13-28.

Glasgow, R.E., Fisher, E.B., Anderson, B.J., LaGreca, A., Marrero, D., Johnson, S.B., Rubin, R.R., & Cox, D.J. (1999). Behavioral science in diabetes. *Diabetes Care, 22*(5), 832-843.

Golden, M.P. (1998). Incorporation of quality-of-life considerations into intensive diabetes management protocols in adolescents. *Diabetes Care, 21*(6), 885-886.

Golin, C.E., DiMatteo, M.R., & Gelberg, L. (1996). The role of patient participation in the doctor visit. *Diabetes Care, 19*(10), 1153-1164.

Grey, C., Tinsley, B., & Griesar, P. (1996). So Much to Say [recorded by D. Matthews, C. Beauford, S. Lessard, B. Tinsley, L. Moore, & T. Reynolds]. On *Crash* [compact disk]. New York, NY: BMG Entertainment.

Grey, M., Boland, E.A., Davidson, M., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W.V. (1998a). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care, 21*(6), 902-908.

Grey, M., Boland, E.A., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W.V. (1998b). Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care, 21*(6), 909-914.

Hanna, K.M., & Guthrie, D.W. (1999). Involvement in health behaviors among youth with diabetes. *The Diabetes Educator, 25*(2), 211-219.

Hanson, C.L., DeGuire, M.J., Schinkel, A.M., & Kolterman, O.G. (1995). Empirical validation for a family-centered model of care. *Diabetes Care, 18*(10), 1347-1356.

Hanson, C.L., Henggeler, S.W., & Burghen, G.A. (1987a). Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology, 55*(4), 529-533.

Hanson, C.L., Henggeler, S.W., & Burghen, G.A. (1987b). Model of associations between psychosocial variables and health-outcome measures of adolescents with IDDM. *Diabetes Care, 10*(6), 752-758.

Hanson, C.L., Henggeler, S.W., Harris, M.A., Burghen, G.A., & Moore, M. (1989). Family system variables and the health status of adolescents with insulin-dependent diabetes mellitus. *Health Psychology, 8*(2), 239-253.

Heidegger, M. (1996). *Being and time* (J. Stambaugh, Trans.). NY: State University of New York Press. (Original work published 1953).

Hentinen, M. & Kyngas, H. (1992). Compliance of young diabetics with health regimens. *Journal of Advanced Nursing, 17*, 530-536.

Hirsch, I.B., Farkas-Hirsch, R., & Skyler, J.S. (1990). Intensive insulin therapy for treatment of type 1 diabetes. *Diabetes Care, 13*(12), 1265-1283.

Hoffman, M. (1997). *The NPR classical music companion*. NY: Houghton Mifflin Company.

Husserl, E. (1931). *Ideas*. New York: Macmillan Company.

Husserl, E. (1965). *Phenomenology and the crisis of philosophy* (Q. Lauer, Trans.). New York: Harper & Row. (Original work published 1911)

Kyngas, H. & Barlow, J. (1995). Diabetes: An adolescent's perspective. *Journal of Advanced Nursing, 22*, 941-947.

Kyngas, H. & Hentinen, M. (1995). Meaning attached to compliance with self-care, and conditions for compliance among young diabetics. *Journal of Advanced Nursing*, 21, 729-736.

Kyngas, H., Hentinen, M., Koivukangas, P., & Ohinmaa, A. (1996). Young diabetics' compliance in the framework of the mimic model. *Journal of Advanced Nursing*, 24, 997-1005.

La Greca, A.M., Swales, T., Klemp, S., Madigan, S., & Skyler, J. (1995). Adolescents with diabetes: Gender differences in psychosocial functioning and glycemic control. *Children's Health Care*, 24(1), 61-78.

Meldman, L.S. (1987). Diabetes as experienced by adolescents. *Adolescence*, 22(86), 433-444.

Mendez, F.J. & Belendez, M. (1997). Effects of a behavioral intervention on treatment adherence and stress management in adolescents with IDDM. *Diabetes Care*, 20(9), 1370-1375.

Neumark-Sztainer, D., Story, M., Toporoff, E., Cassuto, N., Resnick, M., & Blum, R. (1996). Psychosocial predictors of binge eating and purging behaviors among adolescents with and without diabetes mellitus. *Journal of Adolescent Health*, 19, 289-296.

Palardy, N., Greening, L., Ott, J., Holderby, A., & Atchison, J. (1998). Adolescents' health attitudes and adherence to treatment for insulin-dependent diabetes mellitus. *Developmental and Behavioral Pediatrics*, 19(1), 31-37.

