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Factors Affecting Dietary Compliance In The Adolescent With Type 1 Diabetes

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Factors affecting dietary compliance in the adolescent with type 1 diabetes

(TITLE)

BY

MaryJean K. Bargren

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

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YEAR

I HEREBY RECOMMEND THAT THIS THESIS BE ACCEPTED AS FULFILLING
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Abstract

The purpose of this study was to research adult persons with type 1 diabetes and determine what factors played a role in both compliance and non-compliance of their diabetes management as an adolescent. The purpose was also to determine what factors may have caused an adolescent to be non-compliant throughout their adolescent years but who in adulthood became compliant.

Managing diabetes throughout adolescence can be difficult with many changes occurring both hormonally and socially. A medium sized hospital in the Midwest was used to obtain participants for this study. Questionnaires were distributed to patients at their medical appointments. There were 14 participants that completed the questionnaire portion and eight participants that completed the phone or personal interview. Both instruments used for the research were created by the researcher. The questionnaire consisted of 23 questions asking demographic information and retrospective thoughts on what may have contributed to their diabetes management during adolescence.

This study did not find any statistical significance among the participants. Individuals had been compliant throughout adolescence therefore not allowing the researcher to determine what issues may have increased the risk for non-compliance during adolescence. Many participants did not have accurate diabetes equipment during their adolescent years making it more difficult for them to closely manage their diabetes. Many of the participants did not have access to an outpatient dietitian during their adolescence, therefore it was difficult for them to accurately answer the questions related to seeing a dietitian.

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Chapter 1

Diabetes is a serious disease that affects the micro and macrovascular systems within the body. Compliance of the person with diabetes is essential to minimize the risks of future complications. Adolescence is a time that includes hormone shifts, lifestyle changes and the gaining of independence. Lifestyle choices adopted during adolescence form the basis for successful diabetes care both now and in the future (Cameron, 2003). Research has shown that non-compliance in the management of diabetes decreases throughout adolescence. This may include taking scheduled medications, monitoring blood glucose levels, using special dietary products, participating in physical activity and/or failing to attend appointments with medical providers (Kyngäs, 2000). Medical nutrition therapy can help in decreasing the risks associated with type 1 diabetes. Nutrition intervention throughout adolescence can help decrease the long-term health complications from poor diabetes management. Determining both the issues adolescents with type 1 diabetes struggle with related not only to their diabetes, but also to every other aspect of their young lives may help to minimize their non-compliance of diabetes care during adolescence.

Statement of Problem

Adolescence is a time when metabolic control starts to decrease and chronic health complications begin to appear (Sochett & Daneman, 1999). Near-normal blood glucose values are difficult to achieve throughout adolescence (Grey, Boland, Davidson, Li & Tamborlane, 2000). Medical nutrition therapy (MNT), as defined by Daly, Warshaw, Green-Pastors, Franz and Arnold (2003), involves assessing the individual, setting goals, intervention and evaluation of the intervention. They suggest that use of

MNT can reduce blood glucose levels by 50-100 mg/dL by positively affecting glycosylated hemoglobin A1c (HbA1c) levels and reducing them 1-2 percent. Proper care of diabetes throughout adolescence is essential to minimize the risks of health complications in the future.

Purpose of the Study

The purpose of this study was threefold:

1. To research adults with type 1 diabetes and determine what factors played a role in both compliance and non-compliance of his/her diabetes management
2. To determine what caused them as an adolescent to determine if they were going to be compliant or non-compliant throughout their adolescent years but now in adulthood to be currently compliant
3. To determine what major factors caused the individuals with type 1 diabetes to change and/or to maintain their diabetes management

Research Questions

Four research questions were explored in this study:

1. What factors had the most influence on diabetes management in the adolescent person with type 1 diabetes?
2. After adolescence, was the patient more likely to comply with medical advice? If so, what influenced the patient's decisions?
3. Throughout adolescence, what reasons do adolescents with type 1 diabetes have for adhering to, or neglecting the advice of dietitians?
4. If during adolescence, adolescent persons with type 1 diabetes missed appointments with their dietitians, what were their reasons?

Significance of Study

Adolescence can be a difficult stage in a child's life in which they are trying to gain independence while experiencing hormonal changes and lifestyle changes. This can lead to an adolescent neglecting the needs of his/her own body. This can also be a time that is very demanding for adolescents with type 1 diabetes. The adolescent must care for their diabetes each day, consume a specific diet and see multiple medical providers, all while trying to handle the day to day activities of an adolescent. Many times diabetes management declines during adolescence. This study researched the many reasons diabetes management may be compromised during adolescence. This study tried to determine the reasons for potential non-compliance during adolescence, and the factors that caused diabetes management to improve or decline. The information obtained from these participants helped in determining the relationship between persons with type 1 diabetes and their diabetes management throughout adolescence. This information will be available to help dietitians create better ways to connect with and to educate adolescents with diabetes more effectively and to help increase compliance throughout adolescence and on into adulthood.

Assumptions

As with all research, there were several assumptions in this study. The assumptions included:

1. The participant was able to recall correctly and remember their experiences throughout adolescence.

2. The participant answered the questions on the questionnaire, interview and/or discussion group honestly.
3. The participant had access to and was willing to give HbA1c records for the past five years.

Definition of Terms

To clarify terms used in this research, definitions are as follows:

Diabetes: Disorder in which the pancreas produces defects in insulin production or action, thus causing hyperglycemia. Carbohydrate use is reduced and that of lipid and protein enhanced. May lead to long-term complications such as neuropathy, retinopathy, nephropathy, generalized degenerative changes in large and small blood vessels, and increased susceptibility to infection (Jacobs, et al., 2005).

Type 1 diabetes: Insulin dependent diabetes (Jacobs, et al., 2005) usually in persons younger than 30 years of age, but can occur at any age, also known as juvenile-onset diabetes (Mahan & Escott-Stump, 2004)

Glycosylated Hemoglobin A1c (HbA1c): One of the four hemoglobin A fractions to which D-glucose and related monosaccharide concentrations are increased in the erythrocytes of patients with diabetes mellitus and can be used as a retrospective index of glucose control over a period of time (Jacobs, et al., 2005).

Body mass index (BMI): A method to assess nutritional status. BMI is used to associate risks of disease with obesity. The formula used is: BMI = wt (in kg) ÷ ht (in m^2) (Jacobs, et al., 2005).

Adolescence: The period from the beginning of puberty until maturity. The process is gradual and may vary among individuals (Taber's, 2005).

Compliance: The act of yielding to a request or command (World Book Dictionary, 2005). Compliance can be measured differently depending on the definition set forth by the researcher (Kyngäs, 2000). For this study, compliance was defined as the degree to which the participant's diabetes care corresponds to the advice given by their medical provider during adolescence and at the present. Compliance numbers for both "current compliance" and "compliance during adolescence" were determined by questions 10 & 12 on the phone and personal interview questionnaire. The average based on the answers given on the Likert scale was used to divide the participants into compliant or non-compliant status. Current compliance was split at six on the Likert scale of one to ten. For the basis of this research, compliance was defined as seven or above.

Non-compliance: For this research, based on the definition for compliance, if the participant marked six or below on the Likert scale he was considered to be non-compliant.

Chapter 2

Review of the Literature

Diabetes is a serious disease that can affect a person at any age. Proper diabetes management during all stages of life is essential to minimize health complications that may occur throughout the person's life. This review of literature will discuss the following topics: an overview of diabetes, diabetes throughout adolescence, diabetes therapy, relationships, weight management, depression, diabetes education, medical nutrition therapy and diabetes complications.

Diabetes is one of the leading causes of death in the United States. Diabetes is a serious disease that can afflict people of all ages and can affect all systems of the body over time. Cardiovascular disease is the leading cause of death among person with diabetes (Bahaskarabhatla & Birrer, 2004). Diabetes can also lead to many other long-term health complications. Some of these complications include: arteriosclerosis, heart disease, retinopathy, neuropathy nephropathy, infection and many others (Hanas, 2005).

Type 1 diabetes has been referred to as "juvenile-onset diabetes" and "insulin-dependent diabetes" (Wysocki, 2006). Type 1 diabetes currently affects about 1 in 600 children and this number is increasing (Wysocki). Type 1 diabetes is an autoimmune disease that occurs when the beta cells in the pancreas are unable to produce insulin (Wysocki). A specific cause for type 1 diabetes has not been found, but researchers have found certain factors which may be linked to type 1 diabetes (American Diabetes Association, 2005). Some of these factors include: genetics, autoantibodies, viruses, cow's milk, oxygen free radicals, chemicals and drugs.

Individuals with type 1 diabetes must take insulin in order to regulate blood glucose levels. Insulin is produced by beta cells in the Islets of Langerhans within the pancreas (Hanas, 2005). Most individuals with type 1 diabetes suffer from a lack of beta cells in the pancreas (American Diabetes Association, 2005). Insulin is needed to allow glucose to enter the cells. Insulin stimulates proteins to migrate to the surface of the cells allowing it to capture the blood glucose and disperse it within the cells (Hanas).

Glucose is needed to produce energy (Hanas, 2005). Cells in a person with type 1 diabetes act as if they are in a state of starvation (Hanas). The cells are lacking glucose and therefore the body believes this is due to low levels of glucose in the blood. Glycogen stores are released from the liver, forming glucose and thereby increasing blood glucose levels (Hanas).

A lack of insulin in the individual with diabetes causes an overabundance of ketone production (Hanas, 2005; Scheiner, 2004). The body then tries to expel the ketones into the urine which causes acidity in the blood. This is referred to as ketoacidosis (Hanas). Ketoacidosis occurs when fat is broken down to be used by the muscle cells (Collazo-Clavell, 2001). This may occur due to lack of insulin, stress or illness (Collazo-Clavell).

Glycosylated hemoglobin A1c (HbA1c) tests measure the percentage of hemoglobin in the red blood cells that have glucose attached to them (Hanas, 2005). HbA1c tests are a measure of average glucose levels over a period of time, generally three months (Hanas). Glucose binds to hemoglobin in red blood cells for the life of the red cell (Hanas). Throughout puberty the HbA1c levels may be slightly increased, approximately 1%, due to an increase in growth hormone at this time causing blood glucose levels to rise (Hanas). The American Diabetes Association recommends HbA1c levels of less than seven percent (Hanas). As HbA1c levels decrease, the risk for long-term health complications also decreases (Hanas).

The Diabetes Control and Complications Trial Research Group (DCCT) (1994) studied 1441 patients, 13-39 years of age, with insulin-dependent type 1 diabetes over a mean of 6.5 years. The patients were assigned to either conventional therapy or intensive therapy. Conventional therapy did not adjust insulin levels and included insulin injections either once or twice daily. Intensive therapy included blood glucose monitoring multiple times throughout the day and three or more insulin injections, adjusted as needed, per day. Intensive therapy was done to facilitate blood glucose levels becoming normal or as close to normal as possible. The DCCT found intensive therapy helped to minimize the risk for complications. They also found that if there was a pre-existing diabetes related complication in the patient, progression was slowed when using intensive therapy. The DCCT found evidence that poor control of diabetes for even short periods of time can increase the risk for microvascular problems related to diabetes. Proper self-management of diabetes at a young age can allow for more dietary freedom and a healthier body both now and in the future (DAFNE Study Group, 2002).

