University of Nevada, Reno

Factors that Hinder and Help Adolescents to Medically Manage Type-1 Diabetes

A thesis submitted in partial fulfillment of the
requirements for the degree of
Master of Science in Social Work

by

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May, 2010

THE GRADUATE SCHOOL

We recommend that the thesis
prepared under our supervision by

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entitled

Factors That Hinder And Help Adolescents To Medically Manage Type-1 Diabetes

be accepted in partial fulfillment of the
requirements for the degree of

MASTER OF SOCIAL WORK

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May, 2010

ABSTRACT

Type-1 diabetes is a chronic illness that affects roughly 23.6 million Americans each year (American Diabetes Association: All about diabetes, 2007). This disease is typically diagnosed when an individual is around adolescence or younger. Adolescence can be a difficult time, especially for those that have type-1 diabetes. There are multiple factors influencing the choices of an adolescent to adhere or not adhere with medical recommendations about diabetes care. The purpose of this study is to address the following research question: What factors influence an adolescent, age 12-18, with type-1 diabetes, to adhere or not adhere to medical recommendations regarding their diabetes care?

Upon completing a literature review, it was determined that there are few studies that focus on adolescents with type-1 diabetes that have been conducted in the United States. To address this issue, a mixed method analysis was conducted. A quantitative analysis was completed using participants (N=22) who were asked to fill out a survey on the online survey tool of Survey Monkey indicating the frequency of diabetes management behaviors that their predominant caregiver did during their adolescents. They were also asked what diabetes management behaviors would have been helpful or unhelpful using the Diabetes Family Behavior Checklist. Qualitative data was gathered by interviewing participants who consented to a follow-up interview and a key informant who works with adolescents with type-1 diabetes in the community. The data were analyzed using SPSS. Notably the “age of onset” variable was identified as the variable that most influenced both the frequency of diabetes management behaviors and the helpfulness or unhelpfulness of those diabetes management behaviors.

DEDICATION AND ACKNOWLEDGMENTS

This study and final project has been a long time in development. I am pleased that is has finally come to fruition and that the results are finally known. For their patience and understanding, this thesis is dedicated to: Dr. Linda Anngela-Cole for putting up with interesting weekly meetings about ideas on how things should be done and endless support and reassurance in the process; Dr. Denise Montcalm for allowing me to explore this topic and helping me to formulate this thesis into a logical and fully formed document; and Dr. Wei-Chen Tung who helped with data analysis, the usefulness of Survey Monkey, and edits to help create a useable product.

I would also like to thank and acknowledge my fellow graduates who went through this process with me. We were never at a loss for a good laugh and the ability to make the process bearable and enjoyable.

And finally, I would like to thank my family for pushing me to never give up on a subject matter that I wanted to explore and for making sure I never gave up on myself as well as a tremendous amount of financial support so I could focus on my scholastic opportunities. I want to give special thanks to my good friends Amy Sabatino and Pam Wangsness for helping out this past year and for their ideas, editing and love. Above all, I want to thank Anne Thomas for giving me support and love throughout this entire process. I could not have completed this task without everyone's support and patience.

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INTRODUCTION

Diabetes is a life altering chronic illness that affects roughly 23.6 million Americans each year (American Diabetes Association, 2007a). This chronic illness is increasing dramatically, especially among youth. The complications that can arise from diabetes can be devastating. Individuals with this disease can look forward to a life that may include blindness, cardiovascular complications like heart attacks and strokes, and neurological complications like neuropathy and even amputations of limbs. There are two types of diabetes: type-1 and type-2. Type-1 diabetes is commonly referred to as juvenile diabetes, or insulin dependent, because onset can happen at a younger age and the individual will be dependent on insulin the rest of his/her life. The number of individuals with type-1 diabetes in America is approximately 1.4- 2.8 million (American Diabetes Association, 2007a). Of these, non-Hispanic white youth under the age of 20 have the highest incidence of type-1 diabetes, as well as the highest number of new diagnoses compared to other ethnic groups (National Diabetes Information Clearinghouse, 2007). There are many factors that influence an individual with type-1 diabetes to make decisions to adhere to medical recommendations. The purpose of this study is to explore factors that contribute to adherence, along with identification of factors that detract from adherence among adolescents.

This study focuses on the behaviors of adolescents in order to gain insight into what may help or hinder their adherence to medical recommendations for type-1 diabetes. The introduction is organized in the following manner. First presented is an overview of type-1 diabetes, followed by the economic cost and management techniques of type-1 diabetes, with a brief section about why adherence to medical recommendations can be challenging for adolescents. Each section leads to the research question of: What factors influence an adolescent, age 12-18, with type-1 diabetes to adhere or not adhere to medical recommendations regarding their diabetes care?

Description of Type-1 Diabetes

Type-1 diabetes is a genetic disease that targets the pancreas. The pancreas produces insulin which breaks down food and transforms it into energy for the body, including the vital organs. In people with type-1 diabetes, the pancreas does not produce any insulin to help in the production of energy for the body. To help with this deficit, a person who is diagnosed with type-1 diabetes must use supplemental insulin. This supplement can either come in the form of multiple daily injections or an insulin pump. For those individuals with diabetes choosing insulin shots, they may have to give themselves up to 6 injections in a single day. Many individuals with diabetes, especially adolescents, are choosing an insulin pump to receive their necessary insulin. The insulin pump is a compact machine, about the size of a cell phone that has small tube which is inserted subcutaneously. This tubing is changed every few days and delivers a small amount of insulin throughout the day mimicking the process of a pancreas. The individual with diabetes must still increase the dosage of insulin when food is consumed in order for the body to have enough insulin in it to break down the food for the body to use effectively.

Management of Type-1 Diabetes

Management of this disease involves a balance of medication (insulin), proper nutrition, blood glucose checks multiple times a day to adjust the insulin amount accordingly, and proper exercise. The management of diabetes, especially type-1, can be quite difficult. There is debate within the medical community as to what qualifies as adherence. Some medical professionals want their adolescents with type-1 diabetes at blood glucose levels of those without diabetes, which include a hemoglobin A_1C of less than 7 percent. The A_1C is a blood test that measures the average of the previous 2-3 months of blood glucose level (American Diabetes Association, 2007b). For some medical professionals, this average of the blood glucose is their determining factor of the patients' overall adherence. If the A_1C is above the level that the individual professional has deemed appropriate, then the corresponding average blood glucose indicates how far the patient is from proper adherence. Some professionals take into consideration this recommendation of what is an indicator of "good control" but apply other factors to determining their own assessment of the patients' level of adherence. Adherence can fluctuate over time, depending on the patient's life stressors or situation over the previous 3-4 months; his/her overall adherence level may suffer or fluctuate as well.

Proper nutrition can also play a role in indicating adherence. If an adolescent with type-1 diabetes does not consume a balanced diet, a diet that is recommended by their medical professional, then blood glucose levels can be hard to control. Aslander-van Vliet, Smart, & Waldron (2007) concluded that adherence to a proper diet leading to appropriate diabetes management in adolescents is impacted by a larger context of their family, and societal system. This demonstrates that not only does the individual with diabetes play a role in determining proper nutrition, but in most cases the family and surrounding environments do as well. Since there can be many different influences into the choices for proper nutrition, an adolescent needs to be able to seek knowledge and others so help guide them through the choices.

Why Adherence is Challenging during Adolescence

There are personal and societal situations that can lead a young person with diabetes to forgo proper management and increase the chances and early onset of severe complications (DeVries, Snoek, & Heine, 2004). When an individual reaches adolescence (age 12-18), their behaviors, as well as their bodies, change. Many adolescents go through what can be commonly referred to as “adolescent rebellion” where they attempt to become their own individual from their family and learn to be an independent person (Court, Cameron, Berg-Kelly, & Swift, 2009). For some adolescents, this can be a very difficult time in their lives. For adolescents with type-1 diabetes, rebellion can have lasting consequences if they choose to rebel against the diabetes. Because of this, some adolescents with type-1 diabetes may not typically maintain good control of their disease during adolescence, which can lead to early onset of complications associated with the disease (Court, Cameron, Berg-Kelly, & Swift, 2008).

Economic Consequences of Diabetes

Improperly cared for diabetes can also be a huge economic drain on the family, individual with diabetes, or the health care system. According to Hogan, Dall, Nikolav, and Petersen (2003), the direct medical expenditure for care and complications associated with diabetes was $91.8 billion in the United States. This was broken down into $23.3 billion for basic care, $24.6 billion for complications directly attributed to poor care, and $44.1 billion for other medical conditions associated to diabetes (Hogan et al., 2003). According to their research, the total expenditures on medical care for an individual with diabetes is $13,243 and for an individual without diabetes $2,560 (Hogan et al., 2003). These figures include costs associated with supplies, doctor visits, lost workdays, and treatment for complications that can arise. Those with diabetes, who are too young to drive themselves, require that their parents take off of work and lose wages in order to properly care for their child with diabetes. If the individual with type-1 diabetes is in school or employed, they will miss classes or lose wages. However, some adolescents do follow the medical recommendations set forth by their medical providers. This adherence can decrease the chances of early onset of complications.

The numbers and figures within this section are roughly seven years old, and with the increased number of those being diagnosed with diabetes, these figures have probably also increased dramatically. Hogan et al. (2003) is the most comprehensive article that discusses the economic components of diabetes care and compares this data with those without diabetes, and therefore is the reason these figures are reported from 2003. The economic consequence of lack of adherence is a rationale for the current study.

Guiding Research Question

Due to the individuation of an adolescent and the consequences of non-adherence, both medically and economically, the following research question is proposed. There can be multiple factors influencing the choices of an adolescent to adhere or not adhere with medical directives about diabetes care. The purpose of this study is to address the following research question: What factors influence an adolescent, age 12-18, with type-1 diabetes to adhere or not adhere to medical recommendations regarding their diabetes care?

LITERATURE REVIEW

Literature that focuses on motivational factors with adolescents for or against adherence with type-1 diabetes is scarce. There are studies that have focused on gaining better adherence, but many of them have used type-2 diabetes participants in their studies (Lou and Zhang, 2006; Simmons, Gamble, Footet, Cole, & Coster, 2004 Viklund, Ortqvist, & Wikblad, 2007). Type-2 diabetes can be more easily controlled by changing the individuals' environment. This can include more exercise or better nutrition and rarely does type-2 diabetes require insulin. Among individuals with type-2 diabetes, the pancreas may not produce enough insulin or their body may not absorb enough, so a pill may be effective in helping both of these situations. With type-1 diabetes, the pancreas does not produce insulin, so changes in exercise, nutrition, or a pill will not help the insulin utilization unless the insulin is injected into the body for use.

There are studies that focus on adolescent adherence with regard to their chronic illness; however, they do not focus specifically on type-1 diabetes (Chen & Wang, 2007; Deakin, Cade, Williams, & Greenwood, 2006). In addition, most of these studies have been conducted outside the United States (Kettunen, Liimatainen, Villberg, & Perko, 2006; Viklund et al., 2007). Though studies conducted outside of the United States may be suitable for use within the U.S., there is still a great deal of room for the exploration of adolescents with type-1 diabetes specific to the United States, and identification of factors that influence their choice to adhere or not adhere to the medical recommendations of their diabetes care. The United States has a unique framework that includes family dynamics, economics, and eating habits that shape how adolescents interact with their environment. Studies conducted outside the United States may not share these same framework elements resulting in a lack of direct correlation. Since these studies may not apply directly to adolescents within the United States, there is a need for further United States specific research or replication of these other studies.

The following review of the literature addresses the issue of adolescent development and its relationship to managing type-1 diabetes. Gaps in the current literature regarding adolescent care of their diabetes are identified, resulting in the need for the current study. The following literature review is organized into seven sections: 1) Overview of theories; 2) Adolescent development; 3) Adolescents with manageable chronic illness; 4) Adolescents with type-1 diabetes; 5) Family involvement; 6) Medical influence; and 7) Identified gaps in type-1 diabetes literature. The literature review culminates in providing a rationale for the current study.