Pichert, J.W., Meek, J.M., Schlundt, D.G., Flannery, M.E., Kline, S.S., Hodge, M.B., & Kinzer, C.K. (1994). Impact of anchored instruction on problem-solving strategies of

adolescents with diabetes. *Journal of the American Dietetic Association*, 94(9), 1036-1038.

Pipher, M. (1994). *Reviving Ophelia: Saving the selves of adolescent girls*. NY: Ballantine Books.

Powers, B.A. & Knapp, T.R. (Eds.). (1995). *A dictionary of nursing theory and research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.

Resnick, M.D., Bearman, P.S., Blum, R.W., Bauman, K.E., Harris, K.M., Jones, J., Tabor, J., Beuhring, T., Sieving, R.E., Shew, M., Ireland, M., Bearinger, L.H., & Udry, R. (1997). Protecting adolescents from harm: Findings from the National Longitudinal Study on Adolescent Health. *Journal of the American Medical Association*, 278(10), 823-832.

Rodham Clinton, H. (1996). *It takes a village and other lessons children teach us*. NY: Simon & Schuster.

Rubin, R.J., Altman, W.M., & Mendelson, D.N. (1994). Health care expenditures for people with diabetes mellitus. *Journal of Clinical Endocrinology and Metabolism*, 78(4), 809A.

Schlundt, D.G., Pichert, J.W., Rea, M.R., Puryear, W., Penha, M.I., & Kline, S.S. (1994). Situational obstacles to adherence for adolescent with diabetes. *The Diabetes Educator*, 20(3), 207-211.

Schutz, A. (1967). *The phenomenology of the social world*. Evanston, IL: Northwestern University Press. (Original work published in 1932).

Schwartz, S. (1991). Children and adolescents who happen to have diabetes. *Nurse Practitioner Forum*, 2(3), 193-195.

Smiley, T.M., (1988). *Independent/dependent conflict in the adolescent with diabetes mellitus type 1*. Unpublished doctoral dissertation, Texas Women's University, Denton, Texas.

Spiegelberg, H. (1971). *The phenomenological movement: A historical introduction*. The Hague: Martinus Nijhoff.

Standiford, D.A., Turner, A.M., Allen, S.R., Drozda, D.J., & McCain, G.C. (1997). Personal illness models of diabetes: Preadolescents and adolescents. *The Diabetes Educator*, 23(2), 147-151.

Tamborlane, W.V., Gatcomb, P., Held, N., & Ahern, J. (1994). Implications of the DCCT results in treating children and adolescent with diabetes. *Clinical Diabetes*, September/October, 115-116.

Tercyak, K.P., Johnson, S.B., Kirkpatrick, K.A., & Silverstein, J.H. (1998). Offering a randomized trial of intensive therapy for IDDM to adolescents. *Diabetes Care*, 21(2), 213-215.

Thompson, C.J., Cummings, J.F.R., Chalmers, J., Gould, C., & Newton, R.W. (1996). How have patients reacted to the implications of the DCCT? *Diabetes Care*, 19(8), 876-879.

United States Department of Commerce, Bureau of the Census. (October 1994). *Health insurance coverage – 1993*. Statistical brief (SB/94-28). Washington, DC: Author.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: SUNY Press.

Wdowik, M.J., Kendall, P.A., & Harris, M.A. (1997). College students with diabetes: Using focus groups and interviews to determine psychosocial issues and barriers to control. *The Diabetes Educator*, 23(5), 558-562.

Wehmann, T.W. (1985). Diabetes mellitus and the adolescent. *Physician Assistant*, 9(10), 16,19,23,27-28,56.

Weissberg-Benchell, J., Glasgow, A.M., Tynan, W.D., Wirtz, P., Turek, J., & Ward, J. (1995). Adolescent diabetes management and mismanagement. *Diabetes Care*, 18(1), 77-82.

Whiteside, M.B. (1936). Who has known heights? In H. Felleman (Ed.), *The Best Loved Poems of the American People* (p.610). NY: Doubleday.

Wolfsdorf, J.I. (1999). Improving diabetes control in adolescents. *Diabetes Care*, 22(11), 1767-1768.

Wysocki, T., Hough, B.S., Ward, K.M., & Green, L.B. (1992). Diabetes mellitus in the transition to adulthood: Adjustment, self-care, and health status. *Developmental and Behavioral Pediatrics*, 13(3), 194-201.