Adolescence

Adolescence is a time when metabolic control can start to deteriorate and chronic complications can begin and progress further (Codner, et al., 2004). An adolescent person with diabetes needs to learn early in their life how to incorporate healthy regimens into their schedules (Strawhacker, 2001). Healthy lifestyle choices adopted during adolescence will help shape the success of diabetes care for their future years (Cameron, 2003). Bryden, et al. (1999) states that behavioral problems with diabetes management evidenced in the adolescent person with diabetes are likely to continue into adulthood causing early manifestations of diabetes-related complications.

The American Diabetes Association (2002) states that the overall goal in MNT, for the adolescent person with type 1 diabetes, should be to limit the risk for hypoglycemia by maintaining good blood glucose levels to help achieve normal growth. The Diabetes Control and Complications Trial (1994) found that adolescent persons with diabetes were 33% more likely to experience hypoglycemia than adult persons with diabetes. Hypoglycemia can lead to severe problems both immediately and later in life.

Diabetes Therapy

The goal of current diabetes therapy is to mimic normal pancreatic function, although it may not always be completely possible to do this (Wysocki, 2006). This may lead to fluctuations in blood sugars that may lead to hypo or hyperglycemia (Wysocki). Diabetes therapy has changed in the past decade. Some of these changes include insulin pumps, three or more daily insulin injections, carbohydrate counting, frequent blood glucose testing, and more involvement of the family (Wysocki).

The Hvidore Study Group on Childhood Diabetes conducted a quantitative study on glycemic control and the effect on quality of life in adolescents (Hoey, et al., 2001). The study consisted of 2,101 adolescents from 10-18 years old from 17 different countries (Hoey, et al.). The study took place over six months. Questionnaires were given to an adolescent, a parent and the health care provider of the adolescent to determine how much burden was created for the family of an adolescent with diabetes. The researchers found that as glycosylated hemoglobin levels increased, the quality of life of the adolescent decreased (Hoey, et al.). They also found that teenage boys had fewer difficulties with diabetes management when compared to girls (Hoey, et al.). The Hvidore Study Group suggests that a person with diabetes with a higher quality of life may be better able to care for their diabetes (Hoey, et al.). Faulkner (2003) and Hoey, et al. state that as adolescents age, they better understand the ramifications that may occur due to poor metabolic control. When this happens, the burden of their diabetes decreases.

Relationships

The person with diabetes is going to be more motivated by positive, encouraging, supportive parents (Kyngäs, 2000). Children are more motivated and compliant when there is parental support and encouragement (Kyngäs, 2000). Children living in a family environment that is chaotic tend to have poor control of their diabetes (Forsander, Sundelin & Persson, 2000). Kyngäs (1999) found that parental support improved motivation for proper self-care in a person with diabetes. Svensson, Engström, and Åman (2003) found a positive association between the number of biological parents living within the household and the child's or adolescent's HbA1c levels. Kyngäs (1999) also found that fear of health-related complications in children negatively impacted compliance in adolescents. If the child was not fearful, compliance improved (Kyngäs, 1999).

Forsander, Malmodin, Elkund and Persson (2003) found that the educational level of the parents did not affect the dietary choices of the person with diabetes patient. They found that children with diabetes, with well-educated mothers consumed diets higher in saturated fat than the children of less-educated mothers (Forsander, et al.). Nemours Children's Clinic assesses recently diagnosed children with type 1 diabetes and completes a family assessment to determine if there are any barriers within the family that may contribute to poor control of the diabetes (Wysocki, 2006). Time of diagnosis plays a part in the dietary compliance of a person with type 1 diabetes. Poor familial eating habits/patterns at the time of diagnosis may lead to more difficulties in adjusting current dietary recommendations (Forsander, et al.). A stressful family life increased the risk for eating disorders in adolescent females with diabetes. Maharaj, Rodin, Olmsted and Daneman (1998) found that adolescent female persons with type 1 diabetes that lived in an environment with conflict, had poor parental communication and/or suffered from lack of parental trust and sensitivity to issues were at an increased risk for eating disorders.

The adolescent person with diabetes begins to seek less support from their parents as they try to become more independent and manage their own disease (Hanna, Jarez, Lenss & Guthrie, 2003). It is suggested that parents of children with a chronic illness are more likely to be overprotective and controlling than parents of children without a chronic illness (Holmbeck, et al., 2002; Power, Dahlquist, Thompson & Warren, 2003). Hanna, et al. found better metabolic control in adolescents that were responsible for making diabetes management decisions on their own. Anderson, Brackett, Ho, and Laffel (1999) found the opposite to be true. They found that as parental involvement in care decreased, glycemic control also decreased.

Kyngäs (2000) found that peer support played a large part in the compliance of persons with type 1 diabetes. Kyngäs found that limitations which may influence non-compliance in adolescents may also increase the negative impact it has on relationships with peers. This can be influenced by the requirement of interruptions in activities and physical activity to perform the treatment needed for diabetes management (Kyngäs).

Greco, Pendley, McDonell and Reeves (2001) researched the effect that would occur when friends were educated on diabetes management. Parents reported improved adjustment and less diabetes related conflict after the intervention (Greco, et al.). They also found that peers had an improved self-perception following the intervention (Greco, et al.).

Breaking away from the current clinic style healthcare and utilizing intervention strategies that incorporate the family, peers and outside networks may increase patient compliance (Olsson, Toumbourou, Bowes & Walsh, 1998; Court, 1998). Kyngäs and Rissanen (2001) found support from medical providers, family and friends has the greatest influence on good compliance in the adolescent person with diabetes. Adolescents want to be included in the decision making regarding their diabetes. Kyngäs, Hentinen, and Barlow (1998) found that some adolescents feel that their medical providers are making all their decisions and not asking them for their input. Communication between both the provider and the young patient may help in deciding the best management for that individual (Kyngäs & Rissanen, 2001).

Kipps, et al. (2002) cites a challenge adolescents with diabetes may encounter is the change from a pediatric provider to an adult provider. This may increase their anxiety and decrease attendance of the adolescent patient with their new adult provider. Kipps, et al. found that attendance at appointments decreased two years pre- and post-transfer of medical provider care.

Weight Management

In a study by Dabadghao, Vidmar and Cameron (2001) they found that BMI increased in adolescent females with diabetes as metabolic control decreased. The researchers do not attribute the weight gain to the “honeymoon effect” and do not cite any reasons for the weight gain (Dabadghao, et al.). Tylleskär, Tuvemo and Gustaffson (2001) researched adolescent females and a relationship between HbA1c levels and BMI. They found that as HbA1c levels increased, BMI also increased. They found correlation strength increased between higher BMI levels and higher HbA1c levels. There was a weak correlation during preadolescence, but throughout adolescence the correlation became stronger with the strongest correlation during late adolescence. They suggest that a higher BMI earlier in puberty not only increased the likelihood for a higher BMI in late adolescence but also for increased HbA1c levels. Adolescent female persons with type 1 diabetes have been shown to have higher BMIs when compared to healthy non-person with diabetes females of the same age group (Ingberg, Särnblad, Palmér, Schvarcz, Berne & Åman, 2003). Codner et al. (2004) state that weight gain during adolescence may lead to “adverse metabolic effects” currently as well as in the future.

According to the DCCT (1994) intensive therapy increases the risk of overweight by two times in adolescents with diabetes when compared to conventional therapy. The American Diabetes Association (ADA) states that insulin therapy may lead to an increase in body weight (ADA Task Force, 2002). Engström, et al. (1999) state that the excess body weight may be attributed to the intensive insulin treatment, but may also be due to disordered eating and overeating.

Daneman, Olmsted, Rydall, Maharaj and Rodin (1998) state that the key to nutritional counseling of these individuals is to stress healthy eating and not stress dietary restraint. Dabadghao, Vidmar and Cameron (2001) found as females aged from childhood to adolescence, control of their diabetes declined. They found an association between loss of control and an increased BMI. Dabadghao, et al. found as BMI increases in females during adolescence, glucose control declines. Increased body weight can negatively influence insulin sensitivity leading to poor glycemic control (Ingberg, Särnblad, Palmér, Schvarcz, Berne & Åman, 2003). Fat deposits are located in the abdominal region of the body creating more insulin resistance and increased lipid levels (Ingberg, et al.). The risk for insulin resistance increases with an elevated BMI leading to a need for larger insulin dosages (Dabadghao, et al.).

Tighter glycemic control increases the risk for hypoglycemic episodes (Forsander, Malmodin, Elkund & Persson, 2003). This may lead to a higher fat intake due to higher caloric and higher fat foods used for immediate compensatory behavior (Forsander, et al.). Forsander, et al. found higher mean intake of total fat was evidenced in children with type 1 diabetes with poor glycemic control when compared to children with better glycemic control. Higher fat intake then leads to increased weight gain.

Jones, Lawson, Daneman, Olmested and Rodin (2000) found that adolescent persons with type 1 diabetes have a greater risk for eating disorders than the general population. Pinar (2005) suggests that adolescent persons with diabetes are at a risk four times greater than that of a peer without diabetes in experiencing disordered eating. The more severe the eating disorder, the higher the HbA1c levels of the patient (Rodin, et al., 2002).

The treatment rate for eating disorders in adolescent persons with type 1 diabetes is lower than in groups that do not have diabetes (Hoffman, 2001). According to Daneman, Olmsted, Rydall, Maharaj and Rodin (1998) adolescent females with diabetes with an eating disorder have a lower treatment success rate when compared with adolescent female without diabetes.

Neumark-Sztainer, et al. (2002) cite insulin misuse or insulin omission as a common weight loss technique, more often in females with type 1 diabetes (Jones, Lawson, Daneman, Olmsted & Rodin, 2000). Adolescents want to avoid weight gain due to insulin use and therefore some discontinue or limit their use of insulin potentially causing lifelong health complications. Insulin causes weight gain and adolescent girls discover this around puberty (Bryden, et al., 1999). About 50% of females with diabetes take less insulin to keep weight off (Brackenridge & Rubin, 2002). Higher blood glucose levels cause the body to excrete more sugar in the urine and therefore causes the child with diabetes to lose weight (Betschart & Thom, 1995). The most immediate problems with limiting insulin are the increased risk for ketoacidosis, hyperglycemia and glycosuria (Hoffman, 2001; Rodin, et al., 2002).

Rodin, et al. (2002) state the current changes in diabetes treatment may help minimize the risk for eating disorders. Diabetes treatment may include carbohydrate counting and/or insulin pumps where insulin dosage is determined from the amount of carbohydrate being consumed.

