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PARENT AND ADOLESCENT READINESS IN THE TRANSITION TO ADOLESCENT DIABETIC SELF CARE

By

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ABSTRACT

PARENT AND ADOLESCENT READINESS IN THE TRANSITION TO ADOLESCENT DIABETIC SELF CARE

By

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The purpose of this study is to explore parents and adolescents experiences transitioning adolescents to independent care for their Type 1 diabetes. Adolescence is the stage of development when youth can physically and cognitive function in ways that are necessary to transition to independent responsibility for diabetes care. Parents have to transition adolescents into responsibility for the care roles they occupy. Adolescents may perceive their parents involvement to be imposing and threatening to their pursuit of independence and autonomy. Adolescents' resistance to parent involvement can cause relational conflict and individual distress. These interfere with parents and adolescents working together to engage in the transition process. Employing a modified grounded theory qualitative research approach, this study sought to identify the parent and adolescent characteristics that facilitate their readiness for and determine their experiences and outcomes of the transition process. Guided by developmental and Bowen Family Systems theories, this study proposed that adolescents developmental readiness and parents emotional readiness influence the ease and effectiveness of the transition experience. Forty people (n=20 adolescents ages 12 to16 and n=20 primary caregiver parents) recruited from a diabetes summer camp in Wisconsin participated in the study. Participants independently completed a semi-structured interview that queried their readiness for, roles initiating and relational experiences during the transition. To validate the

interview data about parent emotional readiness for and support of the transition, parents also completed questionnaires that assessed the concepts of parents': differentiation (Differentiation of Self Inventory); encouragement of adolescent autonomy (Diabetes Specific Parental Support of Autonomy Scale); and miscarried helping behavior (Help for Health Inventory). **Results:** Through the transition process they conducted, parents gradually transferred responsibility for three main roles: caregiver, decision maker and healthcare systems manager. Parents determined when and how the process started and progressed based on their perception of their adolescents' readiness. Adolescents' developmental characteristics that indicated their readiness included: mature cognitive and emotional processing, self confidence effusing temperaments; and competent and consistent performance of care tasks. Adolescents' inconsistency in performing care tasks, due to immature cognitive functioning and preoccupation with socializing, caused parents to delay starting and progressing through the transition. Parents' differentiation influenced their perception of adolescents' readiness to start and the timing and approach they chose for conducting the transition. Consequently, parents' differentiation affected participants' experience and outcomes of the transition. Well differentiated parents conducted easy, efficient and effective transition processes because they employed approaches that addressed their adolescents' developmental readiness and needs. Implications for family therapists, healthcare providers and parents are discussed.

Dedication

I proudly dedicate this dissertation as a gift to:

The loves of my life: Harold, Donovan and Landen Burden

and

My Parents, Rev. Jessie and Kathleen Smith, Jr.

Acknowledgements

My deepest gratitude goes to the most important people in my life: my family and husband. I appreciate all of the love, support, and encouragement you give me and your steadfast faith that I would indeed accomplish what I set out to do. I honestly re-committed myself to completing this dissertation so that I could earn my doctorate and give it to you all as a return on these intangible investments. I was able to complete it because of your physical, emotional and spiritual care. Now to each of you, individual thanks:

I begin by addressing the first people in my life, responsible for effecting and witnessing my entry into this world: my parents: Thank you for all that you have given and done to mold me into the person I am. It is because of your genes, parenting, modeling, and unwavering belief in, support of, and pride in me and what I desired to accomplish that I was able to dream and then live out my graduate school goal. You set me on such a firm foundation morally, spiritually and academically that I could do nothing else but rise to your generous expectations of me. Oh, how richly and abundantly blessed I am to have such a family to have given me a great start and continued support in life. I promise to make it a great finish and beyond by how I extend the precious gifts you gave to me on to my children. I am forever your middle child. To my sister thank you for providing the emotional support of a great sista'-best friend. Your staying up through the night with me as I finished this paper spoke volumes of your love for me and your character as a Christian. I am thankful to be able to live out our lives and dreams together. I love you.

To my beautiful blessings, Donovan and Landen and any future children: I am amazed, proud and grateful to God that I am the mother of such intelligent, gifted and talented boys. You are more precious than gold to me. I want this accomplishment to be a documented example of how you can do all things through Christ Jesus who strengthens you. May you achieve all you dream of, and may it be pleasing in the eyes of the Lord. Remember, God made me your mother so that I may do anything in my power to help you do that. Always in love with and in support of you – Mama.

In memory of my God-uncle Robert Bonds: Perhaps the greatest gift you gave me was what you uttered the last time we talked. You were dying, but in spite of the weakness in your voice, I heard you say in the most certain tone and with compassionate resolve, "I never doubted you would". I was stuck in being able to write this dissertation and that simple phrase of faith in me gave me the push I needed to get back in the race. Thanks for letting God use you to tip me back onto the path HE started me on when I first met you. Your life exemplified God's grace and mercy and I watched how you in turn showed that to others. I will honor you by the way I raise my children and move forward to live out the purpose HE has for me.

I finish addressing my family by extending my appreciation to the person I plan to finish out my life with, Harold my husband of 9 years and best friend of 15. I know God loves me because he gave me you: You are the most reliable and helpful friend, God-honest Christian, and willing worker I have ever met. The love, concern for my best interest, physical care and moral support you consistently shower me with are the actualization of what I prayed for as a little girl when I asked God to give me knowledge, wisdom, understanding and ***consistency***. Thank you for encouraging me to finish this

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Now to you Most Heavenly Father, I give the highest praise: Hallelujah to your name. You alone have done this great thing and it is marvelous in my and my family's sight. May all the praise and glory I can profess be unto you, always. I honor your many gifts with my life, forever. Amen.

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Chapter 1

Introduction

For youth diagnosed with Type 1 diabetes, survival and quality of life are dependent on consistently meeting the enduring challenge of effectively managing their diabetes. For adolescents, managing Type 1 diabetes may complicate the experience of an already challenging developmental phase. The primary feature of successful diabetes management is adherence to a daily regimen of tasks, including: insulin injections and (possible) dosage changes, blood glucose checking, monitoring and recording, and meal planning. Proper adherence requires sacrifice, self control (delay of gratification) and organization (attention to detail in record keeping and regimen schedule). Independently managing diabetes also requires an advanced level of cognitive functioning that is characterized by a future orientation which facilitates constructive decision making.

Statement of the Problem

When a person has Type 1 diabetes, to survive and live free of complications that devastate one's health and quality of life requires effectively controlling it through consistent, proper management of a comprehensive healthcare strategy. The primary components of the strategy involve administrating and performing a daily regimen of care tasks; making decisions about the treatment protocol; and managing a comprehensive system of healthcare services. The most complex component of the treatment plan is the multiple task care regimen. The necessity to adhere to the protocol of self-administering the regimen daily distinguishes Type 1 diabetes as perhaps the most strenuous chronic illness to independently care for. Therefore, when diagnosed during childhood successful survival to adolescence requires parents to function as primary managers and caretakers

of the diabetes. Parents need to continue to be involved during adolescence so they can monitor them to ensure that they maintain a healthy lifestyle and oversee their growth in the capacity to care for their diabetes independently so that have optimal immediate and long-term health. However, adolescence is the developmental stage when the desire and necessity for parents to transfer the reigns for controlling diabetes care heightens. Adolescents view continued parent involvement as a challenge to their desire for autonomy and a threat to their growth towards being independent. In contrast, adolescent autonomy may conflict with attaining optimal metabolic control if not accompanied by the competence and skill necessary to perform, and a commitment to consistently adhere to, the necessary diabetes-care regimen. Being confidently and competently capable of independently performing the daily regimen and managing the multifaceted care plan is necessary for adolescents with Type 1 diabetes to emerge into a healthy functioning adulthood. Given adolescents' underdeveloped capacity to understand and function consistently in all these necessary ways, they need their parents' involvement in the form of guidance and support. These roles involve parents overseeing adolescents' proper performance and adherence to the regimen as they teach them how to independently manage the complexity of diabetes care. If adolescents protest their parents' involvement, they may have conflict with them which affects the cohesion and cooperation that is necessary for parents and adolescents to effectively engage in the co-working relationship that is required. Thus, parents and adolescents inability to effectively engage with each other about diabetes care negatively affects adolescents' health and the transition process. Thus, it is of vital importance to the survival and growth of adolescents with Type 1 diabetes to indentify the factors that facilitate or hinder parents and adolescents readiness to engage in the transition process.

Background

Given that Type 1 diabetes is chronic rather than fatal only if it is well controlled consistently throughout one's lifetime, if children and adolescents want to continue to exist throughout adulthood independent of their parents' control, they need to learn how to competently perform and make decisions about all of the aspects of their treatment plan. According to Eric Erikson (1950), gaining independence from parental control and establishing autonomy over decision making about one's life is a primary component of adolescence's psychosocial goal of identity formation. Effectively attending to both achieving autonomy and performing and adhering to the diabetes treatment regimen has vital implications for adolescents' health and development. Increased independence and autonomy before an adolescent is prepared for it is associated with inconsistent adherence to diabetes treatment, which leads to poor metabolic control (Diabetes Control and Complications Trial [DCCT] Research Group, 1993; Marshall, Carter & Rose, 2006).

Even as they are demanding and often contending challenges, the routes to achieving the psychosocial goals of adolescence and taking on full responsibility for the diabetes care regimen intertwine, affecting the well being and development of adolescents. Gaining increasing independence and autonomy necessarily causes an increase in adolescents' responsibility for their diabetes care. In turn, independence and autonomy are more fully developed and established through adolescents taking on increased responsibility for their diabetes care (Drotar & Evers, 1994; Sternberg, 1999). Regardless, adolescents may perceive the diabetes treatment regimen as threatening their independence and thus diminishing the quality of their life. That is because, the work and responsibility required to independently manage and perform the regimen is at odds with the characteristic ways adolescents function: being self-conscious about differences,

desiring to fit in and appear normal; taking risks and testing boundaries; engaging in present-focused reasoning; and having the autonomy to determine daily events (Erikson, 1950; Santrock, 2009; Schreiner, Brow, & Phillips, 2000). If adolescents view the regimen as a threat to their freedom and this perception exacerbates the negative aspects of their challenging ways of thinking, they may resist performing it. When this happens, the characteristics of normal adolescent functioning interfere with proper treatment adherence which is necessary for adolescents with Type 1 diabetes to stay healthy. They become obstacles to adolescents continued healthy development and threats to their life (Diabetes Control and Complications Trial [DCCT] Research Group, 1993; Marshall, Carter & Rose, 2006).

Supportive parental involvement is associated with adolescents adhering to their diabetes care regimen and attaining optimal metabolic control (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Murphy, Thompson, & Morris, 1997; Weissberg-Benchell & Antisdel, 2000). Specifically, adolescents identify parenting that provides guidance, non-intrusive monitoring, and emotional support as helpful and facilitative of their taking care of their diabetes (Champaigne, 2001; LaGreca and Bearman, 2002). This is important because, people with Type 1 diabetes who do not develop healthy, self care patterns of behavior during adolescence have a reduced life expectancy compared to those who do (DCCT, 1993). Adolescents push for independence and autonomy may challenge their continuing the type of relationship with their parents that is necessary for optimal diabetes control (Diabetes Control and Complications Trial [DCCT] Research Group, 1993, Erikson, 1950; Marshall, Carter & Rose, 2006). Rather than perceiving parental involvement in their diabetes care as necessary and helpful, adolescents may perceive it as being at odds with establishing the coveted independence and autonomy.

Reconciling adolescents' perceived contention between their stage-specific need for independence and their diabetes-specific need for dependence on parent involvement is necessary to facilitate adolescents' transition to general and diabetes-specific adulthood responsibility. Instead of being at odds with adolescent autonomy, parent involvement facilitates autonomy when it includes teaching adolescents how to perform their care and overseeing that they adhere to it. These types of involvement help adolescents to be healthy and equipped to move forward with autonomy. Supportive parenting behaviors facilitate adolescents' development of the maturity, competence and skills that are necessary to be responsible for self care. When adolescents display this responsibility in the forms of adherence to and capable management of their diabetes care regimen, they demonstrate achievement of a level of cognitive and social maturity that denotes their preparedness for the autonomy of adulthood with Type 1 diabetes (Ott, Greening, Palardy, Holderby, & DeBell, 2000). Thus, parent involvement, autonomy and adherence connect to affect adolescents' with Type 1 diabetes survival and growth

To achieve this end, a paramount part of parents' responsibility as primary caregiver is to transition their adolescent into independent self care. Beyond teaching them how to perform diabetes care tasks, ensuring the enduring success of adolescents' transition involves preparing them to be the manager of their diabetes care. The transition occurs gradually, determined by adolescents' progressive cognitive and emotional maturity and display of readiness for the responsibility. Parents also have to prepare themselves to relinquish the primary caregiver role and its benefits of being aware of and in some control of their adolescents' health affecting behaviors. Having fulfilled this role up until the transition point, parents are intimately aware of both its weight and the consequences for their child of poor diabetes management. Giving up

control and being uncertain of their adolescent's ability to handle the responsibility may cause parents to be reluctant to prepare their adolescent for and actually transition them to diabetes management autonomy. When adolescents demonstrate readiness for diabetes management autonomy and self care independence but their parents are reluctant to relinquish the primary caregiver/manager role, adolescents' development of autonomy can be hindered or stunted. In this case, adolescents may perceive their growth and independence as being threatened by their parents' involvement in their lives via managing their diabetes. Parent involvement in adolescents' diabetes care causes conflict when it extends beyond what is developmentally and individually appropriate for the adolescent. Parent-adolescent conflict is negatively associated with adolescents' adherence to their diabetes treatment regimen, which is related to poor metabolic control (Liakopoulou et al., 2001). In contrast, less parent involvement is associated with less parent-child conflict and greater child self efficacy but poorer metabolic control (Steinberg, 1999).

A few studies have examined the parent-adolescent relationship dynamics that facilitate adolescents' diabetes care-specific autonomy and responsibility. Most related in focus and methodology to the proposed study is Hanna and Guthrie's (2000) qualitative study designed to identify what 17 parents of 11-18 year-olds with type 1 diabetes perceived as being benefits and barriers to their decision making regarding their adolescents' assuming responsibility for managing their diabetes. Analysis of interviews with parents' revealed that they perceived the benefits for themselves of transferring responsibility for diabetes management to their adolescents as being: relief from the burden of responsibility; and knowledge of and pride in their adolescents' abilities. They identified freedom, independence, and control as benefits for their adolescents. Parents

identified their own fear of dealing with consequences, and loss of control and supervision as the barriers they perceive as guiding their resistance to allowing their adolescents' responsibility for managing their diabetes. Parents perceived their adolescents' barrier to be adolescents' perception of the burden of responsibility. Further examination of the interviews by Hanna and Guthrie (2001) revealed what parents and adolescents perceived as helpful and nonhelpful support from parents in facilitating adolescents' assumption of responsibility for managing their diabetes. Parents and adolescents agreed that the helpfulness of parents' provision of directive guidance and tangible assistance depended on parents' degree of directness and adolescents' perceived need for help. Thus, both parents and adolescents could identify the factors that serve as incentives to and thereby prompt parents to initiate the transfer of responsibility to their adolescents. Both also identified parenting behaviors that are helpful for effectively engaging in the transition process.