Theoretical Framework: Adolescent Adherence with Chronic Illness

The theoretical basis of the study describes, in brief, the differing theories that are applied within this study and how each was determined and utilized. These theories describe adolescent development in multiple domains including physical, emotional, mental, and even hormonal changes. These changes within the adolescent can be difficult or can occur with little interruption in their daily lives. Adolescents with a manageable chronic illness can experience their own challenges due to their chronic illness as well as developmental changes that affect all adolescents. When an adolescent has type-1 diabetes, this manageable chronic illness not only affects the individual adolescent but it can affect the entire family. This section reviews the literature focusing on family dynamics and the family influence on adolescents with and without a chronic illness. How a family works with an adolescent with type-1 diabetes can be influential in the medical adherence of the adolescent. Medical protocols are typically derived from the medical model of treatment of disease. This literature described indicates the draw backs of the medical model and provides possible solutions to work better with individuals with type-1 diabetes. The next to last section of the literature review examines the theoretical basis of this study more in depth and how these theories have influenced the study and led to the research question. The final part is an overall summary of the current literature as it applies to this study and highlights the gap that this study attempts to answer.

Overview of theories

There are many theories that attempt to explain the behaviors of humans as individuals, within a family, and within their environment. With this in mind, it was decided that for the purpose of this study, the following theories best describe the process of human development as well as how individuals function within a family setting and within their environment: 1) Erik Erikson's Eights Stages of Man, 2) Systems theory, and 3) Person-in-environment approach.

Erikson's Eight Stages of Man

Erik Erikson was a theorist who came up with eight stages that a human progresses through as they develop. For the relevancy of this study, Erikson's stage 5 correlates with the adolescent age period. In this stage, the individual is in the "Identity vs. Role Confusion" stage which signifies the time that an adolescent attempts to create a lasting identity by determining their own drives, opportunities, and desires (Robbins, Chatterjee, & Canda, 2006). According to Robbins et al. (2006) this stage is where the adolescent struggles between what is known and familiar and attempts to integrate with where they see their future. Erikson's stage helps to identify the idea that the transition through adolescence can be difficult for many youth and that there are many forces that may have more influence over choices that the adolescent may experience. This period in an individual's life that has a chronic illness like type-1 diabetes can lead to poor control resulting from a lack of medical adherence, risk-taking behaviors, erratic meals, and erratic exercise patterns (Court, Cameron, Berg-Kelly, & Swift, 2009). Erickson also believed that the lack of integration between what was known and what can be, into a single unit, can lead to delinquency (Robbins et al., 2006), which can be an influence on medical adherence for those with type-1 diabetes. These influences are also examples of the struggles that an adolescent goes through as they age and seek to individuate themselves from their family units. Erikson does not specifically address adherence to medical recommendations during adolescence, but the link between becoming an individual away from the patterns of what has been known can also pertain to the level of adherence that an adolescent may achieve. As an adolescent progresses through Erikson's stage, they may deviate from the previous level of adherence in order to develop their own sense of adherence.

Systems Theory

Within systems theory, the family unit itself is a distinct system surrounded by larger systems. One of the main tenants of systems theory is that "everything is connected" (Robbins et al., 2006 p433). This involves every member with a family as well as everything that comes into contact with that family. Each family member has a role that contributes to the whole of the family. As an individual reaches adolescence, the boundaries of what are known are challenged (Robin & Foster, 1989). These boundaries can be flexible with the adolescent moving fluidly between autonomy and dependence on the family for support and help (Robin & Foster, 1989). How families deal with these issues of boundaries and what techniques are used to assist an adolescent in becoming a functioning individual can be difficult. When an adolescent has a chronic illness like type-1 diabetes, these boundaries are pushed in multiple directions, as they attempt to become an individual while still being a member of their family unit. In attempting to maintain boundaries within a family, the family is attempting to regain or remain in homeostasis. Homeostasis is a concept where the balance is maintained. Robin & Foster (1989) describe that within a family, when an adolescent seeks to be an individual from the family unit that there is an increase in the discord within the family while the family is struggling to regain that homeostasis. This struggle to maintain homeostasis or continuity within a family can happen in any type of family.

The struggle for adolescent independence can occur seemingly overnight to most caregivers, and as a result, the caregiver attempts to regain control by tightening the rules and regulations (Robin & Foster, 1989). This can lead the adolescent to “rebel” or push away from what the norm has been. Broderick (1993) indicates that as an adolescent feels more pressure from within the family to remain under their control, the more they resist and want to become an individual. This push toward becoming an individual by the adolescent can be devastating with regard to the medical adherence of the type-1 diabetes. Broderick (1993) also explains that to expect adherence to adult societal norms is unrealistic during this stage of development since it is more likely that the adolescents peer support will hold more influence than the typical family environment. While this study examines a retrospective approach to behaviors that were elicited from family members toward the individual as an adolescent, the data reveals how the idea of boundaries and maintaining homeostasis can be evaluated through the results.

Person in Environment Approach

The concept of how a person interacts within their environment is another aspect of a system theory. It emphasizes that a person has an effect on their environment as well as that the environment has an impact on an individual (Walsh, Price, & Craik, 2000). In the context of this study, the term environment not only represents the natural environment but also any outside influences that can play a role in an adolescent's life. This includes school, work, friends, and any source of influence that does not come from the family. How an adolescent interacts with his/her environment can be crucial in determining the choices made to adhere or not adhere to medical recommendations for their type-1 diabetes.

When an adolescent becomes more involved in his/her environment, for instance their peer group, rather than their family, their support structure may change. During this transition from a family dominated support system to a support system dominated by members outside the family, an adolescent responds to more influences on their choices from their peers, educational placements, or employment placements (Barker & Galambos, 2005). Their new environment may include different choices and influences that the adolescent may not have been previously exposed to and now has to attempt to integrate these factors into their understanding of these choices as to what is, and is not, appropriate for adherence.

Adolescent Development

When looking at adolescents with type-1 diabetes, it is important to remember that they are developing and changing, physically, emotionally, and mentally. This time period can be tumultuous to any adolescent. Barker and Galambos (2005) found that in a survey of 170 adolescents, 71 percent indicated independence as a crucial part of their development toward adulthood. Adolescents not only go through chronological aging but they also attempt to achieve individuality and other changes that can have an effect on their psychological and emotional well-being. For instance, some adolescents seek out their peers, rather than adults, as their main source of information (Cohen, 1980).

Autonomy can be a vital part of growing up and a difficult situation for those adolescents who have a disability (Crittenden, 1990). Crittenden (1990) examined adolescent development as a main component in determining choices and developing their autonomy. Due to the significance of type-1 diabetes, adolescents have many choices in determining if they are going to adhere to medical recommendations or not. As adolescence is a time period where many changes are occurring for an individual, this stage of development can have the most lasting impact on the individuals' life. The choices made can have repercussions for later in an individual's life with regard to their health and well being

Adolescents with Manageable Chronic Illness

Adolescents with chronic illnesses, like type-1 diabetes, go through the typical changes in their transition toward adulthood; however, they must also learn how to adapt to the extra responsibility of their illness. Adolescents with diabetes can face the stigma of having a disease that they will have for the rest of their life, a disease which could eventually kill them. In a 2007 study, Debono and Cachia found that adolescents who feel stigmatized and do not fit into the regular adolescent society have a lower quality of life, as self reported. Also, the psychological impact of being an adolescent with type-1 diabetes can be damaging. Kokkonen and Kokkonen (1995) found that about 17 percent of the country will have a depressive episode in their lives. However, adolescents with type-1 diabetes have an 18 percent chance of having a depressive episode. The number of adolescents with type-1 diabetes is increasing; thus it would stand to reason that the number of depressed adolescents would also increase.

Adolescents with Type-1 Diabetes

Though there are studies and other literature about type-1 diabetes, adherence is something that is spoken of from a theoretical perspective, with few actual studies published, regarding motivational factors for adherence. Olsen and Sutton (1998) utilized surveys to explore the role of how formal and informal supports that adolescents with type-1 diabetes receive with challenges that arise regarding stressors to adherence. It was determined that there were no direct links between the type of support that an adolescent receives, but rather the motivation to adhere from the adolescent. There needs to be a deeper understanding of the influences in an adolescent's life that influence their choices of following medical recommendations for controlling their type-1 diabetes. Once these factors are identified and explored, more effective approaches could develop to help these adolescents with their diabetes. Literature is starting to demonstrate a shift in thinking in developing individualized medical plans to incorporate the view of the patient (Christie, Romano, Thompson, & Hindmarsh, 2008; Knight, Dornant, & Bundy, 2006). While this is a good start, there also needs to be an additional focus on incorporating the unique life influences of the adolescent. Each individual has the ability to make decisions for him/herself and become empowered to make those that best serve their specific needs. Each adolescent, especially with a chronic illness like type-1 diabetes, has an idea of what motivates him/herself to adhere or not adhere. Allowing adolescents to have input into their medical treatment may be a good way to gain or maintain adherence.

Adolescents with type-1 diabetes are taught about the complications that can arise from poor control of their glucose and insulin. However, some adolescents still have low adherence to their medical recommendations (Court et al., 2008). There may be many reasons that adolescents do not adhere to medical recommendations, including: 1) choosing to express their freedom as a natural part in the life span development; or 2) pressures that society, their family, or some other entity places on them to fit into societal norms. Societal norms of being “normal” or not ill are unattainable to those with type-1 diabetes since diabetes has no cure nor does it ever go away. Often the opposite is true. It can become more intrusive on an individuals’ life as they age. The best an adolescent with type-1 diabetes can hope for is that the complications will not start to affect them earlier than necessary. However, no matter how good the control is, the disease will wreck havoc on the body and could eventually kill through body system failure (National Institute of Health, 2006). Knowing these inevitable facts, it is possible for an adolescent to express and become an individual while still maintaining control of their diabetes. When, if ever, an adolescent should gain complete control over their diabetes is not a definite, but it is an individual pursuit, as each adolescent is a unique individual.

Family Involvement

When a member of a family is diagnosed with type-1 diabetes, it affects the entire family. Fisher (2005) found that in dealing with families where a member has a chronic illness, if the family as a whole has poor conflict resolution skills, then the family member with the chronic illness is less likely to be in good health or maintain proper management. This fact can drastically increase the risk to the youth with diabetes directly or indirectly. In situations where a child or adolescent is diagnosed with diabetes, the entire family dynamic changes and the entire family should be involved in making decisions (Rosin, 1997). Within a family, especially if a child has been diagnosed with a chronic illness, the other members may need to help in gaining or maintaining the health of the child who has been diagnosed with type-1 diabetes, with the help of their medical professionals.

Parents and family members can also put an undue burden on an adolescent with type-1 diabetes. If the adolescent was diagnosed as a young child, then the primary care giver most likely has been the parent. But as the child ages, they usually want to gain more freedom in their life. As the adolescent wants more freedom, the parents may want to restrict that freedom out of fear for their child's welfare. In many instances, this fear of losing control can be at times unfounded and can actually be detrimental to the adolescent gaining self control over their disease. In households where there was negative communication and conflict resolution between the parent and the adolescent with diabetes, the adolescent described lower levels of adherence and metabolic control (Weissberg-Benchell et al., 2009). Adolescence is a transitional stage and utilizing both the parent and the adolescent rather than either party attempting to dominate and over power the other, seems to be the best way that an adolescent can pass through this stage, as well as attempt to adhere to the requirements of their chronic illness (Spear & Kulbok, 2004). With proper freedom and guidance, the adolescent should be able to learn balance and responsibility for their disease. The ability of an adolescent to accept responsibility and make appropriate decisions about their care and their illness is a valuable lesson that should be explored (Crittendon, 1990). Also, Knopf, Hornung, Slap, DeVellis, & Britto (2008), found that few parents and adolescents wanted to make their treatment decisions independently, but rather wanted it to be a collaborative process with their medical team. Though there was this desire to make it a collaborative process, the results were inconclusive if this technique was the most helpful in the overall treatment process and adherence to the recommendations.