Depression

Adolescent persons with type 1 diabetes are at an increased risk for depression. Stewart, Rao, Emslie, Klein and White (2005) found 9-27% of persons with diabetes patients suffer from a depressive disorder. Childhood depression increases with persons with type 1 diabetes as parental stress increases due to the parent believing the child is vulnerable to many problems related to the disease (Mullins, Fuemmeler, Hoff, Chaney, Van Pelt & Ewing, 2004). Grey, Davidson, Boland and Tamborlane (2001) found depression in persons with diabetes leads to poorer metabolic control. They suggest the depression should be addressed as treatment goals are likely to not be achieved otherwise (Grey, et al.). Depression not only negatively affects the diabetes, but also the person's life as a whole. Grey, et al. found persons with type 1 diabetes with poor metabolic control suffered from a lower quality of life.

Diabetes Education

The Dose Adjustment for Normal Eating (DAFNE) course created by the DAFNE Study Group educates persons with type 1 diabetes, over 18 years of age, on ways to improve self-management skills (DAFNE Study Group, 2002). The participants have either moderate or poor glycemic control. Participants have the choice of attending a five-day training course in small groups initially and/or to receive diabetes care for six months and then attend the DAFNE course. The researchers suggest compliance will improve, leading to a better quality of life, when individuals are taught the skills to manage their diabetes properly. The goal is if persons with diabetes are educated with how to properly manage their diabetes, it may not only help their physical body, but also improve their quality of life. The researchers found the greatest positive change in HbA1c values in participants educated initially versus the participants educated six months after treatment began.

Klein, et al. (2001) state that studies have shown improved quality of life, compliance and coping strategies as a result of patient education in patients with chronic illnesses. Divertie (2002) feels that patient education targeting the specific needs of the patient is most effective.

Repetition is the key to learning. Patients are most likely to remember the first and last items discussed in an appointment. Repeating points and goals throughout an appointment are necessary for a patient to adequately remember what has been discussed (Divertie, 2002).

Medical Nutrition Therapy

Diet is extremely important in proper diabetes management. Food choices are the primary influence on blood glucose levels. Spikmans, et al. (2003) suggest that patients may not feel challenged by what the dietitian tells them. They may already know this information and therefore they may feel that their visit was not worth their time or the money.

Medical nutrition therapy (MNT) can help reduce fasting blood glucose to between 50 and 100 mg/dL and reduce HbA1C levels by 1-2% (Daly, Warshaw, Green-Pastors, Franz & Arnold, 2003). Glycemic control is influenced by the diet and therefore is a major part in diabetes management (Spikmans, et al., 2003). Dietary intake has a direct influence on metabolic control and influences the risk for development of microvascular and macrovascular complications (DCCT Research Group, 1994).

Spikmans, et al. (2003) found many other reasons patients with diabetes may miss their dietitian appointments. Some of these reasons include: satisfaction with the dietitian, beliefs about the effectiveness of the treatment, not visiting other caregivers and selfrated health (Spikmans, et al.). Spikmans, et al. also found patients that did not attend their dietitian appointments had higher BMIs, lower risk perceptions of their diabetes, less satisfaction with the outcome of their dietitian appointment and the outcome efficacy of the dietary advice to be lower. Spikmans, et al. states one of the explanations for this is the expectation level the patients have about what the dietitian is telling them at the appointment. They may feel the information is repetitive and/or the information is too complicated.

Grey, Boland, Davidson, Li and Tamborlane (2000) studied the effect coping skills training had on adolescent persons with diabetes. They found patients that had coping skills training had improvements in their diabetes management (Grey, et al.). They stress the need to not only address the issue of diabetes management, but also the tools on how to deal with everyday changes in life.

Kyngäs (2000) states the satisfaction with the interaction and treatment between the dietitian and the patient largely influences the compliance level of the patient. Kyngäs reminds healthcare providers that treatment for this chronic disease is only one part of the adolescent's life. There are many other factors that must be taken into account to fully understand the patient's lifestyle and compliance.

Diabetes Complications

Persons with type 1 diabetes are not able to reverse the physical problems to their body due to their poor metabolic control. They are only able to limit or prevent further complications by improving their metabolic control (DCCT, 1994). Proper diabetes management is essential to reduce the risks for further complications. Green-Pastors, Warshaw, Daly, Franz, and Kulkarni (2002) suggest there is a 30% reduction in the risk for microvascular complications when HbA1c levels decreased by only one percent.

Summary

There are many factors that play a role in diabetes management. Each factor needs to be considered when determining the compliance or non-compliance of an individual with diabetes. Adolescence is a time to discover independence, yet it may also become a time to neglect proper diabetes care. Diabetes management is needed throughout life to minimize the risks for diabetes related complications. Dietitians play an important role in the management of type 1 diabetes.

Chapter 3

Methodology

Research Design

This was both a qualitative and quantitative study that examined compliance in adult persons with type 1 diabetes during adolescence at two hospitals in the Midwest. The participants were over 20 years old and had type 1 diabetes during some or all of their adolescent years. A questionnaire (see Appendix A) was used to obtain general information about the participants. If the participants were agreeable, interviews and/or discussion groups were formed.

Sample

The researcher used convenience, purposive sampling to obtain information. Convenience sampling was used as individuals report to appointments periodically allowing an easier method to obtain information. Purposive sampling was performed as there were specific criteria one needed to meet in order to participate in this study. The participants included adult persons with type 1 diabetes in the outpatient clinic at two hospitals located in the Midwest, Hospital A and Hospital B.

Criteria used to assess the participant's eligibility for the study included:

1. Participant has type 1 diabetes.
2. Participant had type 1 diabetes during all or part of their adolescence.
3. Participant was treated by a medical provider for their diabetes periodically throughout adolescence.

Hospital A distributed 25 questionnaires. On average, 24 adult patients with diabetes attend medical appointments during a two month time period at Hospital A. A total of four males and eight females participated in this study. Participant ages ranged from 22 years old to 58 years old (see Table 1). Fourteen questionnaires were returned. Two consent forms were not signed and therefore not valid to be used for the research. Twelve questionnaires were valid and able to be used for data collection. Three of the eight participants interviewed had a sibling with type 1 diabetes at the time of their own diagnosis. Ten of the 12 participants were diagnosed during adolescence. Two participants were diagnosed before adolescence. Males participating in this study were diagnosed later in adolescence than females. Hospital A was used for this study. Hospital B did not produce data and therefore was not used for this study.

Table 1

Demographic Information of Participants

	Current Age				Age of Diagnosis			
	20-29	30-39	40-49	50-59	0-5	6-10	11-15	16-17
Number of Participants	1	5	2	4	1	1	7	3
Males	0	2	2	0	0	0	2	2
Females	1	3	0	4	1	1	6	0

Instrumentation

The instruments used for this research were a questionnaire, focus group questions, personal interview questions and phone interview questions created by the researcher. The questions were created using information from literature reviewed stating issues that may affect adolescents with type 1 diabetes. The personal interview, phone interview and focus group questions were created to expand upon the questions from the questionnaire. This was to allow for additional data to be obtained for a better representation of the information provided by the participants.

Models

This study followed two different models: the Health Belief Model and the Stages of Change/Transtheoretical Model. The information gathered from the research instruments helped in determining the place each participant is at with diabetes management regarding the two models.

Health belief model.

The first model was the Health Belief Model (HBM). This model predicts the more knowledge a person has about the risks of a disease or lifestyle, the more likely they are to want to minimize the possibility of future problems related to the disease or lifestyle (Spikmans, et al., 2003). The premise for this study was that adolescent persons with diabetes have been told about the severity of their disease but do not realize the overall complications that may occur due to the disease. As adolescents age and reach adulthood complications due to non-compliance may begin to take effect. The person with type 1 diabetes may then start to change their lifestyle to properly care for their diabetes.

The HBM has three phases: the readiness factor, the evaluation of feasibility and the cues to action (Aalto & Uutela, 1997). The readiness factor is the apparent threat that a health condition may inflict (Aalto & Uutela). The evaluation of feasibility is what benefits may occur if proper behavior is carried out (Aalto & Uutela). Cues to action are the necessary components needed to carry out a behavior to change (Aalto & Uutela).

The phase in the HBM the participant was at with their current compliance was determined using questions 11, 13 & 14 on the questionnaire and questions 16 &17 on the phone/personal interview.

Stages of change/Transtheoretical model.

The Stages of Change/Transtheoretical Model is the second model that was used. It is based on five different stages of change. The precontemplation stage occurs when the person has motivation to change within the next 6 months, but no intention to change in the next 30 days. The contemplation stage occurs when the individual is aware there is a problem but has made no commitment to take any action towards change. The preparation stage is when the person plans to change within the next 30 days. The action stage is when the person is trying to determine how they are going to make the change. The last stage is the maintenance stage when the person has continued the changed behavior for at least 6 months (Prochaska & Velicer, 1997). Each person approaches these different stages at different times. Interventions need to be adjusted to accommodate a person in any of these stages (Spikmans, et al., 2003).

Using the Stages of Change Model, questions 10, 11, 12 & 13 on the questionnaire were used to determine at what stage of change the individual is currently at with their diabetes management. This theory was used to try and show that many times adolescent persons with diabetes have more motivation to change as they progress through adolescence and near adulthood. Changes through each stage are gradual and motivation increases as age increases.

Pilot test.

A pilot test of the questionnaire was completed on five participants who met the criteria previously mentioned and did not utilize the medical facility used for this study. The ages of the participants ranged from 30-39 years old. Four of the five were diagnosed before adolescence. Overall, friends were answered to be the most negative influence during adolescence on the participant. Each of the participants is currently compliant with their diabetes management though during adolescence the average compliance was less than five on a Likert scale of 1-10. Each of the participants felt family support was essential to good diabetes management both during adolescence and currently. No changes were made to the instruments after conducting the pilot test.

Validity.

Content validity for the questionnaire and focus group/personal interview/phone interview questions were assessed by three professors at a Midwestern university. Content validity is defined as the empirical measurement that reflects the content of a given theoretical concept based on a specific topic or a specific focus (Carmines & Zeller, 1979). Validity was also assessed by three medical providers at Hospital A located in the Midwest. The questionnaire was pilot tested for validity by five individuals who met the required criteria previously mentioned. The questionnaire and focus group/personal interview/phone interview questions contained content validity.

Procedure for Data Collection

Two instruments were used for this study to create a mixed method approach. Not all subjects participated in both research data collection methods. Each participant was asked by their doctor, diabetes educator or dietitian if they would like to participate in a questionnaire and was given information about the objectives of the questionnaire (see Appendix B). The participant was asked to either fill out the questionnaire at the office of the medical provider or take it home to complete and return to the Medical Research office at Hospital A in the envelope provided. Participants at Hospital B were given an envelope to return the response and the completed informed consent letter to the researcher upon completion to eliminate the concern that medical provider may have access to some of the information.