Building on these findings, this study proposes that the occurrence and ease of adolescents' transition to independent self care is influenced by parents' readiness as well as their perception of adolescents' readiness. Further, this study proposes that parents' lack of readiness to transfer responsibility and transition their adolescents into the primary management role can lead parents to engage in behaviors that represent miscarried helping (Anderson and Coyne, 1991). Miscarried helping is a term that describes how parents become emotionally overinvolved when they are motivated by both their: fear of the possible health consequences for their child of poorly managed diabetes; and investment in being the caregiver in control of their adolescents' diabetes care. This emotional overinvolvement is displayed by a pattern of behavior that is controlling, and includes behaviors that adolescent with Type 1 diabetes have identified

as nonhelpful, barriers to their adherence, adjustment and transition to self care (Hanna and Guthrie, 200; 2001; Weinger, O'Donnell, and Ritholz, 2001). This study proposes that miscarried helping is a behavioral reflection of parents' lack of readiness for adolescents' transition to independent self care and underlies the conflict associated with the parent-adolescent relationships of diabetics with poor metabolic control. Further, this study proposes that parents' readiness is influenced by parents' differentiation of self and their perception that their adolescent is not developmentally ready for the transition to independent self care.

Significance of this Study

The important health and development implications for adolescents with Type 1 diabetes of both their and their parents' readiness, for facilitating the adolescent's transition to, independent self care underscore the need to identify a way to match or reconcile their readiness differences. A goodness of fit between parent and adolescent readiness levels may allow them to engage in a relationship that facilitates a cooperative role transfer and successful transition. No study has examined adolescents' and parents' perceptions of how parents' readiness for transferring responsibility to their adolescents influences both the objective and subjective experience of the transfer process. Preventing the negative developmental and parent-adolescent relationship consequences of a clash between parent-adolescent differing levels of readiness requires and starts with understanding the factors surrounding the cause and experience of them. Understanding this could aide clinicians in helping families prepare for, manage and resolve the challenges that differing parent-adolescent readiness presents to effectively transitioning adolescents to diabetes management autonomy in a healthy way. Thus, there is a potential real-life, practical benefit of engaging in an exploratory investigation of parents

and adolescents' relational experiences of transitioning adolescents to independent responsibility for self care and autonomous management of their diabetes regimen.

Purpose of this Study

The current study seeks to contribute to a greater understanding of the role of the parent-adolescent relationship and parent readiness factors in adolescents with Type 1 diabetes experience of transitioning to independent self care. Based on the findings of the existent relevant literature, this study proposes that adolescents ability to take over responsibility for their Type 1 diabetes care and management from their parents would be better understood if it was explored in terms of both adolescents' developmental readiness and parents' emotional readiness. This study proposes that using a grounded theory approach would provide this better understanding of the parent-adolescent experience of transitioning. The semi-structured interview method would yield data that illustrates the real-life experiences that reflect the parent-adolescent relationship dynamics surrounding parents' readiness to transfer diabetes responsibilities to their adolescents and adolescents' transition to self management. Bowen family systems theory's concept of differentiation and (Friedman, 1991) the concept of miscarried helping are used as theoretical guides for the conceptual framework.

Conceptual Framework

The conceptual framework proposes that: The experience of transitioning adolescents with Type 1 diabetes to independent self care is characterized by parents' perception of adolescents' readiness and parents' differentiation of self, which in turn, influence parents' involvement and parent-adolescent engagement. Figure 1 below is a conceptual map that illustrates this proposed relationship.

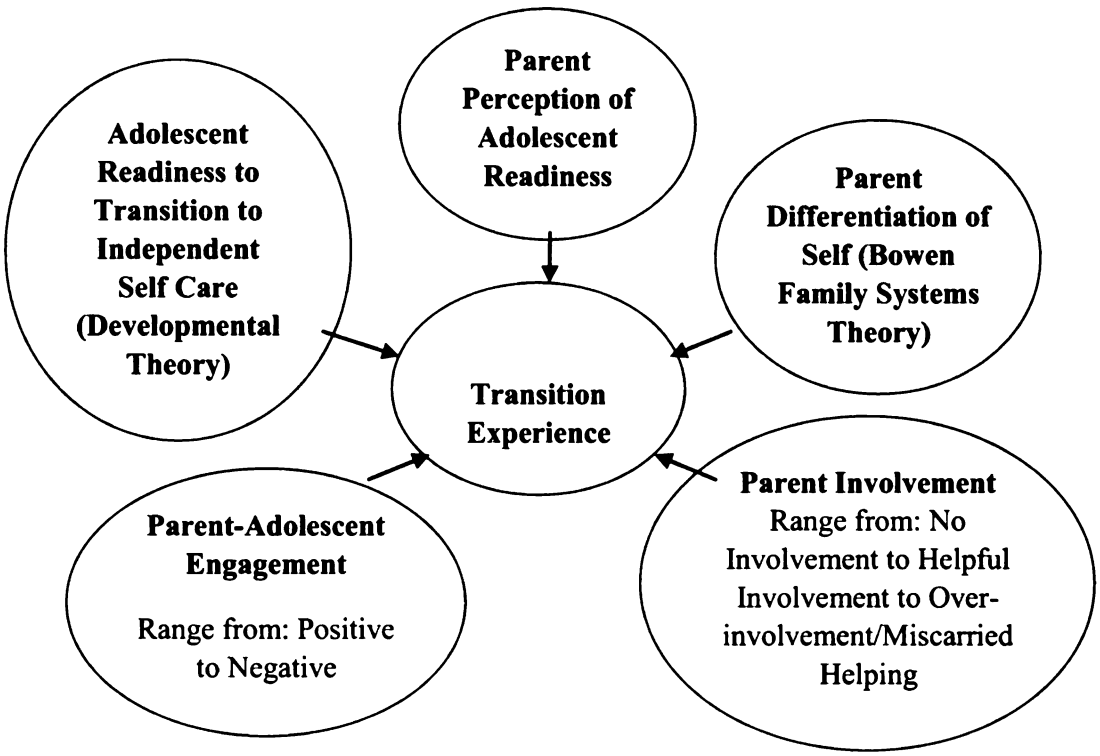

Figure 1. Proposed Theoretical and Conceptual Map

Theoretical Framework

Piaget's Theory of Adolescent Cognitive Development

Diabetes healthcare professionals perceive adolescence as the developmentally appropriate stage to learn, practice and begin to assume responsibility for managing diabetes. This is primarily because adolescence reflects the advent of the level of cognitive functioning Piaget (1962) described as formal operational thinking. Even though physical ability to complete regimen tasks occurs in childhood, professionals agree that cognitive functioning is the primary human process responsible for successful diabetes management (Weissberg-Benchell and Antisdel, 2000).

Piaget's formal operational thinking reflects and involves the ability to engage in: hypothetical deductive reasoning, and abstract thinking (1962). These cognitive skills

make adolescents better equipped to make decisions about modifications to their treatment regimen, which is required frequently and facilitates tighter metabolic control. These cognitive skills also allow adolescents to engage in more future oriented perspective-taking, sophisticated decision-making and advanced problem solving than is possible using the concrete operational thinking characteristic of childhood. Thus, formal operational thinking causes adolescents with Type 1 diabetes to be able to consider the long-term outcomes, both risks and benefits, of immediate behaviors, self care and adherence to their treatment regimen. This capability lends itself to increasing the probability of adolescents considering and acting in ways that effect better treatment adherence and thus enhance metabolic control. For instance, a future orientation can influence an adolescent to delay gratification and adhere to treatment regimen nutrition-wise. Thus, the formal operational thinking that emerges and develops in adolescence enhances adolescents' cognitive capacity, which can then direct behavior in positive ways. Both increase adolescents' readiness (competence and capability) to assume the autonomy that transitioning to successful, independent diabetes management requires. This study proposes that parents' readiness to transfer the primary caregiver role to their adolescent is influenced not only by their adolescent's readiness but also by the parents' perception of their adolescent's readiness. If there is a disparity between the two, parent-adolescent conflict is likely to occur.

Bowen's Family Systems Theory

As for mentioned, research shows that adolescent diabetics who experience family conflict experience poor metabolic control. In a poorly differentiated, fused family emotional system, the parent-child dyad may experience conflict over diabetes management. The differentiation level of the parent who is the primary manager of the

adolescent's diabetes influences the extent to which the parent can manage their emotional reactivity and relinquish control for diabetes management to the adolescent. This paper proposes that parent-adolescent conflict will moderate the interactive influence of parents' level of differentiation and child's readiness for self-care on adolescents' treatment adherence. That is, if fusion occurs (characterized by the parent blurring the boundaries between their self and their adolescent, with regards to responsibility for diabetes management) an adolescent who is ready to assume responsibility for managing their diabetes may react to the unwanted fusion and the lack of opportunity to self-define, by acting out. In particular, the adolescent may act out by sabotaging their good health outcomes by refusing to adhere to healthy behaviors or by engaging in unhealthy diabetes-related behaviors. In this case, the parents' poorly differentiated role anxiety outweighs the adolescent's need for autonomy and interferes with their healthy development. This may lead to the parent engaging in miscarried helping.

In cases in which a poorly differentiated family is cut-off, the family emotional system provides little support and guidance. Thus, the adolescent with Type 1 diabetes may be expected to assume responsibility for managing their diabetes without proper skills or readiness. The result would likely be poor diabetes management and poor metabolic control. If the adolescent is ready for the responsibility, then they will assume it and manage it well (often with the aid of their medical care team/system).

Table 1

Comparison of Theory, Concepts and Research Questions

Theory	**Concepts**	**Participants**	**Research Questions**
Development	Adolescent Readiness	Adolescent	1. How does adolescent readiness influence parent readiness? 2. What adolescent factors inhibit or facilitate parents' readiness for transitioning adolescents to independent, diabetes self care?
Bowen	Differentiation of Self	Parent	3. How does parent differentiation of self inhibit or facilitate the transition process?

Research Questions

Based on the theoretical and conceptual framework, derived from the reviewed literature, the research questions are:

Adolescent Development

Question 1: How does adolescent readiness for transitioning to independent, diabetes self care influence parent readiness?

Question 2: What adolescent factors inhibit or facilitate parent readiness for transitioning adolescents to independent, diabetes self care?

Parent Differentiation of Self and Helping Behavior

Question 3: How does parent differentiation of self inhibit or facilitate the transition process?

Employing grounded theory approach and semi-structured interview method to explore the topics of these research questions allows for the emergence of a theory of how the transition process is grounded in the readiness and relationship factors of adolescents and their primary caregiving parent. Table 2 presents the research questions along with the research concepts they represent and the research methods that will be used by this study to explore them.

Table 2

Comparison of Research Concepts, Questions and Measurement Methods

Concepts	**Research Questions**	**Interview Questions**	**Collateral Data**
Adolescent Readiness	1. How does adolescent readiness influence parent readiness? 2. What adolescent factors inhibit or facilitate parents' readiness for transitioning adolescents to independent, diabetes self care?	1. Tell me about your experiences taking care of diabetes. 2. Tell me about what you do to take care of your (your adolescents') diabetes. 3. Tell me how you feel about taking (your adolescent taking) more responsibility for diabetes care. 4. Tell me about the impact of diabetes on your life.	1. Diabetes Problem Solving Measure for Adolescents (DPSMA)
1. Parent Differentiation of Self 2. Parent Miscarried Helping	1. How does parent differentiation of self inhibit or facilitate the transition process?	1. Tell me about your (and your parent or adolescents') involvement in transitioning you (your adolescent) to caring for diabetes.	1. Bowen Differentiation of Self Measure (DSR) 2. Helping for Health Inventory (HHI)

Table 2 (cont'd).

3. Parents and Adolescents Perceptions of Parent Involvement in the Transition Process.		**Probe:** How did it occur? **Probe:** What was the experience like?	3. Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy development

Chapter Two

Literature Review

Adolescents with Type 1 Diabetes Development within the Family

Adolescence is a stage of development, universally experienced by humans as involving physiological, cognitive and psychosocial changes as they evolve from childhood to adulthood. Type 1 diabetes is a chronic illness most often diagnosed in childhood or adolescence. It requires life-long commitment to a multi-time daily, self care regimen in order to survive and prevent challenging complications. It can be difficult to manage life while experiencing either adolescence or Type1 diabetes, as each presents unique challenges that require adjustments to survive. When they are experienced together, the intensity of their individual impacts on one's well-being may multiply the stress in one's life. Furthermore, adolescence and Type 1diabetes have characteristics that conflict with and aggravate each other. This all makes experiencing adolescent life while managing Type 1diabetes challenging. Given the pre-adulthood status, dependency causing nature of adolescence and the predominately self care orientation of treatment for Type 1 diabetes, they both are primarily experienced within and influenced by the family context. Consequently, parents as the leaders of the family system have a paramount role in overseeing and providing their adolescents diabetes care. Given the limited reasoning and decision making ability, as well as the proclivity for risk-taking and sense of invincibility characteristic of the adolescent level of cognitive functioning, adolescents with Type 1 diabetes good health and survival during adolescence requires their parents support (Piaget & Inhelder, 1962; Santrock, 2009). In addition, adolescents' transition to the independent responsibility for their diabetes care

that is characteristic of healthy adulthood, involves parental engagement and guidance. Thus, parent-adolescent relationships have a primary role in determining the experience of adolescents with diabetes. Following is a review of studies that examine adolescent with Type 1 diabetes development within the family.

Adolescence and Type 1diabetes.

Adolescence and Type 1 diabetes have a reciprocal, challenging effect on a person's experience and successful management of each. Diabetes is a chronic illness that requires achieving consistent metabolic control through careful management, to avoid immediate and long-term health consequences. Adolescence involves stage-specific biopsychsocial changes that threaten those with Type 1 diabetes well-being by challenging their ability to maintain good metabolic control, which is most pertinent to survival and prevention of short and long-term complications. The challenges may come through the routes of: physiologically induced hormonal changes that affect blood glucose levels; cognitive-processing-related perception of stress and reactions to psychosocial experiences that both effect glucose levels and facilitate behaviors and choices that thwart proper adherence to treatment (see Schreiner, Brow and Phillips, 2000). Cognitive changes influence a search for identity, development of self-image and increased self-consciousness, possibly causing worry and anxiety that function as stress that affects metabolic control. A sense of invulnerability may cause testing of boundaries and risk taking behavior aimed specifically at challenging or avoiding the required treatment regimen. Adolescents' push for independence and autonomy may challenge their continuing the type of relationship with their parents that is necessary for optimal diabetes control (Diabetes Control and Complications Trial [DCCT] Research Group, 1993; Erikson, 1950; Santrock, 2009).