Determining how influential family members are in an adolescent's decision-making choices, either for or against adherence, is very much a mystery. In looking at this situation, the current study used the "Diabetes Family Behavior Checklist" also used by Schafer, Glasgow, McCaul, and Dreher (1983). This scale has been used by a wide variety of researchers for over 25 years to explore the frequency of diabetes management behaviors by a predominant caregiver as well as the helpfulness or unhelpfulness or specific diabetes management behaviors had they been or if they were done. The point of this survey is to determine what behaviors the adolescent received from their primary caregiver, and then what behaviors the adolescent perceived would have been helpful or not helpful for proper adherence. Though this scale was used in a different manner for this survey, (i.e., online versus paper format), the goal of obtaining the information was to determine trends or behaviors that were influenced by family members. The extent to which family members determine the adherence level of an adolescent is not an easy concept to explore.

Medical Influence

Doctors or medical professionals are perceived to want to remain in control of the adolescent's disease for as long as possible. Lefebvre (2008) describes the practice of medicine as having three pillars: "knowledge, experience, and when needed, the opinion of trusted colleagues" (p199). The ability of medical professionals to see themselves in this light, allows them to also see themselves as more knowledgeable in their ability to control the behaviors of adolescents with their medical adherence. The literature does emphasize the medical model, where the medical professional is the expert on the issue and has the education to tell the adolescent and/or their family how to care for the disease (Aslander-van Vliet, Smart, & Waldron, 2007; Dickinson, 1999; Grundel, White Jr., & Eichold II, 1999). The medical model of treatment in the care of adolescents with type-1 diabetes may be slowly changing, though. There is an emerging idea that utilizing a dual relationship, both as a support system and an authoritative figure, when working with adolescents may be beneficial (Boyages, Sheridan, & Close, 1999; Christie, Romano, Thompson, & Hindmarsh, 2008). For instance, Karnieli-Miller and Eisikovits (2009) explored the techniques of Israeli doctors in the treatment of chronic illnesses affecting adolescents with gastroenterological issues. They found that there are many techniques to treating adolescents, including the actual words used, the tone of the voice of the speaker, and the location of dispensing news. However the most effective technique was the openness of the doctor to relate to the adolescent as a person and not necessarily as a patient and to put forth a plan of action that addresses all concerned and the issue at hand.

In an editorial by Hirsch (2003), he explored the issue of adherence with adolescents and adults with diabetes. He suggested that one of the major inhibitors of proper adherence is that medical professionals do not spend enough time and are too burdened to actually make effective changes if they are needed in the individual's diabetes regimen. Doctors are commonly confined by policies that require many patients to be seen in a short amount of time. Due to these policies the quality of care can begin to diminish. When a doctor uses his/her power and influence over the patient, the patient may feel as if they have little input into the situation and determining what solutions that may be most beneficial. Despite how much physicians tell patients, the patient is ultimately the one who decides if they will adhere or not. This concept is starting to influence how doctors interact with their patients, but it can be a slow process.

The motivational factors that go into whether or not an adolescent adheres to medical recommendations are numerous. Hysing, Elgen, Gillberg, and Lundervold (2009) explore the idea that adolescents go through many changes, physically, emotionally, and mentally during this time period in their lives which can be difficult to handle. However, those with chronic illnesses, like type-1 diabetes, often face many other factors that influence their lives. There is evidence that indicates that the idea of helping the patient to have an influence in the medical recommendations that are given to them has a stronger influence on overall adherence to the goals set forth (Boyages, Sheridan, & Close, 1999; Dahan & McAfee, 2009; Grundel et al., 1999; Karnieli-Miller and Eisikovits, 2009). By increasing patient involvement and participation in treatment decisions, there is greater follow through with the decisions that are made. Ultimately the literature could not be found indicating specific motivational factors impacting adolescents with type-1 diabetes decisions to adhere or not adhere to medical recommendations.

Identified Gaps in Type-1 Diabetes in Adolescents Literature

Based on the above literature review, it is evident that there is a need for further study in this field. The literature has explored several theories that could be applied to this population, various studies that have been done on adolescent development, adolescents with chronic illnesses, and even individuals with diabetes. However, as described earlier, there are few studies that incorporate adolescents with type-1 diabetes that have been conducted in the United States. Although the design of this study and the sample size will not allow for generalizability, this study is intended to provide some insight into the behaviors that family members do and even what would have been helpful behaviors that influence an adolescent with type-1 diabetes in their level of adherence to medical recommendations. The intent of the current study is to fill a gap in the literature by identifying what diabetes management behaviors were seen as helpful and unhelpful for the individual with regards to their adherence level.

METHODS

This is a pilot study with an exploratory research design. As a pilot study, the ability to expand upon the initial findings collected from this study can be used for further research. This study uses a mixed method design including both quantitative and qualitative approaches. The quantitative data were collected from a survey using the online resource of Survey Monkey. The qualitative data were collected through follow-up in-depth interviews.

Sample

The study was designed to gather data from individuals who had type-1 diabetes as an adolescent, and from professionals who currently work with this population. Thus, two groups of participants were identified: 1) individuals who met the inclusion criteria, of being age 18 or over as well as having had type-1 diabetes as an adolescent, and 2) key informants who currently work with adolescents with type-1 diabetes who hold an M.D., a PhD, or are a Certified Diabetes Educator.

Participants

With respect to individuals who fit into category 1, (i.e., age 18 or over who had type-1 diabetes as an adolescent), there were a total of 22 study participants. In addition, there were 20 who attempted to utilize the survey but did not meet both criteria of the inclusion criteria. Also, 11 potential participants started the survey but did not complete it after meeting the inclusion criteria. Eighteen responded that they wished to complete a follow-up interview with the student investigator.

With respect to key informants (i.e., category 2), the student investigator interviewed a total of one individual, a psychologist who has extensive working knowledge with adolescents with type-1 diabetes in their practice. The student investigator was unable to gain the participation of other individuals within the community, though numerous attempts were made.

Procedures

Quantitative Data Collection

Individuals who met the inclusion criteria were invited by the student investigator at local support groups to participate in the study. Potential participants were given a comprehensive cover sheet that detailed the study, which described how to access the survey through Survey Monkey, and were told that participation is voluntary and confidential. Survey Monkey is an online tool for the collection of research data, where investigators input (or upload) the study questions. Participants access the survey online and with the benefit of doing so at their own convenience.

The “Diabetes Family Behavior Checklist” was used for the survey. This survey was initially developed and used by Schafer, Glasgow, McCaul, & Dreher in 1983. There were a total of five main questions, with two of those questions having 16 or 15 (respectively) sub questions. The survey questions focused on diet, exercise, glucose testing, and medication dispensing which are some of the main components to proper type-1 diabetes adherence. One of the main questions asked: Who in their life as an adolescent did they spend the most time with? In turn, several follow up questions which asked how often this person nagged them about not following their diet?, Criticized them for not recording the results of their glucose test?, Exercised with them? The full survey instrument is located in Appendix A. The last question of the survey asked the participant if they would be willing to participate in a follow-up interview, followed by a page where they could enter their contact information. The page included their name and the best way to contact them, either through email or phone.

If participants contacted through the support group indicated that they would prefer a paper and pencil copy of the survey, one was handed to them with a self-addressed stamped envelope with instructions on how to return the survey to the student investigator. The participants were asked to return the survey within 30 days.

The use of Survey Monkey required approval through the University of Nevada, Reno, Institutional Review Board (IRB). Approval was obtained on December 8, 2009. For Survey Monkey to work correctly, the student investigator established a list of survey questions and the order that they should appear within the survey in order to gather the correct information. The inclusion criteria questions needed to be set up on separate web pages in order for a participant to meet both criteria before entering the body of the survey. Each of those inclusion questions had to have “logic” links set up so that if a participant answered that they did not meet either of the criteria they were redirected to another page that thanked them for their time. Initially, Survey Monkey allows only five questions to be posted for free and since the survey that was utilized required more, the student investigator had to pay $19.99 each month during the data collection phase of this study for the use of the web link. When setting up the survey questions for the Survey Monkey format, questions needed to be designated as to their type (i.e., multiple choice, fill in the blank, only one answered allowed). The Survey Monkey web site allows the creator of the survey to enable certain criteria or not to enable it. For instance, per IRB requirements, no IP addresses could be collected, the IP collection function had to be disabled.

After the data were collected in Survey Monkey, the data were then entered (or downloaded) from the Survey Monkey into SPSS for data analysis. The data were coded for analysis. Each variable was assigned a corresponding numeric code and that data were entered for each participant who completed the survey. For example, question #4 of the actual survey asked for the frequency of behaviors that occurred within the family by the predominant caregiver, identified in an earlier question. A process of reverse coding was used, as some questions were positively worded (i.e., praise, encourage, help, congratulate), and others were negatively worded (i.e., nag, criticize, argue). Once these designations were identified, the positively worded behaviors were given a frequency scale of 1 to 5 and the negatively worded behaviors were given a reverse frequency scale of 5 to 1. Survey question #5 asked about the participants' views of the assessment of the helpfulness or unhelpfulness of the same behaviors, presented in question #4. Each of those sub-behavior questions received a scale score of -3 to 3 with a 0 representing the perception of "Neither Helpful or Unhelpful." Since survey question #5 was the perception rather than recalled behaviors, there was no need to reverse code the responses. After all scale scores were entered into the program, a total sum scale score was found for each participant based on both question #4 and on question #5. The total scale scores and the demographic information that the participant filled in earlier in the survey were used to compute correlational and multiple regression analyses.

Qualitative Data Collection

The follow-up interview included questions regarding the rationale for the behaviors that they exhibited during adolescents. The follow-up interview questions were developed by the student investigator. Three examples of those questions were: 1)

Have you had any complications due specifically to the diabetes?, 2)What was your adolescence like growing up with type-1 diabetes?, and 3)Who was your biggest advocate in dealing with the responsibility of your diabetes? The full list of interview questions is located in Appendix B.

If a participant wished to participate in the follow-up interview, they were contacted by the method that they indicated and a specific time and location was determined based on their availability and request. If the participant was a local Reno area resident, the follow-up interview was conducted in person or via speaker phone. If the participant was a non-local Reno area resident, the follow-up interview was conducted via speaker phone. The initial contact for the follow-up interview occurred within 72 hours of the contact information being retrieved by the student investigator. The student investigator checked the survey twice daily in order to respond in a timely manner to all responses. The online survey took no more than 10-15 minutes to complete and the follow-up optional interview took no more than 30 minutes to complete. These follow-up interviews were audio taped with the knowledge and permission of the participant.

For those participants who were designated as key informants, those with a M.D, PhD, or a CDE, were contacted in person at their offices. The student investigator traveled throughout the Reno-Sparks area seeking practitioners that work with adolescents with type-1 diabetes. Once at a practitioner's office, the student investigator asked to speak with the practitioner for approximately 5 minutes. During this time, the practitioner was handed the cover sheet and the information sheet. Contact information on how to set up an interview with the student investigator was given. A time and place was arranged based on the participants' preference with this part of the study. A follow-up phone call was placed to each practitioner's office also requesting an interview with the practitioner. The interview questions were broad as not to compromise their patients' confidentiality. These interview questions were developed by the student investigator. The following are two examples of the questions asked of key informants: 1) Have you seen any complications due specifically to the diabetes in your patients?, and 2) Does there seem to be a specific moment or commonality as to when the adolescent is given full control and responsibility of their diabetes? The full list of questions asked of the key informants is listed in Appendix C. These interviews were audio taped with the participants' knowledge and permission. All audiotapes of the interviews were transcribed for accuracy and for specific quotes and references.