To comply with the Health Information Portability and Accountability Act (HIPAA) laws, participants were asked to sign a consent form (see Appendix C) stating they understood the privacy laws and the researcher's obligation to protect all information and keep it confidential. The informed consent letter and data collection methods were approved by the Institutional Review Board (IRB) at a Midwestern university (#06-111), where the research was conducted, to ensure the privacy of the participants in the study. Upon approval from the IRB at the university, the informed consent letter and data collection methods were submitted for approval by Hospital A and Hospital B. Participants were given an informed consent letter to sign stating the questionnaire was voluntary and they could discontinue it at any time (see Appendix D). The participants were asked to mail the questionnaire, confidentiality form and informed consent letter to the researcher upon completion.

Implementation took place over a two month period. Medical providers were given 25 questionnaires to distribute to qualifying participants. Doctors, diabetes educators and dietitians handed out the questionnaires to patients who met the established criteria. Upon the completion of the two month time period, the researcher contacted

Hospital A to ask how many questionnaires were remaining. This enabled the researcher to determine how many total questionnaires were given out to participants and how many were completed and returned.

The questionnaire contained basic demographic questions as well as information regarding past and current diabetes control. It also contained questions asking the participant's reasons that may have hindered diabetes control throughout their adolescence. The questionnaire also addressed the number of medical providers each participant had seen within the past year and their attitudes towards their individual providers.

The questionnaire contained a question asking the participant if they would be willing to participate in a focus group, phone interview or personal interview with the researcher at a later date. If the participants were willing to participate, contact information was obtained on the questionnaire. Participants were provided option methods they could contact the researcher. The participants were again reminded that the records were confidential and names would not be used in any way.

The Medical Research office at Hospital A separated the participant information from the questionnaire when opening the envelopes. The name of the participant on the questionnaire was coded by the medical research staff to maintain confidentiality. After coding, the questionnaire had no name identifier on it. The remaining questionnaire information data and separate consent forms with contact information for interviews and focus groups were locked in a filing cabinet in the researcher's home. The researcher was the only individual with the key to the cabinet. If the participant consented to allowing access to their glycosylated hemoglobin A1c records, the participant information was put into the cabinet and the coding system was used to identify the participants. The records will be kept for five years to answer future questions that may arise with future research. After five years, the information will be shredded.

Ten individuals stated, on the consent form, they would participate in a phone interview (see Table 2). Two individuals were not able to be reached and therefore could not participate in the phone interview. Two respondents stated that they would not be willing to participate in a personal interview or a phone interview. No respondents were willing to participate in a focus group. Participants were also asked if they would have access to or would be willing to obtain HbA1c records for the past five years.

Table 2

Participants at Hospital A

Completed Questionnaires	Valid with consent signed	Willing to participate in phone or personal interview	Participated in phone or personal interview	Allowed access to glycosylated hemoglobin A1c results
14	12	10	8	11

The phone interview was formulated to last between 15-20 minutes. The personal interview was developed to last between 25 and 30 minutes. The focus group was created to last between 45 and 60 minutes. A focus group could contain no fewer than three participants and no more than seven participants. The questions used for the phone interviews, personal interviews and focus groups (see Appendix E) were open-ended, developed to expand upon questions on the previously completed questionnaire and were created by the researcher. The questions were validated and considered appropriate to use for this portion of the research. The participants taking part in the phone or personal interviews were reminded of the informed consent letter signed previously during the questionnaire. They were reminded they could discontinue the interviews at any time. The information from the interviews and groups was written down by the researcher. The written information was then put into a locked filing cabinet at the researcher's home and will be kept for five years and will then be shredded.

Data Analysis

The questionnaire included information regarding demographics, diabetes control, medical treatment, overall health, and satisfaction with dietitian. Most of the questions were closed ended with yes or no answers. Three of the questions were on a Likert scale of 1-10. This scale was chosen to give a more accurate representation of the participant's answers. This allowed the participant a wider scale to assess their compliance level. Other questions were multiple choice and fill-in-the-blank.

The questionnaire information was analyzed using a Chi-square test. The information was entered into the SPSS program for analysis. One-dimensional Chi-squares were used based on the questions being analyzed (Gay, Mills, & Airasian, 2006). Chi-square testing was used to analyze each of the four research questions. Statistical significance was established at $p<0.05$. The groups were categorized as either "compliant during adolescence" or "non-compliant during adolescence". They were then categorized as "currently compliant" or "currently non-compliant" based on their submitted information on the questionnaire.

Information obtained from the phone and personal interviews was transcribed by the researcher. The information was then analyzed looking for common themes among answers given by the participants. Themes were then grouped together and analyzed and compared to questionnaire answers. Individual answers obtained from the interviews were compared with questionnaire answers to evaluate consistency between the two methods of data collection.

Summary

This chapter included research design, models, sample, instrumentation, validity, reliability, data collection and data analysis. Results of the data collection will be presented in chapter four.

Chapter 4

Results and Discussion

This chapter displays and discusses both the quantitative and qualitative results of this study. The research questions are addressed and the data collected is provided to help accurately answer the questions. Chi-square statistical information found little statistical significance for the quantitative data. Analysis of the qualitative data produced many similar themes between participants.

Results

Chi-square statistical analysis found statistically significant data with this research. Compliance numbers for both "current compliance" and "compliance during adolescence" were determined by taking the average based on the answers given on the Likert scale. This average was used to divide the participants into compliant or non-compliant status. Current compliance was split at six on the Likert scale of one to ten. For the basis of this research, compliance was defined as seven or above. If the participant marked six or below on the Likert scale he was considered to be non-compliant. The data was analyzed in two groups. The first set of data compared individuals who stated they were compliant or non-compliant during adolescence separately. The second set of data compared individuals who stated they were either currently compliant or non-compliant with their diabetes management separately.

Forty-three percent of the participants were categorized into the compliant group and 57% were identified in the non-compliance group. When assessing the individual opinions of the participants' compliance during adolescence, the same methods were used to evaluate compliance and non-compliance. If the participant marked six or greater on the Likert scale, he was considered to be compliant. Anything five or under was considered to be non-compliance. Sixty-four percent were included in the non-compliance category. The remaining 36% were considered compliant.

The results of the data will be expressed in relation to the research question/s that correlate/s with the compiled data. Data obtained from the quantitative and qualitative portions of the study were combined when answering the research questions.

Research question 1: What factors had the most influence on diabetes management in the adolescent person with type 1 diabetes?

The results for research question one include both positive and negative influences the participant experienced throughout adolescence. Utilizing both quantitative and qualitative data allowed a more accurate picture of the specific influences on the adolescent's diabetes management. These results will be discussed further.

Each participant was asked, in multiple questions, who and what had the most influence, both positive and negative, on their diabetes care throughout adolescence. Ninety-three percent of respondents answered that parents and family had the most positive influence on their diabetes management. The adolescent data showed there was no statistical significance ($\chi^2(1, N = 12) = 1.527$, $p = 0.217$) between the two groups, compliant and non-compliant, when comparing parents, family and friends as positive influences (see Table 3). This is likely due to the fact that in both questions six and seven, 11 of the 12 participants marked the same answer. When asked in the phone/personal interview what or who affected the participant in the most positive way during adolescence, four participants answered that their medical provider had the most positive influence on them. According to Silverstein, et al. (2005), education and support by medical providers, for both the children and the families, needs to be occurring continuously, not just at the time of diagnosis. Data from the phone interview supported these results as six of the eight participants stated that their parents/caregivers handled their diabetes care "well", or "as well as they could have", throughout adolescence.

Friends had both positive and negative influences on the adolescent with type 1 diabetes. When separated into the current adult group of compliant and non-compliant individuals and analyzed, there was a statistical significance ($\chi^2(1, N = 12) = 6.00$, $p = 0.014$). Every current non-compliant adult participant marked that friends during adolescence did not have a positive influence on them. Three participants answered that their friends had the most positive influence on them during adolescence. Four participants answered they did not feel that peer influence played a role in their diabetes management. One participant stated that her friends were very active in the education process and active in helping manage her diabetes. Two participants responded that their friends were educated on diabetes. Another participant stated that only his "closest friends" knew. His friends watched him and helped him stay on track with his diabetes care. Five participants believed that if their friends had been taught about diabetes, they may have taken better care of their diabetes during adolescence. This data is supported by Kyngäs and Rissanen (2001) who determined that a predictor of an adolescent having good compliance with their disease care is how much support is giving by their nurses, physicians, parents and friends.

Table 3

Chi-Square Data Analysis

Question	Group	Variable	P-value
6	Adolescent compliant and non-compliant	Friends	0.217
6	Current adult group compliant and non-compliant	Friends	0.014
7	Current adult group compliant	None	0.003
7	Current adult group compliant and non-compliant	Friends	0.014
8	Adolescent compliant and non-compliant	Diet	0.03

Note. Significance $p<0.05$. See Appendix A for questions.

Hemoglobin A1c level recommendations set forth by the American Diabetes Association are the same for both adults and adolescents. Hormonal changes, growth changes and activity levels of an adolescent may vary significantly from an adult causing diabetes care to be more difficult in the adolescent. Silverstein, et al. (2005) stated that creating guidelines that are difficult to achieve for an adolescent also puts them at risk for hypoglycemia and may give the adolescent a "feeling of failure". Two people answered that knowledge affected them positively. Knowing the health ramifications if they did not take care of their diabetes "right now" helped them to care for their diabetes appropriately.

Fifty-seven percent felt parents, family, friends and medical providers did not have the most negative influence on their diabetes management. This was statistically significant when analyzing the current compliance of individuals ($\chi^2(1, N = 12) = 8.571$, $p = 0.003$). Friends was statistically significant in the current group data when researching the most negative influence on diabetes management (χ^2(1, N = 12) = 6.00, p = 0.014). Grey, Boland, Yu, et al. (1998) determined that when diabetes care included both the adolescent and the parents, metabolic control, overall, was better than if parents handed all of the diabetes care over to the adolescent. When participants were asked what affected them in the most negative way during adolescence, three participants felt how they handled the care of their diabetes had the most negative influence. One participant stated when he would get low blood sugar reactions, it "scared people". Two participants answered their families had the most negative influence. One participant said her dad would eat chocolate and say, "you can't have any".

Ninety-three percent of the participants stated they complied with their insulin regimen throughout adolescence. Fifty-seven percent said they complied with blood glucose monitoring. Forty-three percent stated they complied with the diet recommendations set forth during adolescence. This data is supported by Kyngäs, Hentinen and Barlow's (1998) research finding adolescents with a chronic disease tend to have better compliance when the parents are helpful and encouraging. Kyngäs (1999) found when parents are supportive of their child with diabetes, the motivation of the child increases to become compliant. Two participants said their parents "did the best they could". Anderson, Vangsness, Connell, et al. (2002) found conflict between parents and children leads to lower quality of diabetes control. Three of the participants had other siblings with diabetes also. One participant who answered their parents did not handle their diabetes well stated the older sister and younger brother both had diabetes as well. "Everyone around my sister still fixed sweets." One of the participants with a sibling stated their mother cooked their foods and made sure there were foods available specifically they could eat based on their diet recommendations.