Increased independence and autonomy before an adolescent is prepared for it may lead to inconsistent adherence, which leads to poor metabolic control (Marshall, Carter & Rose, 2006). Diabetes treatment involves a complex daily regimen, which adolescents are not capable of managing independently. Studies show that parents' involvement in their adolescents' diabetes care significantly decreases throughout adolescence and adolescents' adherence to their treatment regimen decreases (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Murphy, Thompson, & Morris, 1997; Weissberg-Benchell & Antisdel, 2000). It is suggested that this decrease in supervision may account for the well documented incidence of metabolic control worsening as adolescents get older (Champaigne, 2001; Leonard, Jang, Savik, and Plumbo, 2005; Hanna, Juarez, Lenss, & Guthrie, 2003; Ott & Pattat, 1997). Failure to maintain good metabolic control can have many short and long-term health consequences. In addition, people with Type 1 diabetes who don't develop healthy, self care patterns of behavior during adolescence have a reduced life expectancy compared to those who do (DCCT, 1993). Thus, adolescent diabetes care is best managed within a supportive family environment.

The burden of responsibility for diabetes-related health outcomes rests on adolescents and their families because, more than most other chronic illnesses, diabetes treatment is anchored in self management. Wysocki and Green (1997) define self-management as "the responsibility assumed by patients and families in monitoring, evaluating, and adjusting diabetes treatment" (p. 171). This obligation can be cumbersome due to what adolescents identify as the difficult, demanding and endless challenges of daily self-care (Davidson, Penney, Muller, & Grey, 2004). The primary component of treatment is a complex, multi-time daily regimen of blood sugar monitoring, insulin injections (or insulin-pump manipulation), meal planning, and

complex insulin, activity and nutritional-intake monitoring and regulation. Thus, adolescents and their parents have the obligation to both perform the daily care tasks and manage the overall treatment regimen (Anderson, 2001; Weissberg-Benchell & Antisdel, 2000).

Given everything managing diabetes involves and that adolescents are not fully matured cognitively, adolescents need the aide of an adult to help them make the important adjustment and regulation decisions involved in effectively managing diabetes. Dependency on parental management flies in the face of what adolescents' ego often causes them to believe they deserve, which is autonomy and independence in managing their own lives. If they perceive their parental involvement as a threat to their independence, adolescents may feel restricted. They may respond by challenging their parents' authority and causing conflict in the parent-child relationship. They may also act in ways that sabotage or interfere with optimal diabetes management (Anderson & Coyne, 1993). Overall, the restrictive weight of diabetes' self care responsibilities on adolescents' and adolescents' resistance to necessary parental involvement threatens the existence of healthy self care collaboration between adolescents and their families, without which, ultimately endangers their health. Therefore, the role of family system factors and parent-child relationships are fundamental to understanding adolescents with Type 1 diabetes developmental experiences. Following is a review of both, starting with a section describing studies of the family system and then a section describing studies that highlight the parental subsystem's influence on adolescents with Type 1 diabetes.

Family influences on adolescents with Type 1 Diabetes well being.

Of preeminent importance to understanding adolescents with Type 1 diabetes development is to examine the family's influence on their lives. The family system is the

primary social context within human development occurs and thus, has an influential impact on the experience of adolescence. The family system's structure and functioning determine the atmosphere within which adolescents with Type 1 diabetes exist. It thereby, provides the environment and interactions that affect the quality and consistency of diabetes care and support, which effects adolescents' healthy development (Carter, & McGoldrick, 1988). "Of all institutions in society it is the family that is most likely to act as a buffer to absorb the strains and stresses experienced by its members" (Venters, 1981, p.289). This is reflected in the plethora of research assessing the influence of several aspects of family characteristics, functioning and structure, on adolescent diabetes adjustment, treatment adherence and metabolic control.

Olsen and Sutton (1998) conducted in-depth qualitative interviews with 21, 14-19 year olds with Type 1 diabetes to examine their perceptions of the substance, content and change over time of their informal (family and friends) and formal (health care providers) relationships. The study revealed that some of the adolescents felt isolated as a result of their increasing independence from their family life and disconnection from formal health services. This suggests that although assuming independent self-care is necessary in adolescence to ensure normal development into adulthood, the resulting loss of contact with family caregivers and provider support systems can precipitate feelings of loss and isolation.

Investigating the relationship between family environment and 30 adolescents with Type 1 diabetes perceived healthcare competence, Hauser and colleagues (1985) found that those who saw themselves as being competent and who adjusted well to having diabetes also had family environments that were orientated towards independence, organization and participation in social/recreational activities. These family environment

characteristics predicted the adolescents' adjustment and competence once social class and age were controlled for.

Wysocki (1992) studied the factors that correlate with poor adaptation and metabolic control. Participants included 115 families of youth with Type 1 diabetes, ages 11-18. Youth who were part of families with healthy communication, conflict-resolution skills, and few structural and functional abnormalities also displayed healthy diabetes adjustment and metabolic control. Wysocki maintains that these findings suggest that families with good differentiation of family roles and boundaries have adolescents with better diabetes outcomes. These findings suggest adolescents' healthy adjustment to having diabetes occurs within healthy functioning families, which support adolescents in making adjustments and adapting to challenges that facilitate their continued normal development.

Family factors that influence metabolic control.

Adolescence is the phase of human development associated with poor metabolic control. Metabolic control may be affected by the experience of stress, which in turn may be influenced by adolescents' experiences within and physiological and behavioral responses to their environment. Several studies investigate the relationship between adolescents' family environment, structure and functioning.

A review of studies investigating the influence of family organization and cohesion on adolescents control suggests that whether a rigid or flexible family type is most supportive differs according to adolescents' individual needs. Seiffge-Krenke (1998) compared the changes in family structural climate over 4 years of 89 adolescents with Type 1 diabetes and 106 healthy adolescents both groups between the ages of 12 and

14. Seiffge-Krenke also analyzed the family structure influence on the diabetics' metabolic control. The findings reveal that adolescents with Type 1 diabetes had families that evidenced more structure, and a less cohesive and stimulating environment than healthy adolescents' families. However, family structure and environment was not related to metabolic control and showed little variation with time, duration of diabetes and adolescents' gender. Evans and Hughes (1987) conducted a study of the relationship between the diabetes control, and individual and family characteristics of 38 youth between the ages of 10 and 17. The findings indicate that children at risk of not developing age-appropriate autonomy and independence are able to achieve diabetes metabolic when they have an external locus of control and a rigid family organization.

One study examined the effects of family composition on 119 adolescents (ages 12-16.75) with Type 1 diabetes health status and treatment adherence (Harris, Greco, Wysocki, Elder-Danda and White, 1999). Adolescents from two-parent families (including both intact and blended families) evidenced better metabolic control than adolescents from single parent families. However, the groups did not differ in regards to adolescents' adjustment to diabetes and adherence to treatment. They also did not differ on measures of parent-adolescent relationship factors, including: general or issue specific conflict, functional and structural family problems and communication skills deficits. Perhaps the results reflect that the availability of more than 1 adult in the family and any relief that it provides beyond parent-adolescent relationship factors creates conditions in two- parent families that facilitate adolescents' metabolic control more than in single parent families.

Several studies have found family functioning to be a primary influence on adolescents' with Type 1 diabetes health. Leonard, Jang, Savik, and Plumbo (2005)

studied the relationship between perception of family functioning, metabolic control and behavior problems of adolescents with Type 1 diabetes. Adolescents who were older and who had a greater amount of behavior problems also reported family dysfunction. Adolescents who perceived family dysfunction, specifically regarding affective responsiveness, had poor metabolic control.

In a cross-sectional study of 55 adolescents and their families the relationship between general family features, and family support for diabetes problems, and adolescents' well being and metabolic control was assessed (deDios, Avedillo, Palao, Ortiz and Agud, 2003). None of the factors were associated with metabolic control. However, family cohesion and support for diabetes problems were associated with adolescents' well being.

Blumberg (1999) conducted a study which examined ethnic differences between the effects of general and diabetes-specific factors on the metabolic control and healthcare regimen adherence of 29 African American, 49 Hispanic and 25 White 11-16 year olds. Family cohesion and supportive family behaviors predicted youths' adherence to their diabetes regimen. In contrast, unsupportive family behaviors predicted poor adherence. However, adherence to healthcare regimen was only marginally related to metabolic control levels. Across all ethnic groups, family stress predicted metabolic control. More frequent hospitalizations for DKA, a health state that indicates dangerously high blood sugar levels, was associated with higher levels of stress, lower family cohesion, and more diffusion of responsibility for carrying out the daily diabetes regimen. These findings suggest that regardless of ethnicity, a close, supportive family environment facilitates adherence, which is associated with diabetes related health.

Whereas a stressful environment family environment may reflect a disorganized and disconnected family which predicts to poor health associated with poor metabolic control.

Liles (2002) employed an ecological framework to examine familial influences on adolescents' metabolic control. Across 98 mother-adolescent dyads, adolescents with good metabolic control perceived themselves as having support oriented families. In contrast adolescents with the poorest metabolic control reported having conflict oriented families. Adolescents' adherence to the diabetes care task of blood glucose testing and mothers' perception of having communication problems with their adolescents, accounted for 17% of the variance for poor diabetes control. These findings highlight the benefit of supportive family environments on adolescents' metabolic control.

Family factors that influence adherence to self care regimen.

Adolescents with Type 1 diabetes health and wellbeing are affected by their emotional and cognitive functioning, as these influence adolescents' behavior choices, including adherence to treatment. Adherence to treatment reflects suggests healthy adjustment and helps facilitate good metabolic control. Given that the family is the primary socializing context for adolescents' stage-specific emotional and cognitive development, it is important to understand how family affects the aspects of cognitive, social and emotional development that in turn affect youth with Type 1 diabetes adjustment and treatment adherence

One study examined the mediating influence of adolescent self-efficacy on the effect of both adolescent personal responsibility and parent supportive behavior on adherence to diabetes treatment (Ott, Greening, Palardy, Holderby, and DeBell, 2000). One hundred and forty-three youth with Type 1 diabetes, ages 11-18, and their parents

completed measures of diabetes self-efficacy and self-care and family's diabetes behavior and responsibility. Self-efficacy mediated the effect of personal responsibility on adherence. Self-efficacy did not mediate the relationships between parental supportive and nonsupportive behaviors and adherence. There was a discrepancy between parents and adolescents' perceptions of adolescents' responsibility for diabetes care tasks. Adolescents reported responsibility for more aspects of their diabetes care than their parents' perceived adolescents were responsible for. The investigators maintain that the study's results provide evidence that adolescents' self-efficacy mediates the relationship between their experience of mastering their diabetes and their adhering to their diabetes regimen.

There are consistent findings that puberty is characterized by poor metabolic control largely associated with adherence that rapidly deteriorates as one progress from early to late adolescence (Champaigne, 2001, Leonard, Jang, Savik, and Plumbo, 2005; Salonius-Pasternak, 2004; Wysocki,1992). This puts adolescents at risk for immediate and long-term health complications (Marshall, Carter and Rose, 2006). Poor adherence is not the exclusive cause of poor metabolic control; the body's response to hormonal changes and stress in can affect blood glucose levels (Weissberg-Benchell & Antisdel, 2000). One study found that many adolescents were not able to achieve good metabolic control despite efforts at adhering to their treatment regimen (Hanson & Henggeler, 1984). However, adherence is the most controllable route to metabolic control. Research indicates that supportive family environments are also associated with adolescents with Type 1 diabetes adherence to their treatment.

Hauser et al. (1990) investigated the influence of family environment on the adherence of 52, newly diagnosed youth with Type 1 diabetes ages 9-16 at their 1st and

4th years after diagnosis. Hauser et al. (1990) found that adolescents' perceptions of their families' conflict was the strongest predictor at the end of a 4-year period of time. In addition, both parents' and youth perception of family cohesion predicted both high levels and improved incidences of healthcare regimen adherence. Through a study designed to develop and evaluate the Diabetes Social Support Questionnaire-Family Version (DSSQ-Family) for adolescent diabetics, LaGreca and Bearman (2002), also assessed the relationship between diabetes-specific family support and adolescents' healthcare regimen adherence. The 74 adolescents who participated in the study identified diabetes-specific and emotional support-oriented behaviors as the most helpful for ensuring their treatment adherence.

Overall, family studies' findings suggest that, the family system's structure and functioning provides an atmosphere that is either conducive or harmful to adolescents' diabetes adjustment, treatment adherence and metabolic control. A health promoting family system is composed of a support-centered atmosphere and cohesive, diabetes-care teamwork. Parent members of the family system play a central role in helping to balance meeting adolescents Type 1 diabetes needs with their developmental needs. Therefore understanding the characteristics and dynamics of the relationship between parents and youth with Type 1 diabetes during adolescence is fundamental to understanding adolescents with Type 1 diabetes health and development.

Parent-specific Effects on Adolescents with Type 1 Diabetes Health and Development

The important role parents play in adolescents well being and development of healthy self care behaviors is evidenced by findings regarding the outcomes of parents' involvement in the adolescents' diabetes care. A decline in

parental involvement in their children's diabetes care occurs during adolescence, as adolescents' responsibility for self care increases (Anderson, 2001). It is suggested that the widely documented decrease in adolescents' adherence to treatment and the poor metabolic control characteristic of adolescence is related to the decrease in parental involvement (DCCT, 2003: Marshall, Carter & Rose, 2006; Weissberg-Benchell & Antisdel, 2000). In contrast, parent continued involvement in their children's diabetes management during adolescence is associated with better adolescent metabolic control, which is the core determinant of a person with Type 1 diabetes physical health (DCCT, 1993).

In addition to parents continued involvement during adolescence, studies indicate that there are specific parenting behaviors diabetic adolescents perceive as supportive and conducive to their adherence and well being. Grey and colleagues (2001) found that after 1 year of implementing a new intensive management program for 81 adolescents with Type 1 diabetes, 30% achieved their treatment goals of better metabolic control. Success was associated with better control at the entry into the new program, participation in coping skills training and parental participation in guidance and control.