After the student investigator began data collection, a modification to the IRB was submitted to include permission to post the web link for the survey using Survey Monkey on e-newsletters and online support groups. These extra web-based recruitments were used to access a broader range of potential participants.

Data Analysis Plan

Following data collection, the quantitative data were inputted into an SPSS data analysis program. Three parts to the data analysis were planned: 1) descriptive analysis, 2) correlational analysis of data components, and 3) multiple regression analysis to identify predictive relationships among variables. The qualitative data were transcribed and a thematic analysis was conducted based on the recordings and the transcriptions by the student investigator. Themes that appeared were indicated and the frequency was observed and indicated.

RESULTS

The data analyses plan included descriptive statistics, as well as correlation, and regression analyses of statistical significance among the study variables. These tasks were performed with the use of data analyses tools from Survey Monkey and SPSS. The next section is organized as follows: 1) Demographic Analysis, 2) Descriptive Analysis, 3) Correlational Analysis, and 4) Multiple Regression Analysis.

Demographic Analysis

For those participants that completed the survey on Survey Monkey, (N=22), there were 14 females and 8 males. Twenty one participants reported their ethnicity as Caucasian and one that reported their ethnicity as African American. With respect to age of onset of type-1 diabetes, seven were diagnosed between 0-4 years of age, five diagnosed between 5-9 years of age, seven diagnosed between 10-14 years of age, and three diagnosed between 15-18 years of age. At the time of data collection, five participants are between 18-24 years, six are between 25-30 years, two are between 35-40 years, four are between 41-45 years, and five participants are over the age of 50 years. The following figures represent the demographic information.

Figure 1 Gender

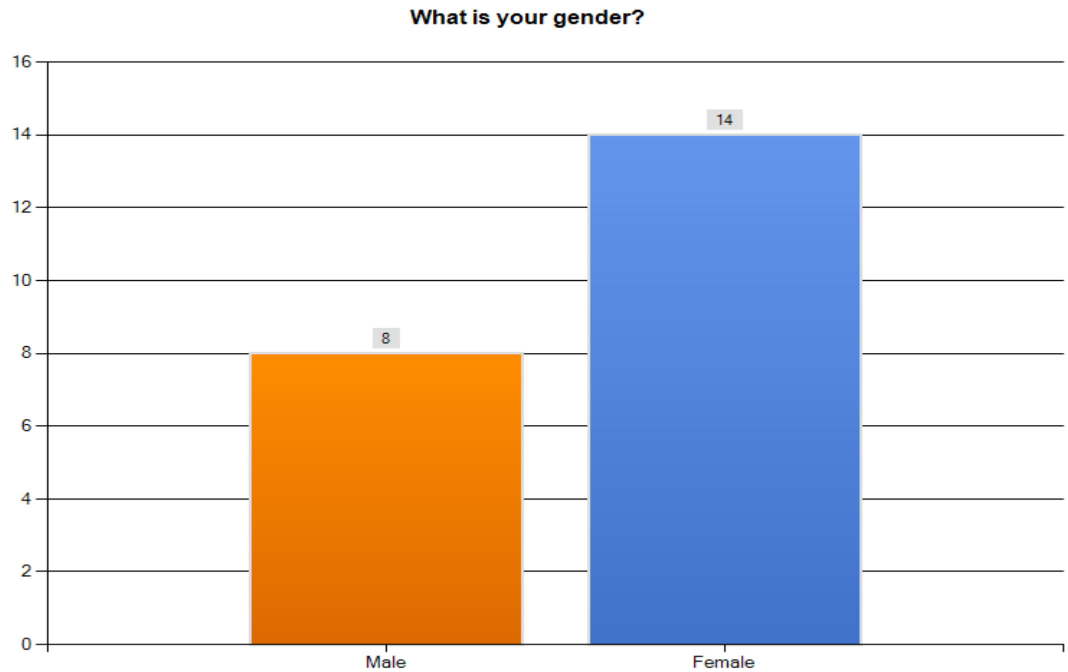


Figure 2 Ethnicity

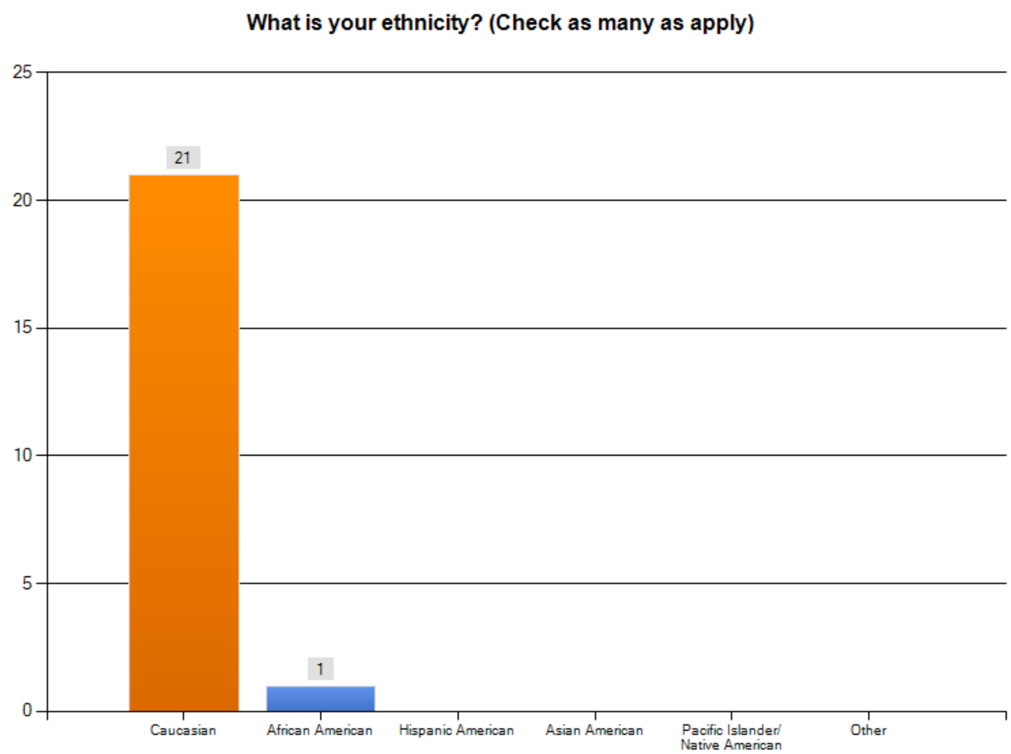


Figure 3 Age of Onset

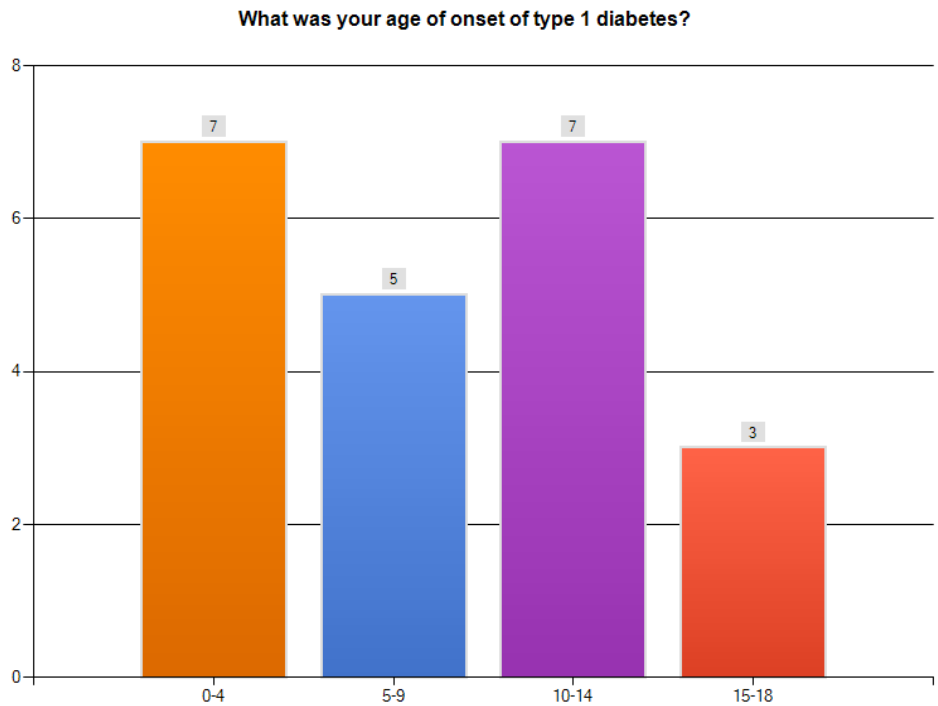
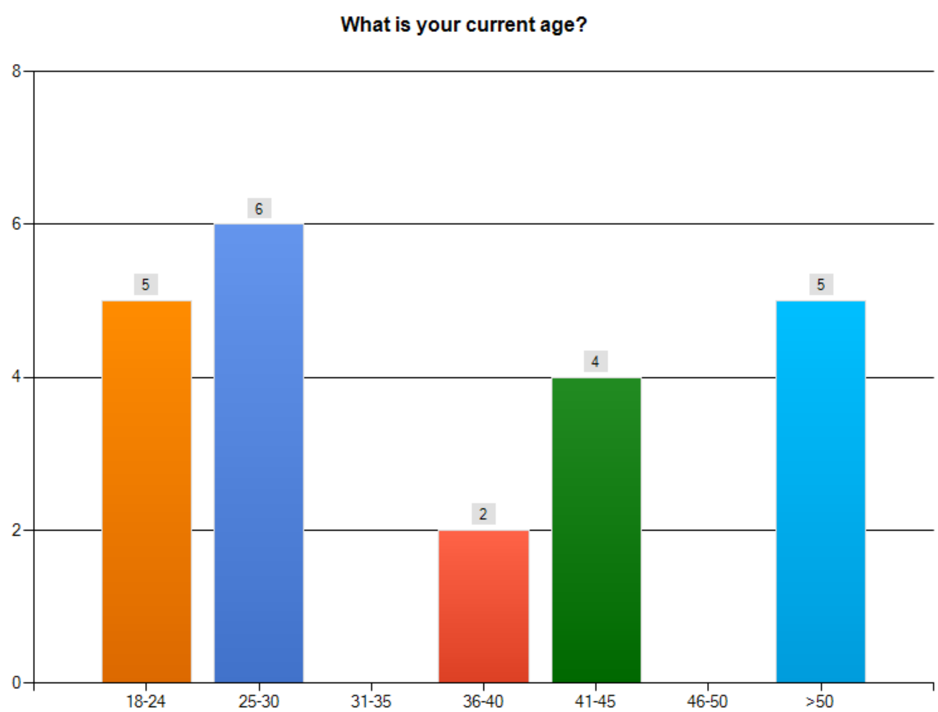


Figure 4 Current Age



Descriptive Analysis

The descriptive analysis was completed using the crosstabulation and filter features of Survey Monkey to generate the pertinent data regarding survey participants. Figure 5 represents the total scale score for survey question number 4 about the frequency of behaviors that did occur during the participants' adolescence, as compared to their current age. Figure 6 represents the total scale score for survey question number 5 regarding the helpfulness or unhelpfulness of behaviors as rated by the participants during adolescence, as compared to the participants' current age. Any value above the 0 line is considered a helpful behavior and any value below the 0 line is considered an unhelpful behavior.