Throughout the first years following diagnosis, positive family relationships predicted adherence to a diabetes treatment schedule (Charron-Prochownik & Becker, 1998). Seven percent of the participants felt friends and medical providers had a positive influence on their diabetes management. Thirty-five percent felt friends had the most negative influence. Based upon literature reviewed, peer influence was found to have a significant influence on the care of diabetes, not only in the presence of the friends, but also diabetes care in general.

Five participants stated they liked their medical provider throughout adolescence. This was not defined as endocrinologist, dietitian or diabetes educator, but rather as a general medical provider. One participant stated that he/she did not like their medical provider. One participant stated that he was "very comfortable" with his endocrinologist which he then made his primary care doctor. He said he saw dietitians that were "quite helpful with meal planning". They "worked a diet around my likes and dislikes". Four of the participants did not see an endocrinologist, diabetes educator or dietitian throughout adolescence.

Six of the participants stated they would define their teen years as either good or normal. Five of those participants believed their biggest struggle throughout their teen years was diet when compared with insulin and blood glucose monitoring. According to the adolescent data, diet was found to be the only option that was statistically significant ($\chi^2(1, N = 12) = 8.571, p = 0.03$). This is supported by the findings from Charron-Prochownik and Becker (1998) who stated that likely the most difficult part of the diabetes regimen is the meal planning. Factoring the insulin adjustments needed to be made in order to compensate for the food consumption makes diabetes management difficult to “master”. Many of the participants did not have the insulin varieties or the insulin pumps available now to help adjust for different food choices. One participant said being diagnosed at 14 years old was a great struggle because “I had to get away from foods I was already used to”. One participant stated after football games she and her friends would go out for pizza. She wanted to be able to eat as many pieces as others in the group, but knew the effect it would have on her diabetes.

Two participants believed the disease, diabetes, itself was the greatest struggle. Six participants felt it was difficult to manage their diabetes and live a “normal life”. One participant stated she was “applying perfect standards to something that can’t be perfect”. Four of the participants stated, voluntarily, they did not “party” during their adolescent years. One participant said, “I never drank or did drugs due to being afraid that no one would know what to do if there was a problem”. One stated, “I had a lot of lows. When it happened, it was embarrassing”. At some time during the interview, each participant stated monitoring blood sugars was difficult to manage or not done at the time. Many said blood sugar monitoring took quite a bit of time, compared to the current methods, and it caused pain.

Influences, both positive and negative, played a large role in the participants’ diabetes management. In general, many of the participants felt diabetes care affected them the same way when compared to other participants’ answers. Many had the same feelings throughout adolescence with regards to diet and monitoring of sugar levels.

Research question 2: After adolescence, was the participant more likely to comply with medical advice? If so, what influenced the participant's decisions?

For this study, compliance was defined as the degree to which the participant's diabetes care corresponds to the advice given by their medical provider during adolescence and at the present. The age range at which participants' felt their diabetes care improved is seen in Table 4. Three participants did not complete this question on the questionnaire. This could have been due to the fact they felt their compliance had not improved as they were already compliant or because they felt their compliance had decreased since adolescence. Glycosylated hemoglobin A1c levels have been used to determine compliance related to diabetes control in people with diabetes (Kyngäs, 1999). According to the American Diabetes Association's Position Statement (2002), the diabetes goal for adolescents should be to try to maintain blood glucose levels that are in an acceptable range to provide normal growth.

Table 4

Improvement Age (Based on Current Compliance)

	20-25 Years Old	26-35 Years Old	36-45 Years Old
Compliance age	3	3	3

Note. Nine participants answered this question. Three participants left this question blank.

The participants were asked if they realized the severity of their disease during adolescence. Five participants stated, yes, they understood the severity of their disease. Most of the participants stated the reason for understanding was one person in their family had diabetes and they either saw the effects it had on their health or were told of the effects. One person stated, “I don’t think it’s [diabetes] a big deal”. One participant stated that on a day-to-day basis, she realized the effects of the diabetes, but stated that she was not thinking about the long-term effects that could be caused from the diabetes. Pound, Sturrock and Jeffcoate (1996) found that adolescence is the time period of life that participants have the worst control of their diabetes.

According to the data reported by the participants, 9 of the 12 participants’ compliance increased slightly after adolescence. Two participants kept the same level of compliance. Faulkner (2003) believes as adolescents grow older, they realize more the effects to their current health, if they have poor metabolic control. One participant stated she was “extremely compliant before having kids and before pregnancy”. She said she would consider herself “semi-compliant” at this time. “I don’t have time. I have other things to do. I would call myself less compliant than when I was an adolescent” she stated.

Ingersoll, Orr, Herrold, and Golden (1986) found diabetes knowledge and risks did not have a direct correlation with the metabolic control in adolescents. Factors that affected the compliance in adolescents with diabetes related more to the Health Behavior Model and the perceived risks the individual felt they were at risk for (i.e. poor health, feeling sick all the time, injuries from low blood sugars). Five of the participants stated as adolescents they realized the severity of their diabetes. One participant stated “on a day-to-day basis I realized the severity, but I was not thinking about the long-term effects”. Of the six participants that did realize the health implications that may occur from not caring for their diabetes, five stated they are currently compliant with their diabetes care. Four replied they want to be healthy long-term and understand the health problems that can occur both now and in the future if they do not currently take proper care of their diabetes (see Figure 1).

According to the adolescent data, a supportive family and spouse is statistically significant in influencing the participant's improvement in diabetes management (χ^2(1, N = 12) = 4.286, p = 0.038). The other options were not statistically significant. Four of the participants said they want to feel better at the present time and they realize how "high and low blood sugars make me feel". Overall, not all of the participants felt proper diabetes care now would affect them both now and in the future. One of the participants remarked if she cares for herself now, "the less likely it is I will lose my feet". The more the participant feels their health may be affected by the lack of care of their diabetes, the more likely the person is to take proper care of their diabetes. There was no statistical significance found from the adolescent data regarding participants' compliance increasing due to the onset of health complications specifically related to diabetes care. One participant stated health problems have started to occur for them increasing the need for further compliance.

If an increase in medical care could be provided to participants with diabetes from the time of adolescence to the present, would it help these participants increase awareness about what could happen to them medically if they do not take care of their diabetes appropriately? Overall, the health behavior model was supported in this study as many of the participants realized during adolescence what the effects may be both short-term and long-term if proper diabetes care is not provided. As the majority of participants were already compliant with their diabetes care, the perceived risks did not change their diabetes care dramatically, though they were reminded of how important proper diabetes care is to prevent current and future health issues.

Figure 1

Reasons for Current Compliance

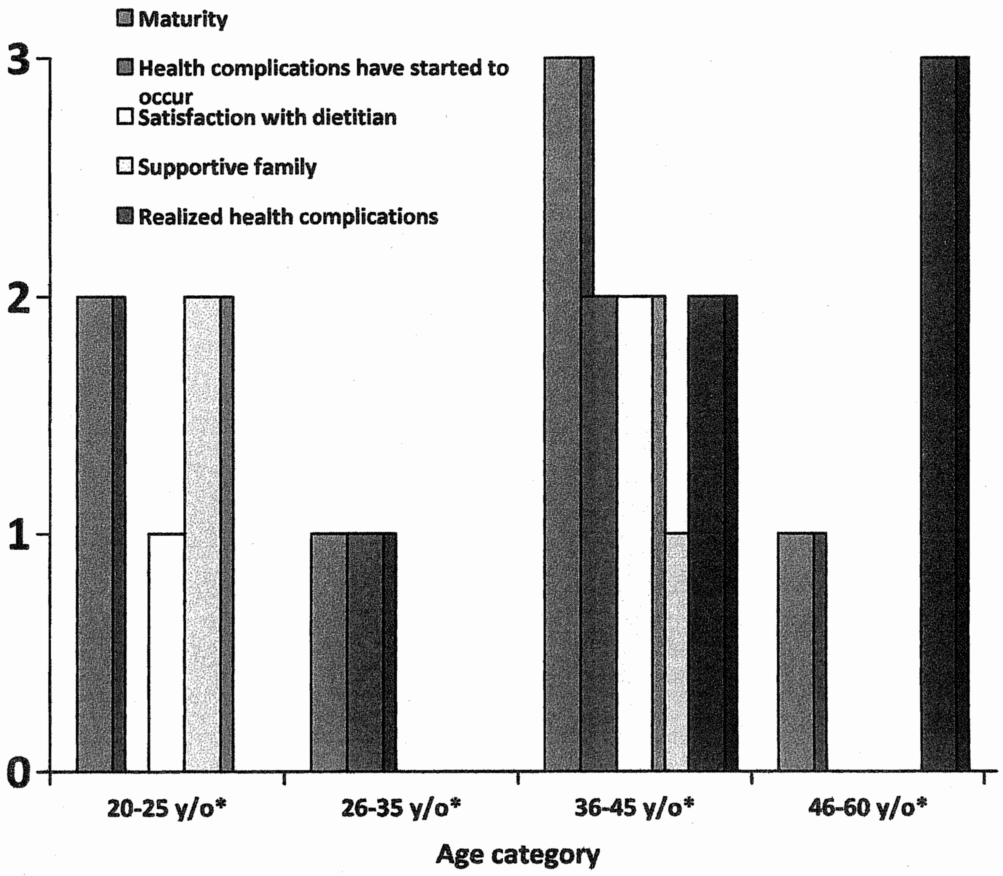

Figure 1. Note. The y-axis is the number of participants. *y/o = years old. N = 8. Many participants stated two or more reasons as an answer.

The Transtheoretical Model states an individual may be at a different "Stage of Change" in wanting to make the modifications needed to improve their health (Prochaska, Redding & Evers, 2002). The stages of change are as follows: precontemplation, contemplation, preparation, action, maintenance and termination (Prochaska, et al.). During adolescence an individual may feel they will improve the care of their diabetes after they are finished with high school, after college, when married, etc. Other adolescents may already be taking the action and following the diabetes plan set forth by their medical provider. From the research gathered for this study, seven of the participants are in the maintenance phase with their diabetes care. One of the participants would be categorized in the action phase as the care for their diabetes is being done, though not consistently. The participants stated they are all currently compliant or semi-compliant and therefore none are in the precontemplation, contemplation or preparation stage. As the care of diabetes does not end throughout a lifetime, and blood sugars can be affected by many things that are out of the control of the individual, it would not be correct to say an individual with diabetes could ever be in the termination phase.