Other studies show that adolescent self-efficacy, which is associated with better adherence, is supported by positive parenting practices. Ott, Greening, Palardy, Holderby, and DeBell (2000) studied the mediating influence of adolescent self-efficacy on the effect of both adolescent personal responsibility and parent supportive behavior on adherence to diabetes treatment. One hundred and forty-three Type 1 youth with Type 1 diabetes, ages 11-18, and their parents completed measures of diabetes self-efficacy and self-care and family's diabetes behavior and responsibility. Self-efficacy mediated the

effect of personal responsibility on adherence. Self-efficacy did not mediate the relationships between parental supportive and nonsupportive behaviors and adherence. There was a discrepancy between parents' and adolescents' perceptions of adolescents' responsibility for diabetes care tasks. Adolescents reported responsibility for more aspects of their Type 1 diabetes care than their parents' perceived adolescents were responsible for. The investigators maintain that the study's results provide evidence that adolescents' self-efficacy mediates the relationship between their experience of mastering their Type 1 diabetes and their adhering to their diabetes regimen.

Parents well being is associated with adolescents likelihood of proper treatment adherence, metabolic control and overall well being. Champaigne (2001) explored the role of general and diabetes-specific family functioning in diabetic adolescents' adherence to their diabetes regimen and their metabolic control. Over a three month span of time, 55 adolescents and their parents completed parental depression, family and marital functioning assessments, and participated in six, 24-hour adherence recall interviews. Adolescents' HbA1c levels were assessed at the beginning and end of the study to provide indicators of metabolic control. Multiple regression analyses showed that over all the adolescents, those who had diabetes longer were in the worse metabolic control, but there was no link between adherence or family relations and control. Some aspects of family relations significantly predicted aspects of adolescents' regimen adherence including: parental depression and general family conflict accounted for variance in adolescents' diet adherence. In terms of specific parenting actions, diabetes-specific guidance-control accounted for variance in exercise adherence. Across adolescents, results indicate that parents remained involved in females' diabetes-care regimen for longer than in males'.

Liakopoulou et al. (2001) explored the relationship between mother's expressed emotion and adolescents' metabolic control and psychopathology. Fifty-five children and adolescents and their mothers and 54 controls and their mothers were administered the Present Episode version of the schedule for Affective Disorders and Schizophrenia for School-Age Children interview and the parental Expressed Emotion instrument. In terms of psychopathology, 58.2% of youth with Type 1 diabetes had symptoms of anxiety and depression as compared to 9.3% of control youth. For expressed emotion, 70.9% of mothers of youth with Type 1 diabetes as compared to 29.6% of control group mothers exhibited high expressed emotion. High expressed emotion was not related to psychopathology in youth with diabetes but, along with its specific component of emotional overinvolvement and excessive detail, was related to metabolic control. Findings suggest that mothers' emotionally anxious and excessive involvement is related to adolescents' poor diabetes health.

Salonius-Pasternak (2004) applied person-focused narrative analysis to examine interviews with 10 adolescents and their families and identify psychosocial themes associated with adolescents' projected resilience or poor functioning in young adulthood. Resilient adolescents were closer to and experienced less conflict with their parents than poorly functioning adolescents. Resilient adolescents also demonstrated better ability to be flexible in managing their illness and other aspects of their lives.

These studies show the connection between parental involvement and specific behaviors and adolescents with Type 1 diabetes healthy functioning. Healthy parents who engage in positive parenting provide proper diabetes care, support treatment adherence and subsequently increase the likelihood of their adolescents' good health.

Parent factors that facilitate adolescents with Type 1 diabetes independent self care.

Besides ensuring adolescents' metabolic control, preparing them for independent diabetes management is the primary objective of parenting adolescents with Type 1 diabetes. During this process of learning skills and developing the cognitive maturity that will enable them to manage their treatment regimen, adolescents adopt a self care pattern they will likely continue to follow throughout their adulthood (DCCT, 1993). Thus, it is important for parents to teach and allow opportunities for their adolescents to practice proper self care while they are under parental monitoring and guidance (Marshall, Carter & Rose, 2006).

In addition, findings suggest that besides taking less responsibility for engaging in direct care, parents further disconnect from monitoring their adolescents' self care behavior, and guiding their adolescents' continued development of healthy management skills. Besides the amount of their involvement decreasing, in one study adolescents reported that the positivity of parents' involvement in their diabetes care decreased (Ott and Patat, 1997). Hanna, Juarez, Lenss and Guthrie (2003) studied adolescents' perceptions of the relationship between parental involvement through support and communication and adolescents' responsibility for managing their diabetes and their metabolic control. A sample of 27 adolescents ages 12 to 19 reported high levels of parental communication (more agreement than amount) and low levels of parental support (more received than sought). Results showed differences across age groups of adolescents. Means for amount of communication decreased over adolescence (from early to middle to late) and means for seeking and receiving support increased from early to middle and decreased from middle to late adolescence.

As the primary caregivers within a family system, parents act as co-laborers with adolescents in care (see definition given on page 2). At the beginning of adolescence, youth share responsibility for care by performing tasks that they are physically and cognitively capable of, and their parents are responsible for managing their regimen and making decisions about their overall treatment (Hanna and Guthrie, 2003). As they progress in age and maturity, adolescents are able to assume increasing responsibility and gradually practice decision-making regarding their diabetes care and management, which prepares them for their eventual independent control (Schreiner, Brow, & Phillips, 2000). Drotar and Evers (1994) assessed 26 mothers' perceptions of their children's (ages 4-14) general independence and their families' responsibilities for treatment-related tasks. Older youth reported higher levels of independence in diabetes management and more sharing treatment responsibilities with parents than younger children. Independence in assuming treatment responsibilities was related to general independence. Many studies have found that, in addition to progressively learning and taking responsibility for more self care tasks, adolescents develop the ability to assume responsibility for managing their diabetes (Drotar & Evers, 1994; Sternburg, 1999). It is a cognitive development goal of this transition phase, because it is a major illness-specific indicator of adolescents' preparedness for adulthood.

As a child with Type 1 diabetes part of maturing in adolescence involves learning to engage in self care and manage one's diabetes' treatment. It is important to understand the role of parents in monitoring adolescents' developmental process and recognizing their maturity and encouraging their becoming more autonomous and independent regarding their diabetes management. Palmer et al. (2004) examined how pubertal status and autonomy relate to decreases in maternal involvement in diabetes management, and

the effect on metabolic control. Adolescents who assumed responsibility for diabetes management without being ready (i.e., autonomy and puberty status) had poor metabolic control. Parents, as the primary care providers, have an important responsibility to use the influence of their role properly, such that they encourage adolescents' autonomy while guiding their development of proper diabetes management skills.

The findings of one study highlighted the influence of parents' emotional well being on adolescents' autonomy development. Wall (2004) conducted a cross-sectional study comparing adolescents with Type 1 diabetes process of developing autonomy to healthy adolescents' process. The objective of the study was to explore adolescents push for and process of developing autonomy within a diabetes specific context. Wall investigated how the process of autonomy development hinders or facilitates adolescents' adherence to their diabetes care regimen and good metabolic control. At two points within a year's time, 122 mother-adolescent pairs completed assessments of autonomy expectations, self-reliance, and diabetes-specific self-efficacy, adherence to the diabetic regimen, emotional adjustment and parent-child conflict. The comparison results showed that mothers and adolescents with Type 1 diabetes expected later occurring behavioral and diabetic-specific autonomy than healthy mothers and adolescents expected. For both groups, adolescents' early push for behavioral autonomy was associated with increased conflict and mothers' emotional maladjustment. Emotional autonomy was related to both better adolescent emotional adjustment and greater diabetes self-efficacy. In terms of the parent-adolescent relationship, better emotional autonomy was related to parental warmth and less conflict. Adolescents with diabetes who showed self-reliance also showed a push for behavioral autonomy and diabetes-specific autonomy. Longitudinally, push for autonomy predicted negative outcomes, including: parent-child conflict; and differences

in mother-adolescent expectations for autonomy predicting worse adherence. Among males with Type 1 diabetes, longitudinally, their self-reliance, predicted their self-efficacy. Greater self-efficacy predicted better adherence to diabetes care regimen and better metabolic control.

As for mentioned, despite adolescents with Type 1 diabetes need for and benefit from parent involvement, part of the developmental challenges of adolescence is to learn independent self care. Thus, parents have the responsibility of preparing their adolescents for and allowing them to assume increasing responsibility for managing their diabetes, as they show the relevant maturity and capability. However, studies indicate that parents may resist allowing their adolescents increasing responsibility and control due to being unsure of their capability of performing well and fearing the resulting health consequences (Buckloh et al., 2008; Marshall, Carter & Rose, 2006)

Weinger, O'Donnell, and Ritholz (2001), conducted focus groups to investigate what 14, 13-15 year olds with Type 1 diabetes saw as the source of the conflict they experienced with their parents and the support they received from their family. The adolescents saw parental worry, intrusive behaviors, lack of understanding, blaming behaviors, and focus on the future verses adolescents' focus on the present as sources of their diabetes-related conflict with their parents. The adolescents found parents' understanding of the demands of diabetes and reassurance about their illness and normative functioning as sources of parental support.

Law (2003) compared the illness representations 30, 13-19 year olds with Type 1 diabetes and their mothers and explored how it influenced adolescents' psychological adjustment. There was congruency between mothers and adolescents in their perceptions of diabetes along all but 2 dimensions of illness representation. A comparison of the

dimensions along which mothers and adolescents differed, revealed that overall, mothers considered diabetes to be more serious than their adolescents: specifically, mothers' perceived diabetes to have more serious consequences and to have a greater emotional impact on their adolescents than their adolescents perceived. However, adolescents' psychological well-being was not related to these differences.

Seiffge-Krenke (1997) maintains that, consistent with developmental theories and especially important for youth with Type 1 diabetes, becoming an adult necessitates differentiating from and resisting fusing with caregiver mothers. Seiffge-Krenke applied developmental and psychoanalytic theories to explain the conflict adolescent diabetics experience when learning to set personal boundaries and navigate the possibly challenging territory of differentiating from their mothers. The author employed a case study, taken from a longitudinal study of 12-16 year olds with Type 1 diabetes and their families, to illustrate the challenge for youth of balancing the need for healthy age appropriate boundaries and the age and illness fueled urge to fuse with mothers. Seiffge-Krenke maintains that normal development of healthy differentiation can be hampered by the multi-time, daily and body-focused healthcare regimen prescribed as a part of the life-long treatment of diabetes. Parents who resist their adolescents' developing independence may fall through on preparing their adolescents for independent self management, which stifles adolescents' development and threatens their health.

Parents may also resist because they value the caregiver role and do not want to give it up. Parent overinvolvement may be perceived negatively by adolescents' and thus, be experienced as ineffective parenting style. Dashiff (2003) examined the differences in adolescents' and parents' perceptions of their division of responsibility for different diabetes management tasks. They also examined how these perceptions

influenced adolescents' metabolic control. A sample of 31, 12-15 year-old adolescents with Type 1 diabetes from two parent families and their parents completed a modified version of the Diabetes Family Responsibility Questionnaire and values of adolescents' metabolic levels (collected 2 months apart) were collected to assess the study's variables. Adolescents' perceptions that their mothers had more responsibility than them for diabetes management tasks was moderately ($r=-.43$, $p=.02$ and $.41$, $p=.03$, respectively) associated with their previous but not current poor metabolic control.

Steinberg (1999) examined the developmental nature (levels and patterns) and associated conflict of parent-child shared responsibility for diabetes treatment. Specifically the study was designed to examine how diabetes treatment responsibility, child's self-efficacy, child's age, and general family conflict predict diabetes-specific parent-child conflict. Correlation analyses revealed that parents delegate and children assume increasing amounts of responsibility for their diabetes treatment regimen with increasing age. There were differences in parents' and children's perspectives of the amount of diabetes–specific conflict that occurred and the amount diabetes-related tasks children were responsible for. Children perceived themselves as having both greater responsibility and greater conflict with their parents than what parents perceived. Younger children also reported having greater conflict with their parents than older children. Predictors of diabetes-specific conflict differed for parents' and children's reports. Based on parents' reports, child self-efficacy, child age and level of diabetes responsibility and an interaction between child self-efficacy and family environment significantly predicted diabetes-specific parent child conflict. This study expands the findings of previous studies by finding greater agreement between older

adolescents and parents in their perceptions and actual sharing of diabetes responsibility. The authors maintain that the results confirm that greater diabetes specific self-efficacy and less parental diabetes treatment involvement predicts positive parent-child relations.

Parent support of adolescent autonomy and transfer of responsibility.

Regardless of the cause of parents' resistance to adolescents' push for autonomy in managing their diabetes, it is necessary for parents to accept it, encourage it and help adolescents develop their ability to effectively manage their treatment. The successful outcome of the eventual transition from parent to adolescent depends on adolescents being prepared for autonomous self care.

Cant (2003) maintained that adolescents' readiness for assumption of diabetes self-care should be assessed from a developmental and family-systems perspective because readiness depends on both the child's age and autonomy and is influenced by family-system factors. To study this, Cant employed the stage of change model as a developmental framework to assess the relationship between adolescents' self-efficacy, adolescents' families' responsibility for their diabetes care, and adolescents' self-care behaviors. Seventy-five youth with Type 1 diabetes, ages 9-13, and their parents completed psychosocial assessments and participated in 24 hour recall interviews about diabetes care behaviors. The youth were identified as being the age and autonomy level indicative of readiness for self care. Regression analyses indicated that parents' reports of family responsibility for diabetes care moderated the relationship between adolescents' self-efficacy and self-care. Of the range of self-care behaviors assessed, this model only predicted adolescents' diet behaviors, specifically, significantly predicting the average calories they consumed.

Palmer et al. (2004) examined how pubertal status and autonomy relate to decreases in maternal involvement in diabetes management, and the effect on metabolic control. Participants, including 127 youth with Type 1 diabetes (ages 10-15) and their mothers, completed assessments of the following: both of their involvement in diabetes management; adolescents' perception of their autonomy; mothers' perceptions of adolescents' pubertal status; and mothers' reasons for transferring responsibility for diabetes care to their adolescent. Child's autonomy and pubertal status partially mediated the effect of age on maternal involvement in diabetes management. Mothers reported that their reasons for transferring responsibility included: responding to their adolescents' diabetes care competence; promoting adolescents' competence and maturity; and minimizing hassles and conflict with their adolescents associated with their involvement in diabetes care. Adolescents who assumed responsibility for diabetes management without being ready (i.e., autonomy and puberty status) had poor metabolic control.