Figure 5 Crosstabulation of frequency of behaviors that occurred during adolescence

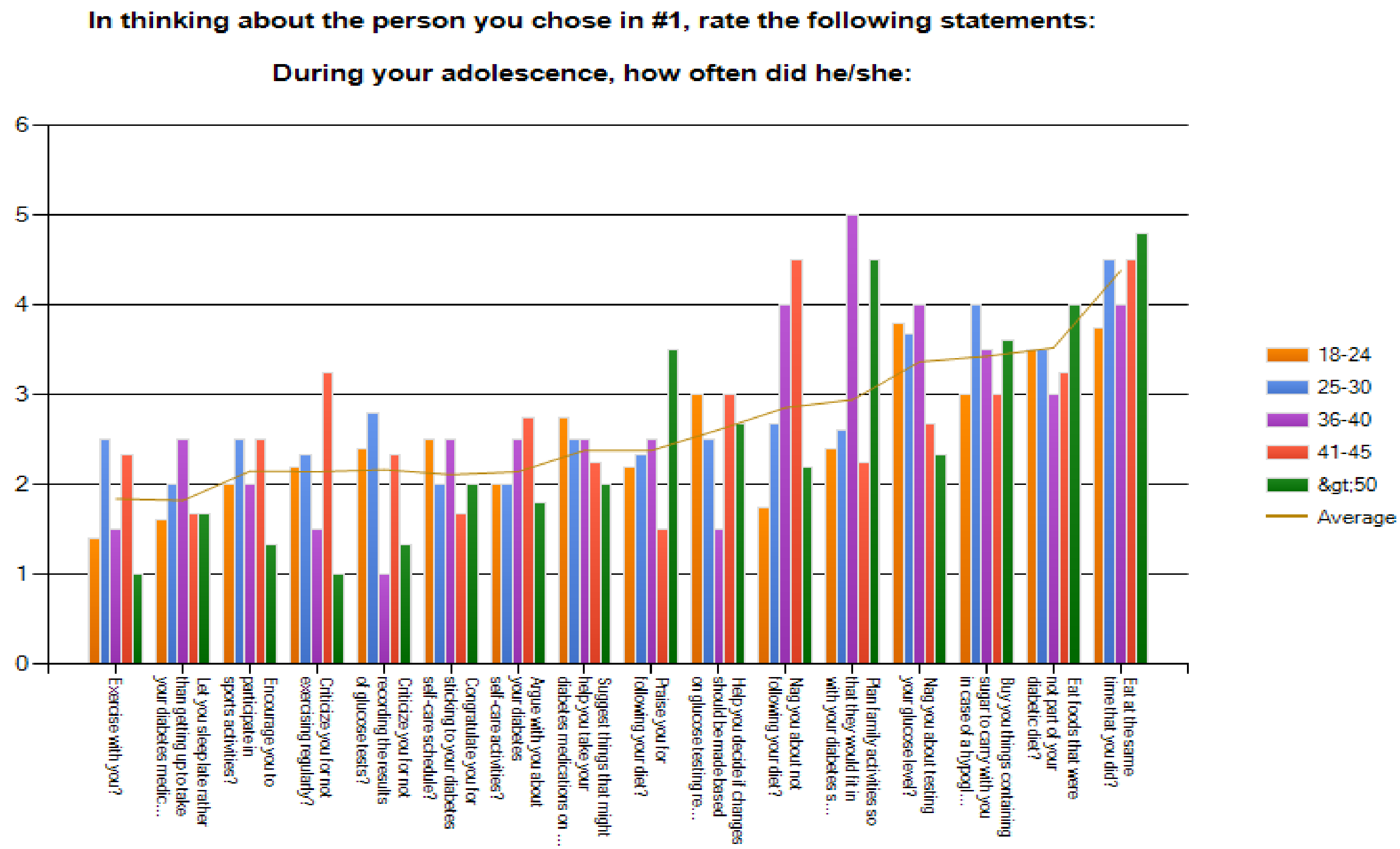
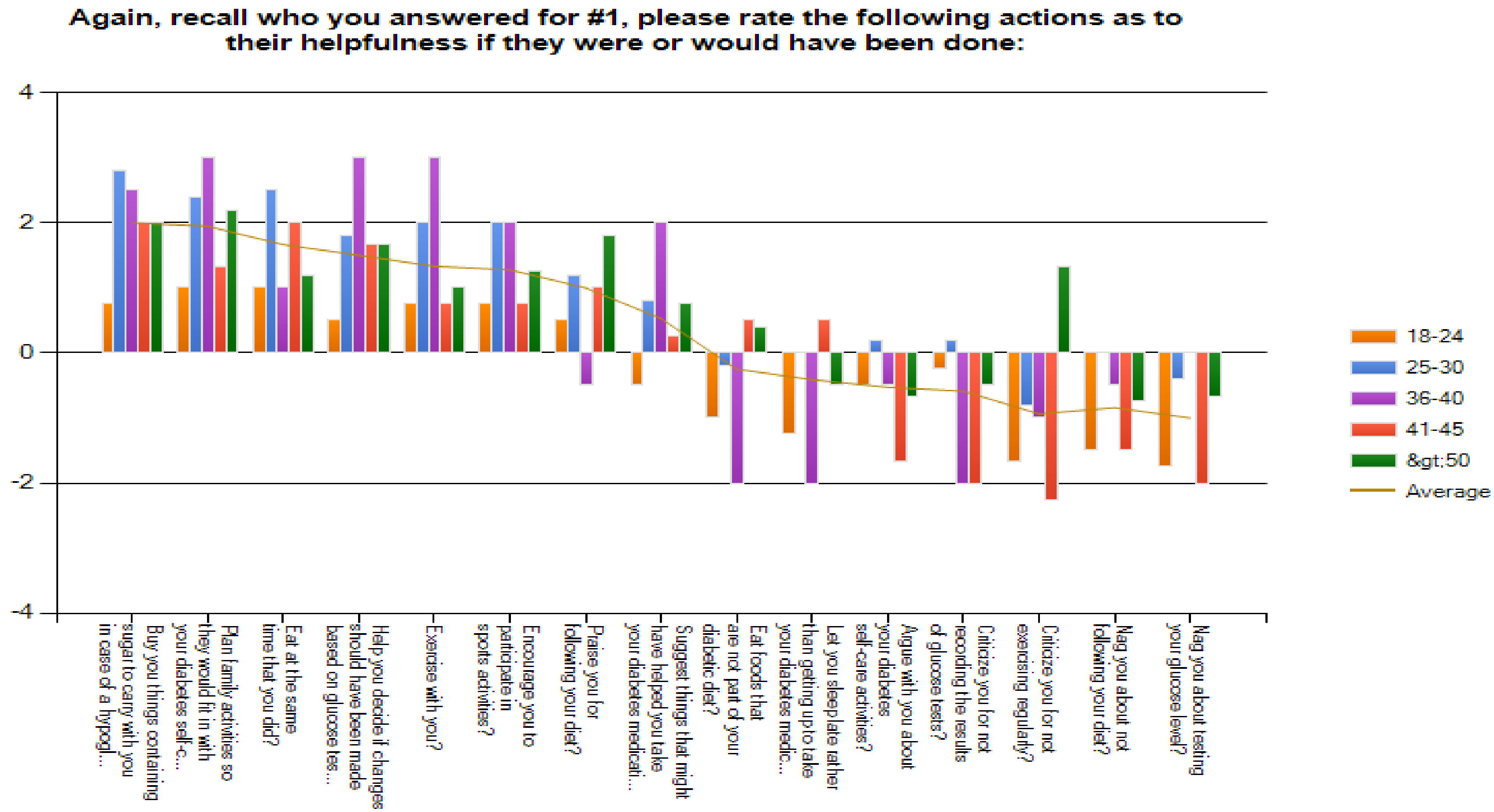


Figure 6 Crosstabulation of behaviors that would have been helpful or hindered adherence during adolescence



Correlation Analysis

The correlation between select demographic variables and the total scale score for question #4, (i.e., frequency of behaviors that did occur during adolescence) and question #5, (i.e., helpfulness of behaviors if they would have occurred), were analyzed using SPSS with Pearson's Product Moment Correlations. Specifically the total scale scores for #4 and #5 were correlated with the demographic variables of gender, current age, and age of onset.

Table 1: The correlation between the total scale score of question number 4 (i.e., the frequency of behaviors) and the current age of participants was $r = -0.282$, $p < .05$ which indicates a negative relationship. As the participants current age increased the total scale score of the frequency of behaviors decreased. There is no statistical significance at this point. There is a positive relationship between the participants age of onset and the total scale score of the frequency of behaviors of $r = 0.260$, $p < .05$.

Table 1

Frequency of behaviors correlated with Demographic Variables

Measure	Current Age	Age of Onset	Gender	Total_Scale_4
Current Age	1.000			
Age of Onset	0.122	1.000		
Gender	-0.096	-0.048	1.000	
Total_Score_4	-0.282	0.260	0.187	1.000

N= 22, $p < .05$

Table 2: The correlation between the total scale score of question number 5 (i.e., helpfulness/ unhelpfulness of behaviors) and the age of onset was r = 0.388, p < .05, which indicates a positive relationship between the participants age of onset and what behaviors they thought would have been helpful or unhelpful. The correlation between the total scale score of question number 5 and the gender of the participant was r = 0.274, p < .05, also indicating a positive relationship between this variable and the total scale score #5.

Table 2

Helpful/ Unhelpful behaviors correlated with Demographic Variables

Measure	Current Age	Age of Onset	Gender	Total_Scale_5
Current Age	1.000			
Age of Onset	0.122	1.000		
Gender	-0.096	-0.048	1.000	
Total_Score_5	0.121	0.388	0.274	1.000

N= 22, p < .05

Indicated in Table 1, there is a negative relationship between the participant's current age and the frequency of behaviors while there is a positive relationship between the age of onset and the total scale score of the frequency of behaviors. Indicated in Table 2, there is a positive relationship between the age of onset and the gender of the participants in relation to the total scale score of behaviors that would have been helpful or unhelpful.

Multiple Regression Analysis

Regression analysis was conducted that included two separate models. The first one included three independent (demographic) variables to identify what contribution they have to the outcome variable based on question #4 (the frequency of behaviors that did occur). The second regression included three independent (demographic) variables to identify what contribution they had to the outcome variable based on question #5, the unhelpfulness or helpfulness of behaviors that would have occurred during the participants' adolescence. The independent variables selected for inclusion into the model were the age of onset, gender and current age of participants. The independent variables were selected based on the diversity and range of selections. The dependent variables selected were the "total scale score" for question number 4. Another model utilized the dependent variable of the "total scale score" for question number 5.

Table 3: Depicts the results of the multiple regression run of the independent variables (age of onset, gender, and current age) in relation to the total scale score for question #4, which is the frequency of behaviors that occurred during adolescence. For the total scale score for question #4, the R^2 showed that approximately 19.7% of the total scale score is predicted by the independent variables of the age of onset, gender and current age, $F(3,18) = 1.471$, $p < .05$.

Table 3

Multiple Regression Frequency of Behaviors

Variable	B	Standard Error	β	t	*p*
Current Age	-1.102	0.779	-0.302	-1.415	0.174
Gender	3.02	3.712	0.173	0.814	0.426
Age of Onset	2.491	1.739	0.305	1.432	0.169
R^2	0.197				
Adjusted R^2	0.063				
F	1.471				
df	(3,18)				

N = 22, $p < .05$

The beta coefficient data, in table 3, indicates that with regard to the behaviors that did occur, (i.e., the total scale score for question #4), and the age of onset of the participant were the strongest contributing factor in determining the total scale score for question #4 at beta = 0.305. The current age of the participant was the second leading demographic variable at beta = 0.302 which contributed to the total score for the behaviors that did occur to the participant as an adolescent

Table 4: Indicates the significance of the independent variables (age of onset, gender, and current age) in relation to the dependent variable (total scale score for question #5 of the survey relating to the behaviors that if they would have happened would have been helpful or unhelpful). When the regression analysis was run for the total scale score for question #5 against the demographic (age of onset, gender, and current age) variables resulted in an R^2 of 24.7%, $F(3,18) = 1.964$, $p < .05$.