Research question 2, addressing if the participant was more likely to comply with medical advice after adolescence and if so, what affected the decision to comply could not be adequately answered based on the questionnaire and phone interview data. Information was obtained based on items that have helped to either increase or sustain their compliance since adolescence. The answers were not directly related to following the advice of the medical provider. It was initially assumed that participants would mark on the questionnaire they had seen an RD during adolescence. The question following this is related to compliance with the advice given by the RD. Many of the participants did not see an RD during adolescence therefore making it difficult to assess if they were more likely to increase compliance after adolescence.

Research question 3: Throughout adolescence, what reasons do adolescents with type 1 diabetes have for adhering to, or neglecting the advice of dietitians?

Fifty percent of the participants stated during adolescence they did not feel the dietitian had an important role in diabetes management. There was no statistical significance ($\chi^2(1, N = 12) = 2.743, p = 0.098$) for this question when analyzed in the adolescent group. Of the 12 participants, 10 of them did not see a Registered Dietitian (RD) at any time during adolescence. Two of the three participants that saw an RD during adolescence complied with the nutritional advice given. Eleven of the participants currently feel it is important for a person with diabetes to see an RD. One participant answered that she does not currently feel that it is important for a person with diabetes to see a dietitian.

When asked, specifically, what some of the reasons are for ignoring the advice of the dietitian, seven participants responded. When the percentages were adjusted for actual responses, 43% percent answered "the diet did not fit into their schedule and/or they felt they had control of their diabetes". Fifty percent of participants said they wanted to live a "normal life". Kyngäs (2000) believes medical providers need to understand diabetes management encompasses not just one facet of the adolescent's life. It encompasses each minute of every day. Twenty-nine percent stated they did not feel health complications would arise if advice from their dietitian was ignored.

Participants were asked how diet affected their diabetes management during adolescence. Four responded it affected them "a lot". One person stated when he followed a "rigid diet" he was "happier". He also said when he was out with friends, "I got off of it". Another participant remarked she felt that diet "ran my life. I based everything on the time I had to eat." When asked if the participants "partied" or dieted during adolescence, six of the eight respondents stated they did not party or diet during adolescence. Of the participants who did "party", both of them stated "partying and staying up all night" affected their diabetes management. They suffered from low blood sugars the next morning which may have been caused by their different sleeping and eating patterns the next day. Three responded it affected them somewhat but not much.

Research question 4: If during adolescence, adolescent persons with type 1 diabetes missed appointments with their dietitians, what were the reasons?

Four participants did not answer the question of whether they missed or rescheduled appointments with the dietitian. Upon further review in the phone and personal interviews, it was found that these participants did not see a dietitian during adolescence. For the older participants the only specific medical care for their diabetes was done in the hospital when they were diagnosed, otherwise all of their care was done by their pediatrician. Eight more participants answered, "no," they did not consistently miss or reschedule appointments with their dietitian. Participants answering they did not miss or reschedule appointments with their dietitian would be described as a measurement error as the answers were inaccurate and the information is not useful when compared to other participants' answers (Dillman, 2007). Another option should have been, "Did not have a dietitian" or "Did not see a dietitian". Based on the phone interview results, many of the participants did not see an RD throughout adolescence and therefore this question did not apply to them, even though they may have answered, "No" to it. These answers were taken into account for the quantitative portion of the research, but were only noted in the qualitative portion of the research. One participant stated, "I only saw a dietitian three times a year so I didn't pay close attention to what they said".

When asked what some of the reasons were participants missed their appointments with the RD, many answers were checked. Ten participants did not answer this question. Two participants accounted for all of these answers. Between the two participants, all categories were marked. These reasons included, but was not limited to, felt they had control of their diabetes, diet did not "fit" into schedule, peer pressure, wanted to live a "normal" life, did not feel health complications would arise, etc. Of the completed questionnaires, 10 participants did not answer the question of the reasons they had for missing or rescheduling their RD appointments. This was likely due to many of the participants not seeing an RD during adolescence therefore making the question not applicable to them. Chi-square test produced statistical significance when the participant was asked if he/she felt they had control of their diabetes in the current compliance group data, ($\chi^2(1, N = 12) = 1.091$, $p = 0.046$). The participant created their own definition of "control of diabetes". This may have been they did not feel the care of their diabetes needed to improve at that time or they did not feel they wanted to do anything to improve their diabetes management. "Control of their diabetes" was not defined by the researcher. One participant answered they did not schedule the appointment with the dietitian because they did not like the dietitian. "I knew it was important, but they had very poor methods, so I avoided dietitians."

Participants were asked what a dietitian could do to positively influence an adolescent with type 1 diabetes. One response was to set a diet that accommodates an individual's likes and dislikes and create an individualized meal plan. Another response was for the dietitian to be persistent in teaching about diet. One person suggested getting the whole family involved by having the entire family eat the same food and not create a separate meal for the child with diabetes. Another participant said to tell the adolescent, "you do this right now and you will benefit from this later". Two participants stated giving the adolescent new information regarding diabetes would help keep the adolescent informed of changes and/or improvements in diabetes care. A few more suggestions were to prepare the individual for struggles they may encounter both now and later in life, discussing the importance of proper diabetes care for both current and future health and trusting the dietitian.

These suggestions are in accordance with the guidelines offered by Anderson and Rubin (1996) to help medical providers effectively inform adolescents how to properly care for their diabetes. The guidelines are as follows: (1) do not assume an adolescent is ready to independently care for their diabetes based on age alone, (2) be clear that diabetes care is a family matter and parents need to be involved, (3) create realistic blood glucose goals, (4) realize the teenager and their parents need help to deal with the feelings associated with having diabetes, (5) ask good questions, (6) focus on the successes, (7) realize the adolescent is in control of their blood glucose levels and no one else can control these levels, (8) be specific about care, help, plans, etc., (9) maintain contact with the adolescent and the parents, (10) help with problem-solving skills, (11) help build emotional strength, and (12) get additional help if needed.

Kyngäs, Hentinen and Barlow (1998) found that approaches need to be made to help in aiding the adolescent with diabetes to determine a way to bring both their diabetes care and their everyday life together for the best and most realistic goals for diabetes management. This idea has been suggested multiple times throughout this research.

When asked if the participant is currently compliant and what reasons they have for being compliant, five answered that health was the most important reason. Three participants answered they feel better when they are compliant. Two participants answered family, both now and in the future, help to keep them compliant. One participant stated it is much easier to stay compliant currently because the tools and tests are so much “easier to deal with than it used to be”.

Discussion

Based on this information, the majority of participants’ compliance level did not change from adolescence to adulthood. One participant’s compliance did slightly decrease from adolescence until the present time. According to Prochaska, Redding and Evers (2002), an individual can stay within one stage of the Transtheoretical Model or they can change stages, with both improvement and/or regression. Based on this information, all of the participants except the one participant whose compliance has decreased would be categorized in the maintenance and/or termination stage. This finding is based on the information provided by the participant regarding their current diabetes management. Each of the participants stated they currently care for their diabetes daily, though at times they may consume foods they know may cause their blood sugar levels to increase. Many of the participants stated that with the insulin pump therapy they are able to consume these foods and live a slightly more “free” life and do not have to care for their diabetes so “rigidly” anymore. Some of the participants may not remember to monitor their blood glucose as many times a day, on certain days, as the doctor recommends, though overall they are managing their diabetes daily. The maintenance stage is defined as a period from six months to five years (Prochaska & Velicer, 1997;

Prochaska, et al., 2002). Based on the information gained from this research, each of the participants would be defined as being in the maintenance stage.

The definition of termination by Prochaska, et al. (2002) is the stage when an individual will not give into health risks, foods, behaviors, etc. that could hinder their diabetes care. They are fully in control of their diabetes. Diabetes is an ongoing issue that must be cared for each day. Termination is not likely to be fully achieved by a person with diabetes as there are many factors that can affect diabetes care, both voluntary and/or non-voluntary. According to Prochaska & Velicer (1997) an individual has "zero temptation" when in termination. A person with diabetes may be tempted to skip one blood sugar reading a month. They may be tempted to eat slightly more carbohydrates than are recommended in their diet plan. They may stay up later than they should based on their insulin regimen. There are many factors that can "tempt" an individual with diabetes and therefore minimize the chances of reaching the full termination stage.

According to this information, an individual that has maintained diabetes compliance for more than five years could be considered in the termination stage, though the information states that the individual would have no temptations to make a poor food choice, to not take their blood sugars the recommended number of times one day, to not exercise as many days of the week as recommended. According to this study, the Transtheoretical Model does not accurately assess an individual with a chronic disease. There is not a stage of change that accurately represents the individual that is compliant with their diabetes care, but wants to maintain a "normal" day to day lifestyle.

Improvement of diabetes management, since adolescence, was related generally to maturity. The most frequent answers behind maturity were satisfaction with the dietitian, having a supportive family and/or spouse, and realizing the health complications that could occur with diabetes. Effectiveness of treatment was also answered as a reason for improvement. The Health Belief Model (HBM) states that an individual's health behavior will be determined by: (1) the need to minimize or eliminate the risk for illness or to improve health and (2) the idea that specific actions will improve or prevent illnesses (Janz, Champion & Strecher, 2002). This is based on the risk the person feels that they may be susceptible to an illness or the worsening of a current illness and the action an individual needs to take to change the risk. The different concepts of the HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy (Janz, Champion & Strecher). Based on the HBM, five participants care for their diabetes because of the perceived susceptibility and/or the perceived severity of what can occur if proper care now is not attained. Three participants "feel better" when they take proper care of their diabetes demonstrating that they are aware of the perceived benefits of feeling better each present day. The medical provider plays a role in providing the individual with cues to action to help ensure the self-efficacy of the individual. It is up to the individual to regard the information from the medical provider and utilize it to better care for their diabetes.

Glycosylated hemoglobin A1c results from the last 5 years were obtained by the Medical Research office at Hospital A. The results were provided to the researcher on July 8, 2008. All other data from the other two instruments had been analyzed by the time the glycosylated hemoglobin A1c values were provided to the researcher. Upon review, the results did not show a change in A1c levels over the timeframe for which the data was provided. Participants' A1c levels varied slightly, but not enough to confer that compliance had changed over either the last five years or at the beginning of the participant being tested at Hospital A.

Glycosylated hemoglobin A1c results were not used for this study. The results were provided to the researcher after analysis had been done using both the questionnaire and interview results. The participants stated they were compliant during adolescence and are still currently compliant with their diabetes care. The overall hemoglobin A1c results did not vary over time, among participants, when reviewed. There were no outliers of A1c levels among the participants. The initial belief of the researcher was that analysis of the A1c results would help to better evaluate if an participant was currently “compliant” and if the compliance had improved during the last five years. If it had improved, the researcher would have asked the participant what they had done that may have contributed to the improvement in their hemoglobin A1c levels. This information could then have been related to both the Health Behavior Model and the Transtheoretical Model. This did not occur however as the participants were, and still are, compliant.