Hanna and Guthrie (2000) conducted a qualitative study designed to identify what 17 parents of 11-18 year-olds with Type 1 diabetes perceived as being benefits and barriers to their making decisions regarding their adolescents' assuming responsibility for managing their diabetes. The parents saw relief from burden and knowledge, and pride in their adolescents' abilities as benefits for them of their adolescents' diabetes self-management. They identified freedom, independence, and control as what they perceived as benefits to their adolescents. Parents identified dealing with consequences, loss of control and supervision as their perceived barriers to their adolescents' assuming responsibility for managing their diabetes. Parents saw their children's barrier as being the burden of responsibility. Hanna and Guthrie (2001) further examined the interviews to identify what parents and adolescents perceived as helpful and nonhelpful support

from parents in facilitating adolescents' assumption of responsibility for managing their Type 1 diabetes. Parents and adolescents agreed that the helpfulness of parents' provision of directive guidance and tangible assistance depended on parents' degree of directness and adolescents' perceived need for help.

Conclusion

Developmental theories suggest that adolescence is the stage of life when one struggles with a conflict between the need to be independent and autonomous and the need to still receive guidance and support from parents. According to Piaget, it is the stage when most humans are cognitively capable and ready to learn how to make decisions that allow them to take responsibility for their daily care (Piaget & Inhelder, 1962). For adolescents with type 1 diabetes, that daily care involves an intense healthcare regimen which one must be consistently faithful in adhering to in order to prevent immediate poor health and long-term debilitating physical complications. Given that adolescents diagnosed with Type I diabetes have to cope with the illness for the duration of their lifetime, learning to independently manage their diabetes care is a necessary part of developing self-responsibility and establishing autonomy. This requires mothers, who are typically their primary caregivers and diabetes managers to transition adolescents into the primary care giver role. Studies have shown that when given independent responsibility for diabetes care before they are ready, adolescents show poor adherence and subsequently poor metabolic control. Thus, there needs to be a gradual transfer of responsibility from parent to adolescent determined by the readiness and ability of the adolescent. There have been studies of the individual and family factors that facilitate and inhibit adolescents' healthcare regimen adherence and metabolic control. However, no study has explored the influence of adolescent readiness on

primary caregiver parents' readiness for and resultant engagement in the transfer. This paper proposes that parent-to-adolescent transfer of responsibility for diabetes management is a function of a developmental process of interaction between parent and adolescent readiness and their relationship. Adolescents' adaptation occurs within the family system and is a result of healthy interactions between them and the parent who primarily manages their diabetes. Following is a review of Bowen family theory to explain how this phenomenon could occur.

Guiding Marriage and Family Theory

Bowen and differentiation.

Bowen family systems theory is employed by this study to explain the emotional basis of adolescent identity development and the emotional connectedness and reactivity of parents that influences their readiness to transition adolescents' to self care. Bowen theory focuses on the universally experienced phenomena of chronic anxiety as the source of humans' problems, including developmental and relational ones (Friedman, 1991). Bowen maintains that all species throughout time have been equipped with a chronic anxiety. At its best, it functions to equip us with response patterns that allow us to act in ways that protect us from harm (provoking the fight or flight response) and to engage in physical activities. Differentiation is the life-long process of balancing internal and external processes to experience self-definition and self-regulation. It is not synonymous with independence, autonomy or individuation. What makes it different from those concepts is that it focuses not on behavior but on one's continuous emotional processing. It involves using objectivity to experience clear-headedness and react beyond one's emotional state/feelings. The balancing of internal and external processes involves

managing one's own chronic anxiety (expressed through emotional reactivity) such that self-definition can evolve and managing one's emotional reactivity to others and experiences (especially stress). The family is considered to be the primary influential emotional system that humans develop within. Self-definition requires differentiation, which involves emotionally distinguishing between the "I" and the "we". The basis of this process is regulating one's emotional reactivity to others, particularly in the family emotional system. The family is the necessary context within which humans develop identity and learn to manage emotional reactivity while engaging with others. We learn who we are and who humans are and how to interact as a human by engaging in our family's system. Thus, according to Bowen, the skill of managing chronic anxiety by controlling our emotional reactivity so that we best use it for our healthy functioning is developed within the family emotional system. We differentiate within this system to become self-defined. Thus, the family emotional system is the context within which differentiation occurs.

Individuals' ability to differentiate is a function of their ability to manage and regulate their emotional reactivity. Again, this is initially and primarily practiced within the family emotional system. This emotional system involves interactions that allow for practicing managing emotional reactivity and self-definition when relating to others. Members of one's family of origin also model ways of responding to chronic anxiety and managing emotional reactivity. In addition, an individual's level of intensity of chronic anxiety and the nature (ways) their immediate (family of origin) differentiates (responds to anxiety and manages emotional reactivity) is influenced by what was enacted and modeled in the families in one's lineage. Multigenerational transmission is the term for this process of one's family lineage (starting most closely with one's maternal and

paternal grandparents) of emotional systems influencing one's chronic anxiety and nature of differentiating. Successive generations of a family have the potential to manage their emotional reactivity (and overall have a better experience differentiating) depending on the grandparents' ability to model differentiation, and provide a healthy family emotional system within which one's parents could develop objectivity and healthy differentiation. Also, the differentiation of the person one marries influences the potential differentiation of one's children. This cycle continues for successive generations of families.

Differentiation is a process and families operate in ways that place them along a continuum that ranges from unhealthy/dysfunctional differentiation (reflecting fusion or cut-off interactions) to healthy differentiation. Families may engage in ways to manage their emotional reactivity to anxiety and stressful circumstances in ways that are unhealthy and reflect poor differentiation. Fusion involves family members being emotionally reactive to each other such that it prohibits self-definition and independent functioning. Members who are fused cannot engage in maintaining a balance between connectedness and independence. They manage anxiety by fusing emotionally with each other. Cut-off involves families who have poor differentiation, and high emotional reactivity to each other. They manage their anxiety being sucked in by their family's emotional system and losing themselves by distancing themselves from the emotional system. They in essence, "cut-off" from the emotional system. The family may project their issues onto a particular family member who becomes the "framed" loci of pathology in the family. Families may also triangle members into emotionally reactive relationships.

The health of a family depends on the interaction of the conditions/circumstances they experience and their response to the conditions. Regardless of the nature and

intensity of circumstances, as the differentiation of one's response increases the more healthy emotional system and thus healthy adjustment a family experiences. Families with poor differentiation high emotional reactivity (as reflected by fusion and cut-off) and have a hard time and display these dysfunctional ways of coping with stress no matter what level of intensity it is (low or high). Families that are well differentiated will demonstrate the ability to cope with stress in healthy ways and will function well when stress doesn't occur. Again, a healthy functioning family emotional system fosters the healthy differentiation of its members.

Application of Bowen's theory to adolescent Type 1 diabetes management.

An application of Bowen Family theory to the issue of adolescents successful adaptation to diabetes management involves considering the emotional system within which the adolescent and parent interaction regarding gradually transferring responsibility occurs. The stress or condition would be the diabetes management. A parent's differentiation would influence their ability to engage in a healthy and functional process of guiding their adolescent's acquisition of the skills and competencies necessary to assume responsibility for diabetes management. Given the potential cost of relinquishing management responsibility to their adolescent that they perceive as no capable, responsible or competent enough to handle it, the transfer of responsibility may be a realistic threat (stress) to parents and families with any level of differentiation. However, as is demonstrated in the graph above, parents who are highly differentiated possess the capacity to manage their emotional reactivity and quell their anxiety enough to engage their adolescents in the process. This creates a healthy family emotional system which then fosters the adolescents' differentiation (ability to manage their anxiety and emotional reactivity). Differentiation fosters the adolescents' emotional readiness.

A healthy family emotional system also fosters an environment in which the adolescent and parent can, (accompanied by managed anxiety) engage in functional interactions designed to develop skill, and create competence that will increase the probability that they will develop adequate ability to manage their diabetes.

Chapter Three

Methods

Research Design

This study proposes that using a grounded theory approach will provide an understanding of the parent-adolescent experience of transitioning. Employing the grounded theory qualitative approach and semi-structured interview method will yield data that illustrates the real-life experiences that reflect the parent-adolescent relationship dynamics surrounding parents' readiness to transfer diabetes responsibilities to their adolescents and adolescents' transition to self management. Grounded theory methodology to doing qualitative research begins with recognizing a phenomenon of interest and questioning: what it is all about, how the people involved experience it; and what roles they play in it (Glaser, 1992; Strauss, 1987). Through the interview method of gathering data, parents and adolescents experiences and perceptions of engaging together in the transition process was illuminated. The constant comparative method of data analysis was used to identify and compare concepts across individual, and group parent and adolescent experiences and within parent-adolescent dyadic experiences. Through this process, recurrent concepts and themes were identified and connected. From it emerged a theory of how the transition process is grounded in the relationship between adolescents' developmental and their primary care giving parent's emotional readiness characteristics. To increase confidence in the validity of the interview data, questionnaires were used to assess the concepts of parent differentiation (Bowen Differentiation of Self Measure) parents miscarried helping (Helping for Health Inventory) and parents and adolescents perception of parents' support of adolescents

gaining autonomy through the transition process (Diabetes-Specific Parental Support for Adolescents' Autonomy Scale).

Instruments

The Differentiation of Self Inventory (DSR) is a multidimensional, 46 Likert scale item, self report measure of Bowen's concept of differentiation. It is designed to assess emotional connectedness in relationships with others as a method of managing anxiety. It has high internal and external reliability. Using Cronbach's alpha, internal reliability estimates for the full scale is .88. For each subscale the reliability estimates are: Emotional Reactivity =
.83; Fusion = .82; and I Position = .80. It has good construct validity, as full scale scores correlate highly with a measure of chronic anxiety; and significantly predict trait anxiety, measured by the STAI-T ($r = .64, p < .0001$) (Skowron & Friedlander, 1998).

The Helping for Health Inventory (HHI) is designed to assess the theoretical concept of "miscarried helping" behavior by parents of youth with Type 1 diabetes. It is a self report questionnaire that includes 15 Likert scale items which probe parents' experience of frustration and conflict when increasing their efforts to ensure their adolescent engages in proper self care. Results of a preliminary assessment of the HHI's psychometric properties indicate it has adequate internal consistency ([alpha] = .81) and 3-month test-retest reliability (r = .74). It correlated positively with parent-child conflict and parent nonsupport for youth's diabetes treatment. It correlated negatively with youth and parents reports of youth's adjustment to diabetes and youth's reports of their adherence to treatment. The HHI did not correlate significantly with metabolic control.

(Harris, Michael A., et al, 2008)

The Diabetes Specific Parental Support for Autonomy Scale (DPSAAS) is a 4 item instrument of which there is a parent and adolescent version. Parents and adolescents completed the DPSAAS to assess their perceptions and experiences of parents' readiness for and support of the transition process and its purpose of effecting adolescents' self care. It has good internal consistency reliability (.80). Its construct validity is supported by its relation to the Supportive subscale, Guidance/Control subscale, Warmth/Caring subscale and full scale of the Diabetes Family Behavior Checklist (Hanna, DiMeglio & Fortenberry, 2005).

Procedure

Before commencement of the study, approval and permission to conduct it was obtained by Michigan State University's Institutional Review Board and the Executive Director of the Minnesota Affiliate of the American Diabetes Association (ADA), which conducts the diabetes summer camp where the adolescents were recruited.

Recruitment

I employed theoretical, purposive sampling to recruit 20 adolescents with Type I diabetes, between the ages of 12 and 18, and their primary caregiver parent. I recruited from Camp Needlepoint, the ADA run summer camp for youth with Type 1 diabetes who reside in Minnesota and Wisconsin. Twenty-five adolescent and parent pairs were approached and invited to participate in the study by this investigator as they waited in line to check the adolescent in for their stay at camp. Participation requirements for adolescents included: being diagnosed with diabetes for at least 1 year; speaking English; and being between the ages of 12 and 18. I choose the qualifying age range because it represents the developmental period when youth living with Type 1 diabetes can

demonstrate the capability and competence necessary to assume increasing independence and responsibility for a variety of tasks that are part of their daily care regimen. It also includes the ages associated with the cognitive development of a level of reasoning and decision-making that equips them with the ability to progressively establish autonomy over managing their diabetes (Schreiner, Brow, & Phillips, 2000; Steinberg & Silverberg, 1986). Recruitment of parents focused on whoever the adolescent identified (and the parent then confirmed) as their primary caregiver, as they would most likely be involved in conducting the transition process (Ehrenberg, Gearing-Small, Hunter & Small, 2001). Parent participants were also required to speak English. The investigator gave interested persons a verbal invitation and written information about the research. Parent-adolescent dyads that indicated interest but did not want to agree to participate immediately upon being asked were given information to contact the investigator if they decided to participate at a later time. Parents and adolescents who decided not to participate were similar in demographic characteristics as those who participated. I asked those who were interested for their permission to be contacted by the investigator via telephone or e-mail to schedule and later be reminded of their participation appointment date. Once they agreed to participate, I scheduled parent-adolescent dyads to participate on the same date for a single 20 minute interview each.

Sample

A total of 40 people, twenty pairs of 1 adolescent and 1 parent followed through with participating, and completed the interviews and questionnaires. Nineteen of the participant pairs resided in Minnesota and one pair resided in Wisconsin.

The adolescents ranged in age from 12 to 16 years old and all had Type 1 diabetes for at least 3 years. The following Table 3 summarizes the demographic characteristics information about the adolescent participants.

Table 3

Descriptive Characteristics of Adolescent Participants (n=20)

Characteristic	Percentage	Frequency	Range
Gender			
Females (n=12)	60%		
Males (n=8)	40%		
Ethnicity			
Caucasian (n=18)	90%		
Native American and Caucasian (n=1)	5%		
Hispanic and Caucasian (n=1)	5%		
School Grade Level		**(Mode)**	
8th (n=3)	15%		
9th (n=7)	35%	11th	8 – 12
10th (n=1)	5%		
11th (n=8)	40%		
12th (n=1)	5%		
Age in years		**(Mean ± S.D.)**	
13 (n=2)	10%		
14 (n=7)	35%		13 – 16
15 (n=2)	10%	14.5 ± 1.5	
16 (n=9)	45%		

The adolescents were diagnosed with Type 1 diabetes at various ages across childhood and early adolescence including: in childhood (n =12; ages 4-9), pre-adolescence (n = 4; ages 10-11) or adolescence (n = 4; ages 12-13). Those diagnosed in early childhood (ages 4-6) started their involvement in caring for their diabetes by performing their first task of checking their blood sugar level at diagnosis (n=1), or within 1-4 years of being diagnosed. Those diagnosed during mid-childhood childhood (ages 7-8) performed their first task of checking their blood sugar level either immediately or within the first 2 years after diagnosis. Those who were diagnosed during pre to early adolescence (ages 9-13) all started their involvement in caring for their diabetes immediately upon being

diagnosed by both checking their blood sugar level and giving their insulin shot. They all continued to assume responsibility for consistently performing at least one of those tasks multiple times daily up until the current time of the study. In fact as all they moved through childhood and into adolescence, they progressively took on increasing amounts of independent responsibility for performing the primary tasks involved in their daily diabetes care regimen. Most diagnosed during childhood and preadolescence performed the caregiver role by the end of pre-adolescence (ages 10-12).