Table 4

Multiple Regression Helpful/Unhelpful Behaviors

Variable	B	Standard Error	β	t	*p*
Current Age	0.517	1.041	0.103	0.496	0.626
Gender	7.305	4.964	0.303	1.471	0.158
Age of Onset	4.396	2.326	0.39	1.89	0.075
R^2	0.247				
Adjusted R^2	0.121				
F	1.964				
df	(3,18)				

N = 22, $p < .05$

The coefficient data, in table 4, indicates that the demographic variable of the age of onset had the highest beta = 0.390 factor in the overall helpfulness or unhelpfulness of the behaviors, (i.e., total scale score for question #5). The second highest independent variable was the gender of the participant at beta = 0.303 to the total score of the behaviors that would have been helpful or unhelpful.

When analyzing the multiple regression analysis, none of the independent variables demonstrate any significance to the dependent variable of the total scale scores for question #4 or question #5; they may indicate an order of leading contributing factors to the total scale score of the two survey questions. The low number of participants are a possible factor as to the low level of significance of the demographic variables (the dependent variables) in relation to the total scale scores (the independent variables).

Findings

When critiquing the descriptive analysis chart, it is noteworthy that participants who are over the age of 50 thought that the behavior of being "Criticized for not exercising regularly," would have actually been a helpful behavior for their adherence to medical recommendations as compared to all other age groups who decided that the behavior would not have been helpful. Also of note is that the current participants aged 18-24 thought that the behavior of "Suggesting things that might have helped you take your diabetes medications on time," was an unhelpful behavior, while all other age groups thought this behavior would have been helpful.

Once the correlational data was analyzed, it was determined that there was no significance to any demographic data but that each total scale score had different factors that seemed to be influential. The total scale score for question #4 had a higher correlation to the participants' age of onset at $r = 0.260$ and to the current age of the participant $r = -0.282$. Both of these values indicate that there was no significance. For the total scale score for question #5, which was a rating of how helpful or unhelpful behaviors would have been to the participant as an adolescent, there was again a correlation between the age of onset at $r = 0.388$, and the gender of the participant at $r = 0.274$. Again, there was no significance

The regression analysis indicated that though there was no statistical significance with the demographic variables (i.e., age of onset, gender, and current age) in the relation to the total scale score for question #4, the age of onset and the gender were the two most impactful variables. There was also no statistical significance between the demographic variables and the total scale score for question #5, and again the age of onset and the gender of the participants had the highest influence.

The coefficients data in the regression analysis also found that when the total scale score of question #4 was compared to the demographic variable, the age of onset and the current age of the participant were the strongest indicators of the total scale score. The total scale score of question #5 in relation to the demographic variables indicated that the age of onset and the gender of the participants were the strongest indicators.

Qualitative Data Analysis

This study resulted in 18 of the participants consenting to follow-up interviews. Of those 18, four were completed. The remaining participants either changed their minds or were unavailable to do to follow-up interview. Each interview was between 30 minutes to 1 hour in length and transcribed for accuracy of the conversation. There were some commonalities between the interviews and some differences. For instance, each participant had been diagnosed for over 15 years but their age on onset was different. Of the interviews that were completed, three of the participants were female and one male. These participants had each had type-1 diabetes for between 15 - 40 years. The participants were currently residing in New Jersey, Tennessee, Washington, and in Virginia. Each interview was thematically coded for consistencies or commonalities between each individual's lives.

Some of the commonalities were: 1) participants who had type-1 diabetes for approximately 30 years or more described how diabetes management was not as intense it is today due to changes in technological advances, and 2) participants who were diagnosed prior to age 4 described spending more time in adherence through their adolescence because, “I didn’t know any different. It was what I always did.” (Follow-up Interview 1, February 15, 2010). These points will be described further in the discussion section.

DISCUSSION

The current study provides preliminary knowledge to fill an important gap in the adherence literature with regard to adolescents with type-1 diabetes. The most interesting variables that kept reappearing as factors that contribute to the total data scores were the participants' age of onset as well as their current age. These two variables showed the most relevance in the behaviors that did occur to the participants, as well as what behaviors the participants thought would have been helpful or unhelpful. This section explores possible explanations, as well as how this information may be useful to professionals working with adolescents with type1 diabetes and their families. As stated earlier, Erikson theorized that human's progress through various stages within their human development. Each stage has its own indicators and changes that occur to the individual. The early years of life are where people are dependent upon others to get their needs met are relied upon by an outside source. At these stages, the management of type-1 diabetes, the needs and the medical recommendations of the disease are dominated by the child with diabetes relying upon their caregiver.

In this section, a discussion of the findings present an exploration of the predominant independent variables and their importance to this study. Also discussed is the relevance of these findings to Social Work and the implications for use of these findings in the Social Work profession. They are discussed as 1) Importance of Age of Onset Variable; 2) Importance of Current Age Variable; 3) Other Factors that Contribute to or Hinder Adherence; and 4) Advanced Generalist Principles applied to Adolescent Diabetes Care.

Importance of "Age of Onset" Variable

This study indicates support for the "age of onset" variable and having influence on the behaviors that did occur as a participant reached adolescence. A possible explanation may be that the age of onset may correlate with the amount of support and care the newly diagnosed individual with type-1 diabetes needs for medical management. If the participant was diagnosed at a very young age, then the primary caregiver was usually in charge of the child's diabetes management. However, if the participant was diagnosed as an older child or adolescent, then the participant may have been given more freedom to make choices to adhere to the medical recommendations. When examining Erikson's Stages of Man, the age bracket of 0-4 years, the individual is dependent on their caregiver for all of their basic needs as well as for support and encouragement versus the age bracket of 10-14 years where the individual becomes able to explore their world to develop new ways to master tasks as well as the beginning of developing ways to integrate their previous way of life with new desires and goals that they have developed as a way to express their identity (Robbins et al., 2006). The age of onset, can be indicative of the stage of development that they are in and under what circumstances they have a choice in their adherence levels. As each participant aged, they went through the different human development stages and gained more autonomy and independence, the participant may have also gained more autonomy and independence with their diabetes management. "I was 12, I knew what was going on. I was always in charge of my own diabetes like my parents would monitor and check my blood sugars but they never gave me shots I did it all myself" (Follow-up interview 2, February 23, 2010). As another participant indicated, "I was diagnosed before I can really remember, so taking care of it was all I knew. There was no other option or knowledge of how to do things.” (Follow-up interview 1, February 15, 2010).

The amount of parental involvement also played a role in the medical management and adherence levels of the adolescent with type-1 diabetes. During adolescence, a youth is attempting to individuate themselves from their immediate support system and develop into the individual they wish to become. As families move through this time period, the dynamics within the family relationship also change. When exploring the dynamics between an adolescent, the family support system, and their peer support system, the expectation to adhere and conform to societal norms is diminished as the expectations of the peer group have more of an influence (Broderick, 1993).

Parents can attempt to control their adolescent when the adolescent attempts to integrate his/her past with what he/she wants the future to be. In dealing with adolescents with type-1 diabetes, a key informant believes,

> Parental support for diabetic adolescents is unhelpful, parental supervision is what is helpful. That means sitting down once or twice a week and going through the meter that means observing your son or daughter testing that means participating in core decisions that means being there not as a cop but as an enlightened person. Not bearing witness to the bullshit but helping to execute the real stuff multiple times a day. Not turning it over to them, saying I’m not going to abandon you because you now have peach fuzz. Saying I’m going to hang in there with you no matter what and watch you do what is right. (Key informant, January 20, 2010).

Parents can play a key role in how their adolescent adheres or does not adhere to medical recommendations. Parents play a key role at every stage in their child's life no matter the stage or the age of onset of type-1 diabetes. Based on the study, participants indicated that if parents would help with diabetes management, or purchase things in case of hypoglycemia, that these behaviors would be extremely helpful. The study also indicated that if parents nagged the adolescent with diabetes to test their glucose or to exercise more, that these behaviors were deemed unhelpful to the participants.

Importance of "Current Age" Variable

Throughout time, diabetes management has changed and developed to a very delicate balance between three major areas: diet, exercise, and medication. Each of these three areas has gone through drastic changes over time. The demographic variable of the participants' current age could be a possible explanation as to the behaviors that the participant thought would have been helpful or unhelpful. In this study, participants were asked to look back at their adolescence, and for some participants, that was upwards of forty years ago. For those individuals, the technology and what was described as type-1 diabetes medical recommendations were quite different. A follow-up participant described his diabetes management as

> It was wake up, pee in a cup, add the acid tablet, if it changed colors then you gave insulin; if it didn't then you went on about your business. Then repeat the process in the evening. There was none of this blood tests and finger sticks. It seems more complicated now. Personally I think that the blood tests actually should be declared a form of self injury… The

> protocol was simple- diet, exercise, and insulin if needed (Follow-up participant 1, February 15, 2010).

This participant illustrates that type-1 diabetes management was dramatically different 40 years ago. This fact could also have played a role in how he answered the questions to the survey as to what behaviors would have been helpful or unhelpful if they were to have occurred. If his perception of diabetes management was different from current day management, then he may have answered the quantitative questions from that thought process and not what would be considered management today. This perception difference could account for why those over the age of 50, who completed the survey, thought that if they would have been criticized more to exercise regularly that this would have been a helpful behavior.

Another factor that can make this variable of the participants' current age interesting is how technology has changed throughout the years. When the participant who indicated that management was basically no more than "peeing in a cup", he did not have the advances in medical technology that face today's adolescents with type-1 diabetes. For instance, today an adolescent has the option of taking insulin injections or using an insulin pump. The insulin pump is designed to mimic a pancreas where the body receives a small amount of insulin subcutaneously on a regular basis with the exception being when food is consumed. At these times, the individual with type-1 diabetes must increase the dosage to compensate for the food that was ingested.

The participants' current age also could have been a factor in the results regarding the duration of their diabetes and whether they have had any complications resulting from their non adherence of their type-1 diabetes. If a participant did not adhere to medial recommendations, then the consequences can be devastating both physically to the body and emotionally for the individual. One participant described how she was not in adherence and ended up getting pregnant. Due to her non-adherence, she ended up having to terminate the pregnancy due to the risk posed to both the unborn child and herself (Follow-up participant 4, March 28, 2010). She describes that during her early years of having type-1 diabetes that she knew the difference between what she was doing and what was considered medical management as “It was kind of more like being a good child… but the older I got the less I complied… it was partly getting really frustrated that even though what I was doing was what was supposed to be done I wasn’t getting the correct results” (Follow-up participant 4, March 28, 2010). After dealing with these complications and mindset, her impression of what behaviors would have been helpful or unhelpful to her as an adolescent would be a representation of her experiences since her adolescence and the consequences of her choices.

Other Factors that Contribute to or Hinder Adherence

After completing the data collection and analysis, there were other characteristics that were possible determinants as to the effect that a participant’s current age had on their responses. Each participant is unique and their personal experiences also played a role in their adherence or non adherence levels to the medical recommendations. Today, the analysis of the Hemoglobin A_1C is a strong indicator of adherence (American Diabetes Association, 2007b). A problem arises however when asking different professionals what exactly adherence utilizing the A_1C indicates. According to the Key informant participant 1,

> … the ADA defines successful disease management for diabetics being between globally between 100-180 75 percent of the time then that's considered well managed diabetes then basically a C is an A then I think what they are doing is addressing the reality of the disease and how difficult it is to function with an artificial pancreas… defer to the A_1C, which is the gold standard and I would say, and I'm very liberal this way, and that is I like to see their A_1C's at 9 percent or lower and typically around 7 percent (Key informant participant 1, January 20, 2010).