Summary

This chapter reviewed the results, the research questions, data related to answering the research questions and a discussion of the results. Summary, implications, recommendations and conclusions will be presented in chapter five.

Chapter 5

Summary, Conclusion, Limitations and Implications

Summary

The purpose of this study was to determine what factors played a role in compliance and non-compliance in the adolescent with type 1 diabetes and what factors may have caused the individual to change and/or maintain their diabetes management after adolescence. The research questions explored in this study were: (1) What factors had the most influence on diabetes management in the adolescent person with type 1 diabetes, (2) After adolescence, was the patient more likely to comply with medical advice? If so, what influenced the patient's decisions?, (3) Throughout adolescence, what reasons do adolescents with type 1 diabetes have for adhering to, or neglecting the advice of dietitians?, and (4) If during adolescence, adolescent persons with type 1 diabetes missed appointments with their dietitians, what were their reasons?

This retrospective study using both quantitative and qualitative data examined a sample of participants with type 1 diabetes and evaluated the care of their diabetes during adolescence and compared it with their current care of diabetes. The sample consisted of 12 participants obtained from a middle sized hospital in the Midwest. The study utilized a questionnaire and phone or personal interviews for data collection. Many of the participants struggled with the same issues during adolescence related to diabetes care. From the data gathered, it was difficult to determine what factors played the largest role in diabetes care. The participants were compliant throughout adolescence making it more difficult to determine factors that may have had a negative influence on the adolescent. Parents and family were found to be the most influential variables in diabetes care. Many of these factors were discussed in this study. The testing tools available now are much different than when many participants were in their adolescence. This has helped many of the participants improve their diabetes management since adolescence even if they labeled themselves as compliant during adolescence.

The small number of participants made it difficult to accurately compare the data from this study with past research. The information obtained from this study can be used to help medical providers and the adolescent person with type 1 diabetes create diabetes care plans that cater more towards each individual and their lifestyle. The information obtained from this study helped to show how imperative it is to have a strong family support system during adolescence to help with diabetes management compliance for the adolescent with type 1 diabetes.

Conclusion

The information gained from this research did not give a good representation of the current adolescent population, nor did it give a good representation of adolescents that either struggled to care for their diabetes due to defiance or inability to accurately understand the medical and dietary aspects of proper diabetes care. The data obtained from this study had some similarities, but not all data was consistent with past research. This study helped to illustrate the differences that participants with diabetes have had to struggle with throughout the years. One person's struggles with diabetes care may be much different than a person 10 years younger.

Improvements in technology have helped make diabetes care more achievable. The care provided to patients with diabetes has improved with more frequent visits to medical providers, the addition of insulin pumps, the flexibility in meal plans, etc.

Diabetes technology and diabetes research continue to improve. With the improvements there is hope that diabetes care will become less time consuming and will allow more flexibility in lifestyle for the individuals with diabetes.

The small number of participants may have caused the research to be inconsistent with past research. Allowing only patients that arrived at their medical appointments to complete the questionnaire limited the number of participants as well. There was information gathered from this study that will be helpful for future research studies.

Limitations

There were limitations to this study. The limitations are as follows:

1. There was reliance upon hospitals and medical providers to give out the information. A recommendation would be to send out questionnaires to all current patients with type 1 diabetes that utilize the medical facility. This may help minimize non-response error and may increase the number of individuals with diabetes that participate (Dillman, 2007). This would allow a better picture of the individual with diabetes that is compliant compared with the individual that is non-compliant.

   This study provides information to help show that each individual with diabetes is different in their needs for diabetes care. Each adolescent has different experiences at different times throughout their youth. The difference in timing is essential for proper diabetes care. Hormones, growth spurts, night life, etc. all play a vital role in diabetes care. In order for the adolescent to properly care for their diabetes while still living a "normal life", each of these items needs to be taken into consideration.

A larger number of questionnaires should be distributed to obtain more information. This should be done by distributing more questionnaires and utilizing more medical facilities. Hospital A handed out the maximum 25 questionnaires. They had seen 24 participants with type 1 diabetes. They would not have exceeded the maximum allotment had more questionnaires been provided. The amount of time the questionnaire packets were being distributed at the doctor's office was limited. Not all adult patients with type 1 diabetes may have had an appointment with a medical provider during the two month time span of data collection.

There were a low number of participants for this study. This could be due to the smaller time span for data collection or the limited number of patients with type 1 diabetes that are seen at the medical facilities. Limiting the population to only adults with type 1 diabetes made it more difficult to obtain current factors that may affect the adolescent with type 1 diabetes. A recommendation would be to research both current adolescents with type 1 diabetes and adults with type 1 diabetes and compare and contrast the data.

2. The average age of participants was over 40 years old. Future research should be conducted on individuals 22-35 years old to better identify current struggles with diabetes care to further create education for the person with diabetes, the family of the individual and the friends of the individual.

The need to rely on the memory of the individual and assume the information was accurate became a limitation. Many participants were recalling information from more than 20 years prior. The accuracy of their answers may not be as reliable as it would be with a younger population.

For this study, personal compliance was used as a factor to determine the degree to which the participant cared for their diabetes both in the past, and currently. Compliance was defined by the participant. If one is following the medical regimen set forth by the medical provider and their blood glucose levels are not "normal", does that indicate compliance? There are medical levels set forth as to what the recommended blood glucose levels should be, but each participant may have a different range based on their own body. It is difficult to have an individual define their own compliance and then use it to accurately compare it to the other participants.

3. Many individuals currently use an insulin pump. One could explore the differences in care during adolescence with the individual that uses an insulin pump and the individual that does not, or has not used an insulin pump.

Implications

This study assessed how diabetes care has changed and the factors that may have affected their diabetes care during adolescence. The information obtained from this research can be utilized to create care plans that focus on the adolescent with type 1 diabetes and their lifestyle versus a generalized care plan for all adolescents.

The information gained from this research illustrated that adolescents with supportive caregivers, who had a part in their diabetes care throughout adolescence, had better diabetes management care skills that carried into adulthood. Findings from this study demonstrated that adolescents that had improved care of their diabetes throughout adolescence and who understand both the current effects and future effects on their body and health are more likely to properly care for their diabetes during adulthood.

The information from this study can be used for parents of children with type 1 diabetes, the individual with type 1 diabetes, dietitians, diabetes educators and medical doctors. Parts of this study addressed each one of these individuals. This study may help in determining how to better care for the individual with diabetes and help provide the best support to help with their diabetes management in their younger years to set the stage for proper diabetes management in their adult years.

There were many commonalities among the answers of participants even though there was a large age variance. The struggles that each participant encountered during adolescence in regards to diabetes care seemed to be very similar. The basic care of diabetes varied based on the technology of glucose testing and insulin available at the time, but overall, the everyday struggles with having diabetes were the same. Most individuals stated diet was the biggest struggle as they wanted to eat the foods available to their friends. With the current diabetes technology available, individuals no longer have to feel that they are unable to "eat as many pieces of pizza as my friends". They are able to adjust their insulin amounts to allow for more "freedom". Diabetes care has improved dramatically over the past decade and continues to improve allowing individuals with diabetes to have a more "normal" lifestyle.

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List of Appendices

Appendix A.

Appendix B.

Appendix C.

Appendix D.

Appendix E.

Appendix A

Questionnaire

Please circle, X, or fill in the answer that describes you the best.

1. Age: ________________

2. Gender: ☐ Female ☐ Male

3. At what age were you diagnosed with diabetes? _________________

4. At what age did parents/caretakers start to give you some control over your diabetes?

   ____

5. Was the control given to you gradually or all at once?

   ☐ Gradually ☐ All at once

6. Who had the most positive influence on your diabetes management during adolescence?

   ☐ Parents/Family ☐ Friends ☐ Medical Providers ☐ None

7. Who had the most negative influence on your diabetes management during adolescence?

   ☐ Parents/Family ☐ Friends ☐ Medical Providers ☐ None

8. What part of diabetes management did you comply with during adolescence?

   ☐ Insulin ☐ Blood glucose monitoring ☐ Diet ☐ None

9. What part of diabetes management was the easiest to comply with during adolescence?

   ☐ Insulin ☐ Blood glucose monitoring ☐ Diet ☐ None

10. Rate your current diabetes control.
    (1=No control, 5=Adequate control, 10=Total control)

    1 2 3 4 5 6 7 8 9 10

11. Rate your diabetes compliance in the last 5 years.
(1=Non-compliant, 5=Somewhat compliant, 10=Very compliant)

1 2 3 4 5 6 7 8 9 10

12. Rate your diabetes control throughout adolescence
(1=No control, 5=Adequate control, 10=Total control)

1 2 3 4 5 6 7 8 9 10

13. If your diabetes management has improved since adolescence, at what age did this occur?

☐ 20-25 ☐ 26-35 ☐ 36-45 ☐ 46-60 ☐ >60

14. If diabetes management has improved, what factors helped to cause an improvement?

☐ My management has not improved
☐ Satisfaction with the dietitian
☐ Supportive family/spouse
☐ Not visiting other medical providers
☐ Health complications occurring
☐ Felt that my health was deteriorating
☐ Maturity
☐ Beliefs about the effectiveness of the treatment
☐ Realized the health complications that can occur with diabetes
☐ Body mass index (Weight)
☐ Other

15. Did you change diabetes medical providers (i.e. doctor, dietitian, diabetes educator) after adolescence (20 years old) or did you keep the same provider into adulthood?

☐ Changed providers ☐ Same providers ☐ Changed some providers

16. Did you ever try a weight loss program during adolescence? Yes No

17. If so, what type/s of methods did you try? Check all that apply.

☐Starvation
☐Low-fat/low-calorie diets
☐Not taking insulin
☐Exercise
☐Vomiting
☐Laxatives
☐ Other

18. Did you see a dietitian throughout adolescence? Yes No

19. If yes, did you comply with the nutritional advice being given? Yes No

20. Mark all that apply:

☐ During adolescence I felt the dietitian had an important role in my diabetes management.

☐ I currently feel it is important for diabetics to visit dietitians.

☐ During adolescence, I did not feel the dietitian had an important role in diabetes management.

☐ I currently feel that it is not important for diabetics to visit dietitians.