Twenty parents identified by themselves and their adolescent as the adolescent's primary diabetes caregiver participated in the study. The following Table 4 presents an organized summary of the demographic characteristics of these parents.

Table 4

Descriptive Characteristics of Parent Participants (n=20)

Characteristic	Number	Frequency	Range
Parent Gender Type			
Mother	(n=18)	**Mode**	
Father	(n=2)	Mother	
Ethnicity		**Mode**	
Caucasian	(n=19)	Caucasian	
Mexican	(n=1)		
Marital Status		**Mode**	
Married	(n=17)	Married	
Divorced	(n=3)		
Age (in years)			
36	(n=2)	**(Mean ± S.D.)**	36 – 54
40	(n=1)		
42	(n=2)	**49 ±**	
44	(n=6)		
47	(n=1)	**Mode** = 44	
48	(n=3)		
50	(n=2)		
51	(n=1)		
54	(n=2)		

Table 4 (con't)

Highest Education Level		**Mode**	
Some College	(n=7)	Bachelor Degree	
Associate Degree	(n=4)		
Bachelor Degree	(n=7)		
Master Degree	(n=1)		
PhD	(n=1)		

Data Collection

Participants were treated in accordance with the APA's ethical standards (APA, 1992) for human research participants. Participants choose where their interview was conducted out of the three options: in a meeting room on the camp's site (n=5); at their home (n=13); or in a meeting room at their local library (n=2). The investigator commenced each data collection meeting by explaining the general purpose of the research, participants' rights and reading and explaining the parent consent and adolescent assent forms. After participants indicated they understood the explanations, they signed the consent forms. Participants were then given a demographic information questionnaire to complete (See Appendices A-6 and A-7). After completing this form, adolescents and parents individually participated in a pre-study projected 20-minute-long interview that was audio-tape recorded (with the participant's consent). The actual interviews lasted between 15-90 minutes, depending on the participant.

The interviewing involved a semi-structured convergent process. The investigator started the interview by asking a narrative-elicitation oriented, open-ended question aimed at getting participants to share their experiences engaging in the transition process. The interviewer continued the interview by choosing from a prepared list of descriptive, contrast, evaluative and systemic (to get at dyads perceptions of each other's involvement in their relationship) questions. The researcher freely probed relevant, unscripted issues

that were brought up by the participants' answers to interview questions, comments, or questions of the investigator. Parents were interviewed first while, in another room their adolescent completed the questionnaires used to provide collateral data that would be compared to the interview data. The questionnaires are: the Diabetes-specific Parental Support for Adolescent Autonomy Scale (DPSAAS) – parent and adolescent versions; the Help for Health Inventory (HHI); and the Differentiation of Self Inventory – Revised (DSR). Parents completed all of the questionnaires and adolescents completed the demographic questionnaire and their version of the DPSAAS. When the parents' interview was complete, the adolescents' interview was conducted while the parent completed the questionnaires in another room. Upon completion of the interview and questionnaires, each participant was thanked and given $10, as compensation for their participation.

Data Analysis

The constant comparative method (CCM), a core method for analyzing grounded theory qualitative research data in a systematic way, was used to inductively develop a theory from the interview data. The audio-tape recorded interviews were transcribed verbatim. CCM and theoretical sampling were employed starting with the first interview and throughout the data collection. Together they make up the methodological representation of the underlying principle of grounded theory, which is, the theory will emerge from analyzing and interpreting the data. Through these processes, I conducted the initial interview and analyzed the data for concepts that characterize its themes. Employing CCM allowed for the identification, description, and theoretical conceptualization of the variety of experiences the parent-adolescent dyads have had transitioning the adolescents to autonomous responsibility for their diabetes care (Boeije,

2002). What was identified from analysis of the initial interview guided me in determining what further data should be collected. I compared all subsequent data to the concepts and themes identified in the first data set. Similarities and differences and any resulting new concepts and themes were identified. Employing the CCM methods (Boeije, 2002), involved making comparisons: within each single participant's interview (open coding to develop categories and understanding); within each parent-adolescent groups' interviews (axial coding to conceptualize the subject, and create a typology of transition experiences); across adolescent groups' vs. parent groups' interviews (triangulation of sources to enrich the concept data fragments and develop a comprehensive picture of the phenomena); within each parent-adolescent group's interviews (open coding for relationship themes, interpretation and conceptualization relationship themes); and between differing parent-adolescent groups (producing a relationship typology). Data analysis continued through this comparison process until the identification of concepts and themes was saturated. I used interpretation to make connections between themes and conceptualize the story that the data tells about the transition experience of parents and adolescents with Type 1 diabetes. Comparison allowed for the identification of the commonalities and differences in participants' perceptions, behaviors, and beliefs about their experiences. I used those to create categories that represent the range of participants' transition experiences. This comparison process was chosen to increase the potential for internal and external validity when using grounded theory approach to execute this study's qualitative research design.

The findings that emerged from the CCM were compared to the results of the DPSAAS, HHI and DSR questionnaires. The major findings described in the Results chapters are findings that emerged through constant comparative analysis of the interview

data and were corroborated by data from the questionnaires. Through this process, themes emerged about the primary ways parents and adolescents' readiness characteristics influence the transition process and the characteristics that are associated with different types of transition experiences.

Ethical Considerations

Establishing Trustworthiness

Reflexivity

My intimate experience with and knowledge of the subject matter has the benefit of providing a platform for establishing trustworthiness. As a part of the rapport building process encouraged when initiating semi-structured interviewing, I informed the participants that I am a Type 1 diabetic who was diagnosed in adolescence. My allusion to a health-related kinship was expected to initiate participants' recognition that my interest goes beyond a scientific agenda and informed by a personal-experienced based understanding. Participants acknowledged that my sharing with them that I have had diabetes since adolescence, as it was intended to, fostered a sense of assurance that the interviewer and the study's primary researcher intended to treat them and the information they shared in a respectful and trustworthy way. Participants also indicated that they perceived my commonality with them as an indicator that I relate and appropriately empathize with them and their experiences. As was expected it made participants feel understood and valued and, I believe, increased their motivation to be forthright in the information they shared.

Validity

For qualitative approaches to doing research, the credibility of the findings is called into question. Thus, one of the methods for buffering against invalidity is triangulation. Cohen and Manion (1986) define triangulation as an "attempt to map out, or explain more fully, the richness and complexity of human behavior by studying it from more than one standpoint"(p. 254). Altrichter et al. (1996) contend that triangulation "gives a more detailed and balanced picture of the situation" (p. 117). O'Donoghue and Punch (2003), describe triangulation as a "method of cross-checking data from multiple sources to search for regularities in the research data" (p.78). To increase confidence in the validity of this study, two types of triangulation were employed: theory and methodological (Denzin, 1978). Theory triangulation involves using more than one theory to interpret or frame the phenomena explored. To underscore its conceptual framework, this study employed the following theories: Paiget's (Piaget and Inhedler, 2000) theory of cognitive development; Erickson's (1969) theory of psychosocial development; and Bowen family systems theory. Methodological triangulation involves using more than one method to gather data. To increase confidence in the validity of the interview data, quantitative instruments were used to assess the concepts of parent differentiation (the DSR and HHI) and parents and adolescents perception of the transition experience (the DPSAAS). Table 5 presented below shows the relationship between these concepts and assessment methods.

Table 5

Comparison of Research Concepts, Questions and Measurement Methods

Concepts	Research Questions	Interview Questions	Collateral Data
Adolescent Readiness	1. How does adolescent readiness influence parent readiness? 2. What adolescent factors inhibit or facilitate parents' readiness for transitioning adolescents to independent, diabetes self care?	1. Tell me about your experiences taking care of diabetes. 2. Tell me about what you (your adolescent) do(es) to take care of your (their) diabetes. 3. Tell me how you feel about taking more responsibility for your diabetes care. 4. Tell me how you feel about your parent taking less responsibility for your diabetes care. 5. Tell me about the impact of diabetes on your life.	1. The adolescent version of the Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy development
1. Parent Readiness 2. Parents and Adolescents Perceptions of Parent Involvement in the Transition Process.	1. How does parent differentiation of self inhibit or facilitate the transition process?	1. Tell me about your experiences taking care of diabetes. 2. Tell me about what you (your parent) currently do(es) to take care of your adolescent's (your) diabetes. 3. Tell me how you feel about your adolescent taking more responsibility for their diabetes care. 4. Tell me how you feel about taking less responsibility for your adolescent's diabetes care. 5. Tell me about the impact of diabetes on your life. 1. Tell me about your (and your parent or adolescents') involvement in transitioning you (your adolescent) to caring for diabetes. **Probe:** How did it occur? **Probe:** What was the experience like?	1. Bowen Differentiation of Self Measure (DSR) 2. Helping for Health Inventory (HHI) - a measure of miscarried helping 3. Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy development

Chapter 4

Results Part 1

Guide to Reading the Results

In order to make the extensive data readable in a coherent and concise way, I divided the results section into four chapters. Each chapter describes and discusses the findings according to one of the following main topics: (chapter 4) the characteristics of the transition process and parents important role in it; (chapter 5) adolescents readiness reflecting characteristics and how they relate to parents readiness for and approach employed to conduct the transition process; (chapter 6) parents level of differentiation and how it relates to the way they engage with their adolescents in the transition process; (chapter 7) the outcome of parents different approaches in terms of adolescents developmental growth and emotional functioning, and parent-adolescent relational interactions experienced during the transition. Effort was made to make the chapters organizationally similar so that they flow coherently into each other and the cohesive relationship between their main topics is apparent. The content of each chapter is organized and named according to its main theme (topic) and sub-themes. Each chapter starts with a table provided to prepare readers to consume the chapters with clarity about how the data fits the research design. That is they provide an organized summary of the themes of the content, how they are connected to each other and how they were probed for and identified by the research and interview questions. The themes are described in detail and accompanied by a representative quote and an illustrative table. When possible, descriptions of the themes include an explanation of how they are related to a research question.

The interviews yielded a plethora of data about the transition process, which was the first concept to emerge from the data analysis. Because this study proposed to focus its exploration of the transition process more specifically on the adolescent and parent readiness factors that influence participants' experience of it, there was no formal research question designed to focus exclusively on delineating the characteristics and components of the process. However, as it is the major phenomenon upon which this study is based, the concept of the transition process was encompassed in the research questions such as research question # 3: How does parent differentiation of self facilitate or inhibit the transition process? Participants' answers to the questions provided data that illuminated the main characteristics of this dynamic process and the collaborative way it is conducted by parents and their adolescents. These findings are more fully described and explained in the rest of the content of this chapter, which immediately follows this introduction. Results Chapters 5 and 6 describe how the dyadic nature of the transition process was revealed by data showing the influence of adolescents' developmental characteristics (Chapter 5) and parents' emotional differentiation (Chapter 6) on parents' readiness for and approach to engaging with their adolescent in the process. Finally, Results Chapter 7 presents participants perception of and introduces and discusses my conceptualization of how parents' approach to conducting the transition process influenced participants' experience and adolescents outcomes of participating in the process. Due to the density of transition process related findings, the results chapters commence by describing it in detail, beginning next and for the duration of this chapter.

The Transition

This chapter summarizes participants' descriptions of the transition process in terms of its purpose, components and progression. As an introduction to the content of

this chapter, Table 6 below summarily presents this study's major findings about the transition by categorizing them as themes and subthemes and relating them to interview questions. For the rest of this chapter, the themes and subthemes will serve as the organizing element for the presentation of more detailed descriptions of the data found about the transition process.

Table 6

Transition Process Themes Related to Research Concepts and Questions

Theory Driven	Theory Operationalized	Sections of Findings according to Themes		
Research Questions	Interview Questions for Adolescents and Parents	Major Themes	Sub-Themes	Relationship to other Major Themes*
1) What is the transition process?	**Question:** Tell me about what you do to take care of diabetes. **Question:** What has the transition experience been like? **Probe:** How did it start? **Probe:** What was the first task you (the adolescent) or your adolescent performed and at what age? **Probe:** How did the transition progress? - In terms of what was transferred from parent to adolescent and when.	1) Transition as an Entity 2) Parents Involvement - Role in:	1a) Purpose – - Why it is important. 1b) Process – - Importance of parents' involvement - What it involves. Parent and adolescent role changes and transfer of responsibilities 2a) Getting transition started 2b) Guiding adolescent's progression through the stages.	2a-c) Parent Differentiation (addressed in Results Chapter 6)

Table 6(cont'd)

	Question: When will it be completed? **Probe:** What will indicate that it is complete? **Probe:** What do you think you can you do to make it occur?		2c) Transferring roles to adolescent. 2d) Getting transition completed.	

Note. Major themes of results for research questions presented in Chapters 5 & 6

The Transition as an Entity

Participants' descriptions of their experiences living with diabetes provided evidence of the existence, importance and necessity of a transition process. Based on participants' descriptions of the ways they engaged in and experienced the transition, I characterize it as: a parent steered, yet parent-adolescent collaboratively conducted, coming of age, developmental process, through which parents teach their adolescents how to take care of and handle the responsibilities involved in controlling their Type 1 diabetes.

Purpose

The occurrence of the transition is developmentally important because during it parents transfer their diabetes caretaker, decision maker and manager responsibilities to their child and in effect move them towards independent self care. Properly taking care of Type 1 diabetes independent of parents help is a developmental milestone that needs to be achieved during adolescence. Accomplishing it equips adolescents to socially advance into and physically survive adulthood with Type 1 diabetes.

In this study, the transition was necessary for the transfer of responsibility for diabetes care from parent to adolescent to occur and allow adolescents to progress toward independent self care and achieve it in time for when it is necessary, adulthood. A mother of a16 year old female diagnosed at age 7 described her perspective about the importance of parents ensuring that it occurs because of its great benefit for their adolescent.

> I'm constantly needing to adapt because my tendency is to want to manage her diabetes more myself. But both she needs for me not to do that for herself to figure it out and I need not to do that because as a parent, I need to let her grow into that. If I'm constantly doing for her, then she can't learn to do it for herself. That's my parenting philosophy so it works into how we deal with her diabetes.

As is common practice, at diagnosis healthcare providers gave all of the parents control over their child's diabetes care and made them responsible for the vital health outcomes. One mother of a 14 year old female who was diagnosed at age 5 reported that physicians emphasized her responsibility to take control of managing her daughter's diabetes in the following way. "Now the one thing doctors told me all along was, 'You take care of her pump and her diabetes now and let her be a child.'" However, as is what normally occurs regarding self-care in general, as participants aged through adolescence their need for their parents' direct and daily provision of care waned. As a 16 year old female who had learned to manage her diabetes over the past 6 years she has had it explained:

> I think if I were a parent of a diabetic child, I would obviously be scared for them too and always want to know what's going on. But it's important that we get

space. You know sometimes it's natural for teenagers just to rebel if they're being smothered.