Since it is difficult to specifically explore what is medical adherence, it is no wonder that many adolescents have a difficult time with this. When asked what other factors may play a role in adherence, peer pressure and self-sabotage came up as deterrents to adherence. The knowledge of not knowing a different way of life and personal experiences with other family members having type-1 diabetes came up as motivators for adherence.

Negative influences were peer pressure. Court (2009) describes how peer influences can result in adolescents exploring life through more risky behaviors and not following their medical recommendations. When conducting the analysis of the qualitative data, follow-up participant 2 (February 23, 2010) indicated that her friends really did not know about her diabetes, and since she wanted to fit in, she would rather stay with her friends than go home and do her "diabetes stuff." Another time, follow-up participant 4 (March 28, 2010), describes that she would do the bare minimum but basically it was self-sabotage to not do the rest.

On the other hand, there was a common theme that emerged in that the participants indicated they did not know another way of life. Follow-up participant 1 (February 15, 2010) and 3 (February 15, 2010) both described that they were diagnosed so young that it was a part of their life and knew nothing different. Follow-up participant 3 (February 15, 2010) also described how when she was an adolescent, her father, who also had type-1 diabetes and did not adhere to medical recommendations, had to undergo a kidney and pancreas transplant. Unfortunately, his body rejected these organs and he passed away within the year. So for her, adherence "wasn't an option, it was what there was, it was what I did. I had no choice since I saw what could happen if I didn't" (Follow-up participant 3, February 15, 2010).

Advanced Generalist Principles and Adolescent Diabetes Care

When applying the principles of Advanced Generalist Practice to adolescent diabetes care, five guiding principles apply: 1) Practice in the micro, mezzo, and macro domains; 2) Policy; 3) Diversity and Social Justice; 4) Research; and 5) Theory. Each of these principles helped to guide this study as well as allowed this study to be used in multiple dimensions of human interactions. Type-1 diabetes care does not occur along one dimension, it occurs along multiple. There are multiple influences and dimensions that can play a factor in adherence among adolescent with type-1 diabetes. The five principles that are crucial to the Advanced Generalist Practice, allow Social Workers and other professionals to explore the different aspects of each dimension and to help the adolescent remain or gain better adherence with their type-1 diabetes.

Relationship of Social Work Practice to Adolescent Diabetes Care

Social Work practice can involve a range of domains. Within Social Work, there is the ability to practice on a micro level, a mezzo level, or a macro level. On the micro level, this study explored specific individuals and their perceptions on certain behaviors that did occur or those that would have occurred. In taking the data that the participants supplied, the analysis could help other adolescents with type-1 diabetes to maintain or gain adherence to medical recommendations. The behaviors that others deemed as helpful or unhelpful could be shared with current adolescents and their families to help with adherence. With the knowledge of how others perceived certain behaviors, current treatment protocols could be developed to incorporate those findings. In addition, if a social worker, or anyone else who may counsel an adolescent and their family, these behaviors that have been decided as more helpful than others could be explored as a means to helping the current adolescent. This information as described in Table 7 could be used to start a conversation with the adolescents with type-1 diabetes and open a dialogue about adherence. These are the top 5 helpful behaviors that the participants indicated through the survey on Survey Monkey.

Table 5

Helpful behaviors for adolescent adherence from their primary caregiver

Top 5 Helpful Behaviors
1. Buying things that contain sugar to carry with the adolescent in case of a hypoglycemic reaction
2. Plan family activities that fit in with diabetes management times
3. Eat at the same time as the adolescent
4. Help the adolescent decide when and how much to adjust their medications
5. Exercise with the adolescent

On a mezzo level, type-1 diabetes management can affect the entire community and the adolescents' support system. What the participants of this study illustrated was that sometimes, though the frequency of a behavior by a caregiver is great, the behavior may actually be unhelpful in the total scheme of diabetes management. The results of the qualitative data also suggest on some of the personal experiences of diabetes management and the factors that influenced adherence or non-adherence. Knowing that sometimes peer pressure can influence the adherence level of an adolescent with type-1 diabetes, social workers can help a current adolescent explore the option of incorporating more of an external family support system. This could include education of the adolescents' educational placement, their friends, and their workplace.

Macro level social work, with regard to adolescents with type-1 diabetes can take the form of advocacy, educating the public as a whole, and educating the medical community of new ways to work with this population. Advocacy groups can push for more funding for treatment and research options. If there are strong advocacy groups, for instance the Juvenile Diabetes Research Foundation and the American Diabetes Association, the knowledge about type-1 and all other forms of diabetes can be distributed to the public faster. Since the number of new cases of diagnosed diabetes is increasing each year, the more people who know about the disease, the treatment options, and the warning signs, the better chance the person with diabetes has to gain control and lead a healthy life.

This study helps illustrate ways that treatment options can be tailored to each individual as well as how to work within families and the community to help this population. Educating the medical field can also help this population. Since type-1 diabetes is a medically chronic disease, a medical professional has to be involved in the care of an individual with type-1 diabetes. As medical professionals become more educated in the needs of their clients, more resources or techniques can be utilized to help. When working with adolescents with type-1 diabetes, medical professionals can use the results of this study to try new techniques to either gain or to have an adolescent maintain adherence to the medical recommendations. Though the results from this study may not work with every individual, it can help in trying other techniques to gain or maintain adherence.

Relationship of Social Work Policy to Adolescent Diabetes Care

There is no direct public policy that requires an adolescent to maintain control of their type-1 diabetes. Many policies on a national level are for the protection against discrimination and the Americans with Disability Act requires places to accommodate, within reason, those individuals who need different work or educational settings. Diabetes, especially type-1, is a chronic medical disease that requires care. Some social policies see medical conditions in adolescents as the family's concern. These social policies, though, do not take into account the tumultuous time period and developmental stage that an adolescent is going through. This also puts an undue amount of pressure on the family or responsible caregiver of the adolescent.

A social policy concern is that this population can be seen as a vulnerable population. The individuals that this study looked to explore where adolescents with a chronic medical condition, for which there is no cure. Another component is the idea that type-1 diabetes management can be very costly. Type-1 diabetes can cross all socioeconomic lines, with little care about who is affected.

> There is no way to predict families who, I mean families who are 6 figure and have all the resources who seem to be doing great to poor families, those who struggle for financial reasons, education, there is really no predicting this disease. Based on those markers there is no predictor (Key informant participant 1, January 20, 2010).

However, the burden of diabetes can impact economically poor families more. It can be difficult for poor families to help their adolescent gain or maintain adherence when they are struggling to provide food or other basic needs. Since diabetes has no boundary on who it affects, there is a real need to explore ways to help those who are unable to follow medical recommendations due to financial hardships.

Overall, there is no policy at any level of society that dictates that medical recommendations need to be followed for any chronic disease. There is a fine line between attempting to determine if an adolescent is causing themselves harm to a point where measures need to be implemented, like the removal of choice through legal means of the adolescent, or if there would be life consequences that would help an adolescent gain control of their type-1 diabetes. This study does not look at this component, though it could be a factor in the level of adherence for some individuals.

Relationship of Social Work Diversity/Social Justice to Adolescent Diabetes Care

Diversity and social justice have been explored though out this study. The participants who responded to the survey did not represent a diverse ethnic sample, but they did represent the ethnic distribution of type-1 diabetes. Adolescents with type-1 diabetes can be discriminated against for their medical condition just as easily as any other demographic variable. This study did demonstrate diversity as to age range of current participants as well as the age of onset of type-1 diabetes. Within a larger context, the results, though not generalizable, can be used to explore how the behaviors that were addressed in the survey are actually represented with each ethnic and cultural dynamic.

Care for adolescents with type-1diabetes can be a social justice issue, in that the individual really does not have complete control if they will develop type-1 diabetes but there are barriers that they must now deal with. For instance, an individual with type-1 diabetes may not enlist in the military. They are seen as high risk individuals, and the requirements for management of the disease (insulin, needles, etc) may not be available in a ready supply in times of crisis.

Adolescents who are not in good control of their type-1 diabetes may also face discrimination when accessing their driver's license. These adolescents need to have a doctor fill out forms that they are not dangers behind the wheel of a vehicle. This can be viewed as a social justice issue since the average individual who chooses to drink and drive can sometimes get a ticket if caught but unless serious damage or they are repeat offenders, they do not have to seek treatment. Each time an adolescent with diabetes wishes to renew their driver's license, in most states, they need to seek their doctor's permission to renew. This is just another example of a social justice issue that can hinder an adolescent with type-1 diabetes.

Relationship of Social Work Theory to Adolescent Diabetes Care

In exploring adolescents with type-1 diabetes, many theories could have been used to explore this population. For this study, it was determined that human development, specifically Erikson's Eight Stages of Man, systems theory, specifically family theory and the person-in-environment approach, were the best suited to explore this population. Each theory or approach shed light on the individual themselves, their immediate family or caregiver dynamics, and then ultimately how the adolescent fit into the greater human society. Though no theory can capture each and every situation, it was determined that these theories best capture the life of an adolescent with type-1 diabetes.

Relationship of Social Work Research to Adolescent Diabetes Care

This study was an exploratory, pilot study where the results were not seen as generalizable. The results of this study allow for further exploration of this population. There is a need for more research into the factors that influence adolescent choices to adhere or not adhere, as well as once some of these factors are know, then what can be done to help this population to gain or maintain adherence.

Though there are limitations to this study, there are also implications for future research. If this study were to be replicated, a longer data collection period would be helpful in gathering more data to seek statistical significance. A longer data collection period may also illustrate other behaviors that could be helpful or unhelpful in working with adolescents with type-1 diabetes. These behaviors could be used in working with this population at multiple levels, from the medical professional to the social worker who helps to counsel a newly diagnosed individual and/or their family. This study also explored some of the factors that contribute to adherence levels with adolescents with type-1 diabetes, but there may be other factors that were not explored. These other factors could be explored to see what influence they may have on adherence levels. The extended family, school environment, work environment and financial factors are just a few of the other areas that could have influenced the participants but were not addressed in this study.

Limitations

There are also limitations to this study. One of the main reasons that the results cannot be generalized is the low sample size. With only 22 participants, though they were from across the country, is not a large enough representative sample to allow generalizability to the population as a whole. Another limitation is the scale that was used. The Family Behavior Checklist only explored the behaviors that did occur and those the participants thought might have been helpful or unhelpful. It did not really explore all components such as peer influence, economic influence, or educational influences that may have played a role in adherence levels with adolescents. A third limitation was the time component. The survey was only open for approximately three months and it could have been open longer with more advertisement. For instance, there was only one participant from the Reno/Sparks area.

CONCLUSION

Gaps were identified in the review of literature for this study. A goal of this study was to help fill these gaps by exploring some of the behaviors that were encountered by adolescents with type-1 diabetes, as well as insights into what behaviors the participants believed to be helpful or unhelpful would they have occurred. This study had a sample size of 22 participants from across the country who all had type-1 diabetes as adolescents. They ranged in age from over age 18 to over the age of 50. There was a range in the age of onset of type-1 diabetes as well. Through examining different theories, Erikson's Eight Stages of Man, family systems theory, and person- in- environment approach, the transition from youth to adulthood can be huge transition period in an individual's life. Both qualitative and quantitative methods were used to explore the motivational factors that may influence the choices to adhere or not adhere to medical recommendations.

The results indicated some interesting findings. The main factors that influenced the results of the total scale score for the frequency of behaviors that did occur were the age of onset of the participant and the participants' current age. The main variables that influenced the participants' views on what behaviors would have been helpful or unhelpful were the participants' age of onset and their gender. With these results, it can be suggested that the individuals' age of onset may be a leading variable into the adherence levels throughout adolescence. The age of onset was shown to influence the diabetes management behaviors that did occur as well what diabetes management behaviors would have been helpful for adherence. These factors have implications for future practice in how practitioners work with adolescents with type-1 diabetes as well as where there could be future research into this area and population.