21. Did you consistently miss/reschedule appointments with your dietitian (more than 3 times per year)? ☐ Yes ☐ No

22. If yes, what were the reasons? Check all that apply.

☐ Scheduling conflicts with school
☐Scheduling conflicts with sports
☐ Did not feel like going
☐ Did not like dietitian
☐ Overweight
☐ I was dieting
☐ Other
☐ Had not followed diabetes plan
☐ Did not want to get lectured
☐ Did not feel diet was important
☐ Did not have a ride
☐ Underweight
☐ I was neglecting insulin

23. If you neglected the advice of your dietitian, what are some reasons for ignoring the advice?

☐ Peer pressure
☐ Did not like to give finger sticks
☐ Did not like to be on a schedule
☐ Had experienced weight loss
☐ Diet did not "fit" into schedule
☐ Wanted to live a "normal" life
☐ Wanted to disobey parents
☐ Had experienced weight gain
☐ Felt you had control of your diabetes
☐ Did not feel health complications would arise
☐ Felt there were too many diabetes related areas to improve ☐ Other

**Thank you for your time and cooperation!

Appendix B

Cover Letter

[Carle letterhead]

Dear Patient:

You are being invited to participate in a research project studying factors affecting diabetic nutritional compliance throughout adolescence. The results of this research project will be used to complete a master's thesis at Eastern Illinois University. The information gained from this study will allow practitioners to better understand issues that diabetic adolescents encounter and how these affect diabetic compliance.

There are four parts to this research and you may participate in <u>any or all</u> of these. The research consists of a questionnaire, a phone or personal interview and a discussion group with 3-7 other participants. The last part involves obtaining your glycosylated hemoglobin A1c records from the past 5 years.

You have been given a packet of information. The enclosed consent form will explain these options to you but if you have further questions, please feel free to contact the researcher, MaryJean Bargren, by phone at (217) 377-5185 or by e-mail at mjbargren@mchsi.com. You may also call any of your medical providers in the Carle Endocrinology Department at (217) 383-3490.

If you wish to participate, sign the informed consent and the HIPAA Authorization form in your packet. Please have a witness sign the consent form. You may keep the additional consent form for your personal records. These documents, along with the completed questionnaire can then be returned to Carle in the addressed and stamped envelope provided to you.

Sincerely,

Dr. Michael G. Jakoby, M.D. Department Head, Endocrinology

Appendix C

Authorization To Use Protected Health Information

Office of the Carle Institutional Review Board

Carle Foundation Hospital, Carle Clinic Association and Carle Foundation affiliates (Carle)

AUTHORIZATION TO USE AND DISCLOSE PROTECTED HEALTH INFORMATION FOR RESEARCH PURPOSES

Factors Affecting Dietary Compliance in the Adolescent with Type 1 Diabetes

The privacy law, Health Insurance Portability & Accountability Act (HIPAA), protects my individually identifiable health information. This health information is called protected health information (PHI). In most cases, the privacy law requires Carle Foundation Hospital, Carle Clinic Association, and Carle Foundation affiliates (collectively Carle) to obtain an authorization (or agreement) signed by me in order for Carle to be able to use or disclose my protected health information for research purposes in the study entitled Factors Affecting Dietary Compliance in the Adolescent with Type 1 Diabetes.

I authorize Carle to use and disclose my protected health information for the purposes described below. If I am admitted to another hospital or medical practice due to an adverse event related to this study, I authorize MaryJean K. Bargren and her research staff to access my medical records at the other institution(s).

My health information, which is contained in various records pertinent to this study (i.e. paper medical record, databases, lab/pathology reports, radiology films, etc.), may include the following identifiers that may be used and disclosed for the purposes of this study:

- Demographic information including age and sex obtained from the questionnaire.
- Glycosylated hemoglobin A1c lab records

This information will be de-identified of personal information.

My protected health information will be used and disclosed for the following purpose(s):

- To conduct this project to research adults with type 1 diabetes and try to determine what factors played a role in compliance and/or non-compliance of their diabetes management throughout adolescence.
- The glycosylated hemoglobin A1c records will allow the researcher to determine the current diabetes control of the participant.

My study-related health information may be used by and shared with any of the following Recipients:

- MaryJean K. Bargren and her research staff
- Office of the Institutional Review Boards at Carle and Eastern Illinois University, when requested for routine audits,
- Government Representatives, when required by law,
- Carle Representatives (including Carle Clinic, Carle Hospital, and all Carle Foundation affiliates),

Once my health information has been disclosed to anyone other than Carle Representatives, the information may no longer be protected under the laws and regulations applicable to Carle.

I do not have to sign this Authorization. If I decide not to sign the Authorization:

- It will not affect my treatment, payment or enrollment in any health plans or affect my eligibility for benefits.
- I will not be allowed to participate in the research study.

After signing the Authorization, I can change my mind <u>at any time</u> and revoke the Authorization by sending a written letter to:

- Barbara D. Hall, Research Coordinator, Health Systems Research Center, 611 W. Park Street-MERC, Urbana, IL 61801

If I revoke this Authorization, Carle Representatives may not continue to disclose my protected health information for this research purpose, except for the following:

- Recipients may use and disclose my protected health information **already** collected for this research study.
- Recipients may still use and disclose my protected health information should I have an adverse event (a bad effect).

If I change my mind and withdraw the authorization, I will not be allowed to continue to participate in the study.

I understand that I will not be allowed to review the information collected for the research until after the study is completed. When the study is over, I will have the right to access the information again.

This Authorization does not have an expiration date.

If I have any questions or concerns about my privacy rights, I should contact the Carle Institutional Review Board (a group of people who review research to protect my rights) at 217-383-4366.

I am the subject or am legally authorized by law to act on behalf of the subject. I have read this information, and I will receive a copy of this form after it is signed.

Signature of research subject or *research subject's legally authorized representative	Date
Printed name of research subject	*Printed name of research subject's legal representative

*Please explain Representative's relationship to Patient and include a description of Representative's legal authority to act on behalf of Patient: ______________________

Appendix D

Informed Consent Form

CONSENT FORM
06-73 Factors Affecting Dietary Compliance in the Adolescent with Type I Diabetes

You are being asked to participate in this research study because you now have type 1 diabetes and had type 1 diabetes during part of your adolescence. You also received medical treatment for type 1 diabetes during that time. The purpose of this research is to identify factors that may affect nutritional compliance throughout adolescence in persons with Diabetes.

Approximately 30-40 Carle patients will participate in this study. Your participation in this study is entirely voluntary. Your decision whether or not to participate in any of the phases of this research will not prejudice your medical care. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

PROCEDURES: You have been given a packet with an introductory letter to the research, this consent form, a HIPAA Authorization form, an addressed and stamped return envelope, and a questionnaire. You may participate in <u>any or all</u> of the phases of this research by indicating consent below:

_______Please place your initials here if you have filled out and are returning the questionnaire in your packet. Your questionnaire will be assigned a code number to keep your answers confidential.

_______ Please place your initials here if you have returned a record of your glycosylated hemoglobin A1c records for the past 5 years in this envelope or if you will allow a Carle research staff member to look up your glycosylated hemoglobin A1 c records from your Carle records. These records will have any information that can identify you removed from them and will be assigned the same code number as your questionnaire. If you send these records to us, they will be returned after the study is finished if you wish.

_______ Please place your initials here if you would like to participate in a 15-20 minute phone interview or a 25-30 minute personal interview. Your responses to questions will be written down by the interviewer or her assistant, but any information that can identify you will be removed and will be assigned the same code number as your questionnaire. Please check which type of interview you prefer:

☐ Phone Interview ☐ Personal Interview

_______ Please place your initials here if you would like to participate in a discussion group of 3 to 7 other people who also had type 1 diabetes as adolescents. This session will be recorded and your non-verbal reactions to questions or discussion by the group may also be written down by the researcher's assistant. Any information that can identify you will be removed and will be assigned the same code number as your questionnaire.

You do not have to answer any questions that make you feel uncomfortable.

RISKS AND BENEFITS: Some questions asked may remind you of undesirable experiences during adolescence and from having diabetes. You may also become concerned about health problems that may occur in the future.

You may not receive direct benefit from this research. Information obtained from this study will be available to dietitians to help create better ways to educate adolescents with diabetes more effectively. This information may increase compliance in diabetes management in adolescence and into adulthood.

COSTS: Taking part in this study will not lead to added costs to you or your insurance company. No funds have been set aside by Carle to compensate you in the event of injury.

You will receive no payment for taking part in this study.

CONFIDENTIALITY: Efforts will be made to keep your personal information confidential. However we cannot guarantee absolute confidentiality. All of the information about you obtained for this research will be given a code number and any information that can identify you will be removed. You will not be individually identified in any report or publication about this research. Your personal information may be disclosed if required by law. You have been given an "Authorization to Use and Disclose Protected Health Information for Research Purposes" form to review, sign and return in the envelope provided. This form will explain what health information can be disclosed, the purposes for which disclosure may be used, and the people and groups that may receive your health information.

QUESTIONS: For questions about the study or your participation in the study, please contact your medical provider in the Carle Endocrinology Department at (217) 383-3490 or the researcher, MaryJean Bargren at (217) 377-5185 or mjbargren@mchsi.com. For questions about your rights as a research participant, contact the Carle Institutional Review Board at (217) 383-4366 or the Eastern Illinois University Institutional Review Board at (217) 581-8576 or eiuirb@eiu.edu. An Institutional Review Board is a group of people who review the research to protect your rights.

CONSENT: By signing below you acknowledge that you have been informed of the study and your questions have been answered. You may request information obtained from this research upon completion of the study. You will be given a copy of this consent and will be told of any new information that may affect your health, welfare, or willingness to stay in the study.

Printed name of participant

Signature of participant Date

Signature of witness to participant's signing of consent Date

Signature of Principal Investigator Date

If you wish to participate in the interview and/or discussion group phases of this study please provide contact information:

Name: ____

Telephone #: ____

E-mail: ____

Which form of communication is better for you? _____ Phone ____ E-mail

Appendix E

Phone/Personal Interview Questionnaire

Questions for Phone Interview/Personal Interview/Discussion Groups

State to each participant: As stated in the previously signed informed consent letter, you may discontinue participation in this interview/discussion group at any time.

Researcher sign after approval of participant: ________________________________

1. Do you feel that your parents/caregivers handled your diabetes well throughout adolescence? Explain.
2. Do you feel they were overly protective? Explain.
3. Did you like your medical providers during adolescence? Explain.
4. How would you describe your teen years?
5. What did you struggle with during your teen years (i.e. diabetes, weight, diet, friendships, parents, siblings, etc.)?
6. Did you feel it was difficult to manage your diabetes and live a normal life at this time? Explain.
7. What affected, either positively or negatively, your diabetes management the most during adolescence? Explain.
8. Do you feel that peer influence played a large role in your diabetes management? Explain.
9. Do you feel that if your friends had been taught about diabetes, your diabetes management during your adolescent years may have been better? How so?
10. How did diet influence your diabetes management during adolescence? Explain.
11. Did you play sports during adolescence? Which sports? How did this affect your diabetes management?
12. Did you party (define) during adolescence? How did this affect management?
13. Did you ever diet during adolescence? What dieting methods did you use? How did this affect your diabetes?
14. What could a dietitian do to positively influence adolescent type 1 diabetics?

15. Did you have other friends with diabetes? Did you have an adolescent diabetes support group? How did this affect your compliance? Do you feel that having more diabetic children around you would have increased compliance?
16. During adolescence did you realize the severity of your disease? Explain.
17. If currently compliant, why are you compliant?