Adolescents' desire and push for self-reliant control over their diabetes care is fueled by their developmental stage-emergent need for independence and autonomy over their life's matters. One father described how he observed this occurring with his 14 year old son's onset of adolescence: "I think now that he's in the teenage years he likes to be independent, to feel like, "I got this". I think it's just more that he's just pushed back and shown independence." Thus, during adolescence it is no longer developmentally appropriate or beneficial for parents to engage in directly performing their child's diabetes care.

The following Table 7 summarizes the start of this occurrence for adolescent participants. It provides descriptive data that allow for comparison of adolescents: age and stage when diagnosed; age and stage when they performed of their first task; and the point in time after their diagnosis when they started taking primary responsibility for performing care tasks.

Table 7:

Descriptive Statistics of Adolescents Diagnosis and Diabetes Task Performance

Characteristics	Percentage	Frequency	Range
Age when Diagnosed (in years)			
4 (n=1)	5%	**(Mean ± S.D.)**	4 – 13
5 (n=3)	15%	8 ±	
6 (n=1)	5%		
7 (n=1)	5%		
8 (n=3)	15%		
9 (n=3)	15%		
10 (n=4)	20%		
11 (n=1)	5%		
12 (n=2)	10%		
13 (n=1)	5%		

Table 7 (cont'd)

Stage of Development when Diagnosed			
Early Childhood (n=5)	25%		4-6
Mid. Childhood (n=11)	55%		7-10
Pre-adolescence (n=3)	15%		11-12
Early Adolescence (n=1)	5%		13
Age Performed 1st Diabetes Task			
5 (n=2)	10%	9 ±	5 – 13
6 (n=1)	5%		
7 (n=2)	10%		
8 (n=2)	10%		
9 (n=4)	20%		
10 (n=5)	25%		
11 (n=1)	5%		
12 (n=2)	10%		
13 (n=1)	5%		
First Diabetes Task			
Checking blood sugar	15		
Administering insulin (shot or pump)	2		
	1		
Counting Carbohydrates	1		
Everything	1		
No answer			
Point after diagnosis when started to take primary responsibility for performing tasks			
Immediately (n=5)	25%		
1st year (n=3)	15%		
2-3 years (n=4)	20%		
4-5 years (n= 3)	15%		
6-7 years (n=2)	10%		
8-9 years (n= 1)	5%		
*N/A (n=2)	10%		

*Has not occurred yet.

This data reveals that adolescents engaged in normal and healthy self care directed behavior at the onset of their diabetes. That is, they pretty immediately took the first steps towards becoming more independently responsible for their care. Many adolescents became involved in their diabetes care by performing their first task within days after being diagnosed. This occurred when these participants were ages that fall within the developmental stages spanning from early childhood to preadolescence.

Although varying in their pace, most continued gradually progressing towards independence as they aged through adolescence. The "Point after diagnosis..." row of Table 6 provides data that suggests that as participants emerged into adolescence their involvement in their diabetes care increased. This is evidenced by the finding that the amount of time it took most to reach the primary caregiver status after being diagnosed resulted in their accomplishing it within the end of the preadolescence to early adolescence years.

Taking on responsibility for performing more tasks as one enters adolescence is common, expected by healthcare professionals, and is the initial step to taking on primary responsibility for one's diabetes care. A 16 year old female described how her desire for independence motivated her to start giving herself shots and checking her blood sugar a few days after she was diagnosed at age 10.

> I thought, you know this is kind of a hassle having my parents have to do everything, and always having to be around. I was already that ***type*** of independent person where it's like I can get things done myself. It's kind of a burden, having to have someone follow you around. So, I definitely wanted to start being independent.

As she described, when adolescents take on responsibility for performing tasks it often reflects or ignites the onset of their desire to gain independent control over their diabetes care. The same 16 year old female explained her perspective about why adolescents desire and need more control over their diabetes care:

> As we get older, teenagers want more independence and so parents need to let them have that. And like as hard as it may be to let go and give that freedom, it's absolutely necessary. If we're ever going to grow up, this is the time when it

starts. So, this is the time when you need that independence the most. My parents were supportive. They want me to have a sense of independence as well. They thought it was a good thing. They definitely encouraged me.

If this first step is encouraged or at least acknowledged, and then supported and directed by cooperative parents' guidance then it initiates the process of parents and adolescents intentionally engaging in moving the adolescent towards independent responsibility. A mother shares the perspective that has enabled her to welcome and facilitate her 16 year old daughter's growth towards independent self care throughout the 7 years she has had Type 1 diabetes.

It's always been my attitude that the growth that your children experience, you have to make room for it. You know? And actually if you make room a little ahead of time then the growth happens a little more naturally. It makes it easier for both of us to adjust. And if I look at it as progress for them, then it's not as sad for me to lose these things. I always look at it as a positive event.

Process - Importance of Parents Involvement

Parents' cooperative involvement is necessary for adolescents' appropriate development through adolescence and readiness for the autonomy and independence expected of them when they reach early adulthood. As natural as adolescents need for and pursuit of independence is, both parent and adolescent participants believed that an adolescent's achievement of *adept* ability to independently manage their diabetes care is the result of their parent engaging them in a transitioning process. One 16 year old female described the value of parents being involved in helping her take care of and then learn how to independently take care of her diabetes:

> It's a huge step, it's a huge change and so it's important that they're there. It's definitely a help to have parents who understand and helped me a lot. Always just being there and being able to give advice and answer questions and just help you along and all that stuff. The fact that they have taught me all these things and that I can ask questions and they are able to give me logical answers that I can understand and that make sense makes me more able to protect myself from complications. At camp there's those people that you meet that you know their moms and dads weren't so involved in their diabetes and they picked up on all this stuff their selves and like you hear different stories of how hard it was. It makes me feel lucky that I have parents who helped me.

As will be described in Chapters 5 and 6, in this study, the transition process occurred through parent-adolescent exchange and its accord was influenced by the interaction of parent emotional and adolescent developmental factors.

Process of Parent and Adolescent Role Changes and Responsibilities Transfer

During this process, adolescents took on the diabetes caretaking roles their parents had commanded since they were assigned responsibility for them by healthcare providers when their children were diagnosed. This resulted in the type and amount of parents and adolescents diabetes care involvement gradually and inversely evolving to the point of parents relinquishing and adolescents taking full control of managing the adolescent's diabetes. A 16 year old female who is grasping at having total independence in caring for her diabetes described how the process evolved and what she needed from her parents to get as close as she was to the end goal.

> Parents need to be there, to help when teens need help. It's like what they need changes. Like at first, it was absolutely necessary that my parents helped me and checked on me as I learned how to do everything. Now I think that I just need to know that she trusts me and that I can take care of myself. I want her to be aware of things. I definitely want to keep her in the loop, you know, but I want it to come from me. I want to be able to tell her, not for her to ask me.

In this study, parents and adolescents were successfully engaging in the process if adolescents demonstrated they were making progress towards being able to independently, competently and confidently perform and manage their diabetes care protocol by the time they reach the end of adolescence. This goal is of vital importance as it is necessary for adolescents to continue properly developing and surviving with Type 1 diabetes when they are independent of their parents in adulthood. The mother of a 14 year old male, who had progressively taken on increased responsibility for his diabetes care since he was diagnosed at age 9, described her perspective in the following way.

> I think it's really important to start younger making them responsible and understanding how to take care of their diabetes so that the parent can let go a little bit and let the kids you know be responsible, and have a life, fairly normal life.

Parents Involvement – Getting Process Started

Because of their occupancy of the main roles involved in taking care of Type 1 diabetes parents had to take the reins of conducting the transition process by transferring the roles to their adolescent. Therefore, parents controlled the transition process,

determining its pace and course. Parents' decisions about the structure and flow of the process set the tone for participants' transition experience and created the potential for whatever outcome occurred. Parents gradually phased themselves out of and their adolescent into responsibility for the diabetes care by engaging their adolescent in the transition process. It was their responsibility to teach their adolescent what they found effective in their tenure as their adolescent's primary diabetes caretaker, so that they equipped their adolescent to successfully function as an independent and autonomous caretaker and manager of it by adulthood.

To successfully, independently control their Type 1 diabetes, adolescents had to learn and take on responsibility for properly doing everything that is required to effectively care for and manage it. Analysis of parents and adolescents descriptions of what they do every day to control Type 1 diabetes revealed 3 primary roles involved in comprehensively caring for it. In the rest of the results and conclusions sections, the following labels are used to name the 3 roles, described here with their associated tasks: caregiver, which involves performing daily care regimen tasks; decision maker, which involves working in alliance with a medical team to make healthcare decisions and independently carrying out and amending the daily regimen as needed; and health care systems manager/liaison, which involves procuring, and funding healthcare services and supplies and coordinating services of healthcare system network. More specifically, the responsibilities of the healthcare systems manager role involve: ordering supplies, making healthcare appointments, providing insurance and financial funding for medical care and supplies, and interacting with insurance and healthcare providers regarding maintaining services. The following Table 8 categorizes the roles and their associated tasks.

Table 8

Main Role Components of Managing Type 1 diabetes

Daily Caregiver	Perform and administrate the daily diabetes care regimen. Oversee the implementation of health care professionals' recommendations.
Decision maker	Work in alliance with the medical team on behalf of the adolescent to: o evaluate o make decisions about o amend healthcare protocol and regimen activities.
Healthcare Systems Manager/liaison	Manage comprehensive diabetes healthcare. o Interact with insurance and healthcare providers o Procure insurance and provide funding for healthcare services and supplies. o Order supplies. o Schedule doctor appointments.

All adolescents increased their involvement in their diabetes care during adolescence as their role evolved through the following levels of dependency in their relationship with their parents: being dependent on parent to be the primary caretaker, manager and decision maker; co-laboring with parent in performing tasks of daily care regimen, while parent continues to be the primary manager and decision maker; being the primary performer of the regimen's tasks while parent supervises and continues to manage and make decisions; being own independent caregiver and emerging decision maker with parent consulting when asked. Thus, regardless of parents' readiness for a change in their role and responsibility in managing their child's Type 1 diabetes, as their children grew older all parents experienced a reduction in: the amount of direct caretaking tasks they performed; and the level of responsibility they had for administrating the daily care regimen and managing the healthcare protocol. Even though their tasks changed, the characteristics of the transition process maintained involved parents' prominent presence in their adolescent's lives because it required them to actively engage in steering the process for it to effectively occur.

Importance of Parents Involvement in the Transition Process

Therefore, in order for adolescents to learn these roles let alone independently take them on, parents had to be ready to engage in the transition and committed to seeing the process through. A mother of an independent 16 year old female described the process in the following way:

> It is a natural progression. Never do for them what they can do themselves. You know, take a time and step back a little and be busy, so they have to do some of their own self-care. And just step away from that responsibility in periodic things. And then kind of evaluate how your child is doing and then just step away more.

Parents performed the 3 main roles since being given responsibility for them by their children's healthcare team when their children were diagnosed. Therefore, parents controlled managing their children's diabetes and were the gate keepers to adolescents' access to them. Because parents had to give up the roles and transfer their responsibilities to their adolescents, adolescents' opportunity and ability to take on the roles depended on parents active partnering with them in the transition process. A mother of a 13 year old male who was diagnosed at age 9 described how she had to squelch her worry driven protectiveness and go against her parental inclination to keep control of his diabetes care in order to accommodate his necessary growth towards healthy independence.

> I think right from the start we knew that it's a life-long thing and that he just needed to incorporate caring for it in his life. And that we just kind of pushed that way from the beginning. It's harder on me, letting go and not nagging him. There was a time when I'd be right watching over him, making sure he was doing

everything right. I guess just concerned. You hear all the complications related to diabetes. I just wanted to make sure that he had a good quality of life through his entire life. Now I know I can trust him. I guess it took maybe taking steps to get to this point. Letting him do it instead of being right there. He does a really good job of controlling the diabetes on his own. He's responsible and um, not, not so much anymore. I'm sure he'll be fine.

This parent's son's reflection on his parents' involvement in his transition experience suggests that he felt their approach was beneficial and fit for his needs.

Kind of both of my parents get me to do more diabetes things. They just kind of like, 'I'm not going to do that anymore" so I have to do it. I'm o.k., 'cause I'm gonna have to do it eventually. I think it's kind of all of us making decisions.

This necessary partnership involves parents directly mentoring and guiding their adolescents in the following ways: teaching them the roles, supervising their development of proficiency at them and then actually handing over the reins of responsibility for them to the adolescents. Parents effectively guided the transition process by the doing the following: facilitating its commencement, by giving up their control over the main roles; steering its progression, by teaching their adolescent to perform the roles' tasks; positioning their adolescents for success, by preparing them to handle the weight of their responsibilities; seeing the process through to fruition, by transferring the roles to their adolescent's control. The parent of the immediately aforementioned 13 year old male emphasized the importance of parents' educating and preparing their adolescent to handle independent responsibility and described it as being a process that starts at diagnosis.

> I think letting the kids start right from the beginning, I know that's not easy for every kid, but let them start right from the beginning, managing themselves or at least understanding why they're doing things. Because if they know why then they'd be more likely to make corrections the right way.

Parents who did this helped their adolescent gradually increase their involvement in caring for their Type 1 diabetes as they shifted away from being dependent on their parent to manage it to being independently in control of and taking ownership of it. A 15 year old male who was diagnosed when he was 9 years old explained how he naturally and gradually starting taking on more responsibility for performing tasks as he aged.

> I mean I started doing all the tasks, kind of immediately and then I just started to understand it more and more as I got older. Like at first I used to have to ask my parents what to do, how much insulin to do or like make sure. But then eventually over time I started doing it myself.

Parents Involvement

Parents' Role Getting the Transition Started

It can be argued that all transitions were started at diagnosis by adolescents healthcare team who followed the typical approach to implementing treatment protocol (aimed at promoting youth diagnosed with Type 1 diabetes development of a sense of diabetes self-care and ownership) of training and assigning newly diagnosed patients to perform a care task under the guidance of their parent, who is assigned to be the primary caretaker, decision maker and manager. Although this was the experience for every adolescent participant, some (n=6) did not immediately continue to perform the task and

some who did continue did not perform it consistently after being discharged from the initial inpatient or outpatient diagnosis and education/training setting. Therefore, this study found that physicians can suggest and even prescribe a transition start point, adolescents can propose and implore their parents for more control, but, parents who control management of their adolescent's diabetes care ultimately determine when the transition process begins. Given this, when the start of the transition process is referred to hereafter, it is means when an adolescent first performed a task(s) that they continued to consistently take responsibility for performing. This task would also have started their eventual repertoire of tasks it was the first one, after which they added more tasks to the things they were responsible for.