The qualitative findings illustrated the specific behaviors or characteristics of each participant's adolescent age and the influences that either helped or hindered them from adhering to medical recommendations. Themes were formed based the follow-up interview participants. Some reasons for adherence were that the participant was diagnosed at a young age where they did not recall life any other way and personal relationships with other individuals within their family who also had type-1 diabetes showed the participant the consequences of poor adherence. Those factors that influenced non adherence included self-sabotage and peer pressure. After the Key informant participant, the current professionals working within the field with adolescents with type-1 diabetes are seeing similar influences on adherence with their current patients. The key informant was able to shed an outside perspective of the struggles with adherence for adolescent and what are some ways that families especially dominate caregivers, can help an adolescent with adherence of type-1 diabetes.

Social Workers can see the impact of poor adherence of type-1 diabetes within their own practice or work placement. Since social work has specific principles that govern the field of Social Work, the knowledge of how to work with adolescents with type-1 diabetes, their families, and how to help the adolescent lead a successful life can be utilized. The five guiding principles of Advanced Generalist Practice can be utilized when working with type-1 diabetes and this study demonstrated techniques and ways for this to be accomplished.

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APPENDIX A- Diabetes Family Behavior Checklist

We want you to recall what is was like in your family at ages 12-18, and respond based on your recollection with that time period. We also want to know how often family members did several things related to your daily self-care activities. Please rate the family member with whom you generally had the most contact. Just put down what happened at home- there are no right or wrong answers.

1. Which family member did you spend the most time with as an adolescent?
   a. Dad b. Mom
   c. Sibling d. Other (specify) ___________

2. How much time did you spend with the person you chose in #1 on a typical day? Count only waking hours. _________ hours

3. How much did this person know about diabetes? (Please circle a number below)

Hardly Anything			Moderate Amount			Great Deal
1	2	3	4	5	6	7

Think of the person you chose in #1 to rate the following statements:

How often did he/she	**Never**	**Once a month**	**Once a week**	**Several times a week**	**At least once a day**	**Not-applicable**
4. Praise you for following your diet?	1	2	3	4	5	N/A
5. Nag you about testing your glucose level?	1	2	3	4	5	N/A
6. Suggest things that might help you take your diabetes medications on time?	1	2	3	4	5	N/A
7. Criticize you for not exercising regularly?	1	2	3	4	5	N/A
8. Help you decide if changes should be made based on glucose testing results?	1	2	3	4	5	N/A
9. Nag you about not following your diet?	1	2	3	4	5	N/A
10. Argue with you about your diabetes self-care activities?	1	2	3	4	5	N/A
11. Encourage you to participate in sports activities?	1	2	3	4	5	N/A

12. Plan family activities so that they will fit in with your diabetes self-care schedule?	1	2	3	4	5	N/A
13. Congratulate you for sticking to your diabetes self-care schedule?	1	2	3	4	5	N/A
14. Criticize you for not recording the results of glucose tests?	1	2	3	4	5	N/A
15. Eat at the same time that you did?	1	2	3	4	5	N/A
16. Exercise with you?	1	2	3	4	5	N/A
17. Let you sleep late rather than getting up to take your diabetes medication?	1	2	3	4	5	N/A
18. Buy you things containing sugar to carry with you in case of a hypoglycemic reaction?	1	2	3	4	5	N/A
19. Eat foods that are not part of your diabetic diet?	1	2	3	4	5	N/A
20. Other supportive or nonsupportive things he/she did: ____________________ ____________________ ____________________ ____________________	1	2	3	4	5	N/A

Now please rate the same behaviors as to how helpful or unhelpful they were.

	Extremely Unhelpful			**Neither helpful or unhelpful**			**Extremely Helpful**	**Not-applicable**
21. Praise you for following your diet?	-3	-2	-1	0	1	2	3	N/A

22. Nag you about testing your glucose level?	-3	-2	-1	0	1	2	3	N/A
23. Suggest things that might have helped you take your diabetes medications on time?	-3	-2	-1	0	1	2	3	N/A
24. Criticize you for not exercising regularly?	-3	-2	-1	0	1	2	3	N/A
25. Help you decide if changes should have been made based on glucose testing results?	-3	-2	-1	0	1	2	3	N/A
26. Nag you about not following your diet?	-3	-2	-1	0	1	2	3	N/A
27. Argue with you about your diabetes self-care activities?	-3	-2	-1	0	1	2	3	N/A
28. Encourage you to participate in sports activities?	-3	-2	-1	0	1	2	3	N/A
29. Plan family activities so they would fit in with your diabetes self-care activities?	-3	-2	-1	0	1	2	3	N/A
30. Congratulate you for sticking to your diabetes self-care schedule?	-3	2	-1	0	1	2	3	N/A
31. Criticize you for not recording the results of glucose tests?	-3	-2	-1	0	1	2	3	N/A
32. Eat at the same time that you did?	-3	-2	-1	0	1	2	3	N/A
33. Exercise with you?	-3	-2	-1	0	1	2	3	N/A
34. Let you sleep late rather than getting us to take your diabetes medication?	-3	-2	-1	0	1	2	3	N/A

35. Buy you things containing sugar to carry with you in case of a hypoglycemic reaction?	-3	-2	-1	0	1	2	3	N/A
36. Eat foods that are not part of your diabetic diet?	-3	-2	-1	0	1	2	3	N/A
37. Other supportive or nonsupportive things he/she did: ______________________ ______________________ ______________________	-3	-2	-1	0	1	2	3	N/A

APPENDIX B- Qualitative Questions for Follow- Up Interviews

1. Tell me about yourself.

2. At what age were you diagnosed?

3. Have you had any complications due specifically to the diabetes?

4. What percentage of time did you adhere to medical recommendations during your adolescents?

5. What percentage of time did you not adhere to medical recommendations during your adolescents?

6. Tell me about times when you did adhere to medical recommendations.

7. Tell me about times when you did not adhere to medical recommendations.

8. What was your adolescence like growing up with type-1 diabetes?

9. Would you elaborate as to what were the motivational factors that you did adhere with medical recommendations?

10. Would you elaborate as to what were the motivational factors that you did not adhere with medical recommendations?

11. Who was your biggest advocate in dealing with the responsibility of your diabetes?

12. Who was your biggest foe in dealing with the responsibility of your diabetes?

13. Do you recall a specific moment when you were given full control and responsibility of your diabetes? Tell me about that time.

14. Is there anything else you could share with me that could help us understand reasons why adolescents adhere or not adhere with medical recommendations?

APPENDIX C- Qualitative Questions for Key Informants

1. Tell me in general about your adolescents with diabetes.

2. What is the average age they were diagnosed?

3. Have you seen any complications due specifically to the diabetes?

4. What percentage of time do your adolescents adhere to medical recommendations?

5. What percentage of time do your adolescents not adhere to medical recommendations?

6. What are some of the stories you have heard from the adolescents about what their day is like living with diabetes?

7. Would you elaborate as to in what ways and what have you observed as to why the adolescents do not comply with the medical recommendations set forward to them?

8. Who is typically the adolescents' biggest advocate in dealing with the responsibility of the adolescents' diabetes?

9. Who is the typically the adolescents biggest foe in dealing with the responsibility of the adolescents diabetes?

10. Does there seem to be a specific moment or commonality as to when the adolescent is given full control and responsibility of their diabetes? Please describe what this looks like.

11. Is there anything else you could share with me that could help us understand reasons why adolescents adhere or not adhere with medical recommendations?

APPENDIX D- IRB Approval Letter

University of Nevada, Reno

Office of Human Research Protection
205 Ross Hall / 331, Reno, Nevada 89557
775.327.2368 / 775.327.2369 fax
www.unr.edu/ohrp

Certification of Approval
Social Behavioral, Panel A
Institutional Review Board

Date: December 17, 2009

To: Linda Anngela-Cole, PhD, MSW
School of Social Work / 0090

CC: Elisha Dillon
School of Social Work / 0090

UNR Protocol Number:	**SA09/10-035**
Protocol Title:	**Adherence among Adolescents with Type 1 Diabetes**
Sponsor Protocol Number:	**N/A**
Sponsor:	**None**
VA Research:	**No**
UNR Assurance Number:	**FWA00002306**
IRB Number:	**IRB00000216**
Action Item:	**New Protocol: Social Behavioral**
Level of Review for Action:	**Expedited**
Expedited Category:	**6 & 7**
Review Period:	**12 months**
IRB Action Date:	**Nov-17-2009**
Expiration Date:	**Nov-17-2010**

This approval is for:
Recruitment flyer and script, as revised
Contact sheet for group 1 participants, as prepared
Cover letter for both participant groups, as submitted
Online survey with informative introduction, as revised
Information sheet for practitioners, numbered and updated (12/16/09)
Protocol application, as revised (12/8/09)

PI responsibilities

- Continuing projects must be reviewed and approved prior to the expiration date.
- Proposed changes must be reviewed and approved by the IRB prior to initiation, except when necessary to eliminate apparent immediate hazards to subjects. Such exceptions must be reported to the IRB at once.
- Any unanticipated problems which may increase risks to human subjects or unanticipated adverse events must be reported to the IRB within 10 days of becoming aware of the issue.
- When the project has been completed, please submit a closure request to the IRB.

Please reference the protocol number above on all related correspondence with the IRB. If you have any questions, please contact Gwenn Snow at 775.327.2368.

Chair, Vice-Chair, or OHRP Director
Susan Ford Publicover, MA, CIP, Director

University of Nevada, Reno

Office of Human Research Protection
205 Ross Hall / 331, Reno, Nevada 89557
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Certification of Approval
Social Behavioral, Panel A
Institutional Review Board

Date: March 2, 2010

To: Linda Anngela-Cole, PhD, MSW
School of Social Work / 0090

CC: Elisha Dillon
School of Social Work / 0090

UNR Protocol Number:	**SA09/10-035**
Protocol Title:	**Adherence among Adolescents with Type 1 Diabetes**
Sponsor Protocol Number:	**N/A**
Sponsor:	**None**
VA Research:	**No**
UNR Assurance Number:	**FWA00002306**
IRB Number:	**IRB00000216**
Action Item:	**Modifications**
Level of Review for Action:	**Expedited**
Expedited Category:	**6 & 7**
IRB Action Date:	**Feb-12-2010**
IRB Approval Date:	**Mar-02-2010**
Expiration Date:	**Nov-17-2010**

This approval is for:
Modifications, January 2010

- Expansion of recruitment procedures to include posts to online support group email-lists and notices in online e-mails, all of which will be specific to people with diabetes
- Copy of the content of the post for the email lists and notice for e-newsletters

Online recruitment script/post, as provided (2/15/10)
Permission from Bella Online to post recruitment "script"
Permission from Nevada Diabetes Association to post recruitment script for Diabetes in Children and Families Support Group and for placement of recruitment script in the organization's e-newsletter
Online information sheet, as revised
Protocol application, as revised (2/15/10)

PI responsibilities

- Continuing projects must be reviewed and approved prior to the expiration date.
- Proposed changes must be reviewed and approved by the IRB prior to initiation, except when necessary to eliminate apparent immediate hazards to subjects. Such exceptions must be reported to the IRB at once.
- Any unanticipated problems which may increase risks to human subjects or unanticipated adverse events must be reported to the IRB within 10 days of becoming aware of the issue.
- When the project has been completed, please submit a closure request to the IRB.

Please reference the protocol number above on all related correspondence with the IRB. If you have any questions, please contact Gwenn Snow at 775.327.2368.

Susan Ford Publicover

Chair, Vice-Chair, or OHRP Director
Susan Ford Publicover, MA, CIP, Director