As the youth participants with Type 1 diabetes either emerged into or developed through adolescence, parents' initial consideration of starting the transition process was prompted by parents, adolescents, or physicians singularly or collectively indicating the necessity of its occurrence to meet adolescent's needs or anyone's expectations. As the pre-transition primary caregiver, decision maker and manager, parents own the responsibility of ensuring that the transition occurs. This means their role is vital to the proper execution of the transition process because it involves: training their adolescent to perform the tasks and manage the responsibilities of the roles involved in taking care of Type 1 diabetes; and then, relinquishing control of the roles and transferring them to their adolescent's control. One mother described how, despite her maternal tendency to want to stay in control in order to protect her son, she was motivated to teach and give him responsibility so that he had the tools he needs to develop self-sufficiency that would yield him lifelong benefits.

It was probably harder for me as the parent, letting go. I don't know, because a mistake when you're a diabetic is such a big deal. I don't know how you do that. I know one boy he doesn't have very good control and he has other health issues. A nod that's I think due to the parents and how they expect him to be responsible for his own diabetes. I think it's really important to start young making them responsible and understanding so that the parent can let go a little bit and let the kids you know be responsible and have a life, fairly normal life.

When parents initiated the transition (n=10), it was for one or many of the following reasons: belief that it was necessary to properly equip their child to be in control of their lives and be able to handle any health emergency even when the parent was not around; concern that their child was not progressing according to professional standards of normal and healthy development; need for relief from caretaking responsibility; or pressure from their adolescent.

Parents Role as Guide for Progressing through the Stages

Parents' controlling status as occupant of the primary caretaker, decision maker and manager roles also gave them the authority to influence the pace and the way the transition progressed. For all participant pairs, parents transferred their roles to their adolescent in the same order and pattern. However, the pace of the role transference varied. Parents started phasing out their involvement in and responsibility for being the primary caregiver before they phased out the decision maker and manager roles. Thus, the bulk of the transition process that occurred during the childhood and preadolescent years primarily involved parents training and providing opportunities for their children to

practice performing various tasks that fall within the realm of the caregiver role's responsibilities.

Parents' responsibility in transferring the caregiver role involved overseeing their adolescent's development of the ability to properly perform the role so that they could ensure that their adolescent would remain alive and healthy once they became independently responsible for it. This involved parents training their adolescent to perform the daily care regimen's tasks and monitoring their performance to assess their increase in skill and growth in role competence. By acting as overseer parents could be assured that their adolescents were developing the competency and demonstrating the consistency necessary to be functionally ready to effectively take on the primary caregiver role. The degree of parents direct involvement in conducting the daily regimen of care tasks ran the continuum, ranging from: regularly performing tasks; to monitoring adolescents task performance; to overseeing that the regimen was consistently completed and adhered to (by checking-in with their adolescent about it on first a consistent and then a random basis); to providing insight and support when their adolescent asked for it. One mother of a 14 year old male diagnosed at age 9 described her experience with her amount and type of involvement changing due to her son maturing and needing less direct care and assistance as he grew older.

> He started doing everything right away at age 9, but he needed assistance. We told him to do the things and we had a set schedule. So, we'd say, "Remember it's 4:30, you need to do this." type of thing. Now just very recently around about age 13 he started becoming more proactive and saying "I need this or I need to do this. Even now the school nurses say he's so independent. They're kind of there

for a double check. It felt good, very good. I am proud of him that he's taking the responsibility. I'm kind of looking forward to that total independence.

The following Figure 2 depicts how the form of the caregiver role parents engage in changes over time. It presents and describes the different forms parents' caregiver role morphs into as they transfer the role through the transition's progression. These consecutively occurring forms of the caregiver role involve increasingly less responsibility for engaging in direct care of the diabetes. This resulting devolution in weight and amount of the caregiver role's responsibility corresponds with adolescents taking on increasing responsibility for the primary caregiver role.

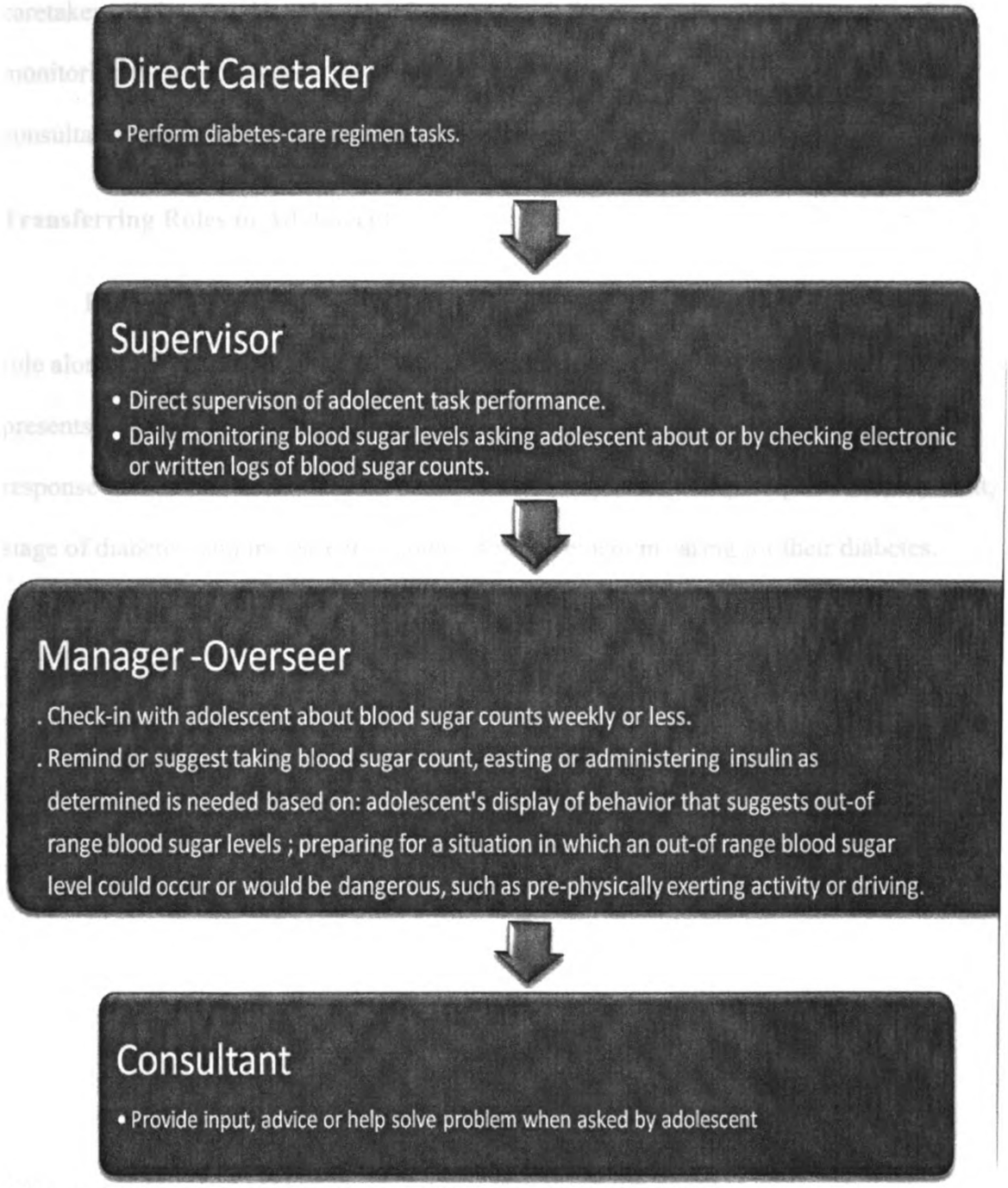

Figure 2. Changes in Parents Form of Caregiver Role Over Time

So, Figure 2 represents a visual of how parent's engagement in the caregiver role evolves as the transition process moves forward. The type of role parents played changed qualitatively as well as the amount of regimen care tasks they performed decreased as their adolescent took on performing more of the diabetes care regimen's tasks. Their

caretaker role became less about performing the daily care regimen to being more about monitoring their adolescent's performance of the regimen and then to providing consultation about changes to the regimen when their adolescent asked.

Transferring Roles to Adolescent

Following is Table 9 which depicts the devolution of parents' primary caregiver role along with a description of the characteristic tasks of each new form of the role. It presents a comparison of the different forms of the caregiver role parents engage in, in response to their adolescent's need-based characteristics including: stage of development, stage of diabetes, and increase in amount of involvement in caring for their diabetes.

Table 9

Conceptualization of Parents and Adolescents Reverse in Caregiver Role

Roles Parents Play By Decreasing Involvement and Responsibilities	**Stage of Diabetes**	**Child's Stage of Development**	**Adolescent Roles by Increasing Amounts of Responsibility and Levels of Involvement**
Chief Operating Officer (perform almost all tasks and make all decisions)	Diagnosis	1. Childhood	**Dependent** Total dependence OR perform1 task (usually checking blood sugar.
Boss (micromanage and make decisions about dosage changes)		1. Childhood 2. Early adolescence	**Parent Helper – Task Performer Trainee** Being trained to administer shots; perform blood testing with much instruction.
Supervisor (guide and hover as a coworker; make decisions about changes in protocol)		1. Early adolescence 2. Childhood 3. Mid adolescence	**Task Performer** Administer insulin (via shots or pump) and perform blood testing with parent help, monitoring and daily reminders). Continue to need guidance with carbohydrate counting and meal planning.
Manager (oversee)	Long time AND/OR	1. High school 2. Early adolescence	**Primary Caregiver** Perform tasks but need parent check-ins and admonishment to maintain consistent adherence when show signs of slacking.
Consultant - help when asked infrequently; provide emotional support (act as advisor or counselor)			**Chief Operating Officer** Perform tasks and make own decisions. Infrequently need to ask for help. Seek parent's emotional support and advice when needed.

When, why, how and at what pace parents conducted this process is unique to each parent's: readiness for the transition, specifically their differentiation which then influences perception of their adolescent's readiness. One 15 year old female who was diagnosed and performed her first task at age 10 described how her parents used scaffolding to move her from dependence to independence in performing her regimen.

> I was diagnosed when I was ten. I just remember I couldn't really go anywhere at first 'cause I was so new to it and I didn't really know what to do to control it. I wouldn't give my own shots. My parents helped a lot, so I think that kind of helped me to get worked up to doing it myself. It kind of like gave me my own time to do my own stuff until I kind of got comfortable with it. When I first gave my shot I felt proud I did it myself. It wasn't half as bad as I thought it would be. When I got my pump, my dad always filled the pump reservoir for me for a little while. But then I started doing it. But he still used to change my site for awhile, until I kind of got used to doing it. My mom helped me with carb. counting at first. But, then after a little bit, I kind of got the hang of it and just did it myself after I had it for about a year and a half. She would check it and double check it. When I was 11, almost 12 I wasn't doing all of it myself, but I kind of got the hang of things. I started doing everything on my own when I was 14. It just kind of happened. My mom would make me do some of the stuff more and she'd try to hand it off. I'd have to do it myself. I would do just do it. I probably got more confident because I thought I could do it all by myself after that. It got a little annoying having them help me, so I asked them if I could start doing things by myself. I think my parents were probably scared that I'd mess up but they were supportive about it.

Starting to Transfer the Decision maker Role

The transition peaked during mid-adolescence with parents turning over responsibility for performing most tasks to their adolescent and engaging with them as collaborators in making decisions about their care. A mother of a 16 year old female, who started being involved in her own diabetes care by checking her blood sugar and giving herself insulin shots when she was diagnosed at age 12, described their current different functions as co-laborers in managing her daughter's diabetes.

> I'm the owner of the company and she's the CEO of her day. I mean she goes through it all but I have to approve it. So, she does the nuts and bolts of it all day long. But we bounce it off each other and we come up with strategies.

By mid adolescence parents acted in roles that range along a continuum from supervisor to as-needed consultant regarding making decisions about and changes to the regimen and overall healthcare protocol. In the following quote, a father of a 16 year old female, who started being involved in her diabetes care by checking her own blood sugar when she was diagnosed at age 6, described the roles he and his daughter play to share the responsibility of caring for her diabetes.

> I am the scheduler of appointments. I download her pump onto the Care Link and print that off for the doctor. I'm in charge of learning new things, investigating things, insurance, ordering, that kind of thing, and she takes care of checking her sugar, eating when she needs to eat, taking her insulin.

This father's description of their responsibilities illustrates the adolescent as daily caregiver and parent as manager co-laboring relationship that families commonly operate according to when their youth with Type 1 diabetes is in middle adolescence.

Completing Transition: Final Stage in Progression; Growing from Independence to Responsible Independence

Once the adolescents became primarily responsible for performing their regimen, they went through a process of further refining their task performance and committing to consistency as they moved toward demonstrating responsible independence. Parents whose children were in middle to on the verge of late adolescence all indicated that, although their adolescents were performing the tasks of the caregiver role, they operated at varying levels of effectiveness in consistently carrying out independent responsibility for the caregiver role. A mother of a 15 year old son who started performing all his tasks immediately when he was diagnosed at age 11 described how she experienced this. Although her son immediately taking on full responsibility for performing his care regimen relieved her from the responsibility to be directly involved in his daily care early on, he still had not achieved the level of control over his blood sugars that would affect optimal metabolic control.

> I think the fact that he has become so responsible with his diabetes, is because he has taken ownership of it. He's been so independent in that way from pretty much the beginning but that's just helped the transition. It's a benefit in the fact that I don't have to have that extra daily concern every day. I mean I'm still concerned but I don't have to worry that I know that he's going to do the checks I know that he's being taken care off, so that's a relief. It's just when you go with

him to his doctor's visits and see the blood sugar numbers you're like, oooh, why wasn't I paying more attention!

This exemplifies the need for continued parental involvement even once adolescents take on the primary caregiver role. At this stage parents primarily engage in quality assurance control by: monitoring and encouraging their adolescent to properly perform the care regimen and consistently adhere to the protocol. Another parent of a 15 year old female describes how she walks a thin line between being a concerned overseer and a menacing, smothering parent.

> I try to take more cues from her, you know, to, make sure that she was checking her blood sugars, before meals or even if she felt a little, you know, high or something, to, maybe check them, to do a correction when she was high instead of waiting until, you know, the next meal time. Just planting little things like that.

Encouraging consistent adherence occurs through reminding. None of the early adolescent participants in this study had achieved performing all the tasks without any reminders. A few of the 16 year old participants' parents reported that giving occasional reminders was their primary role of support and involvement. A mother of a 16 year old female who was diagnosed at 10 years old and performing most of her own tasks within the first year, after distinguished between her adolescent independently performing caregiver tasks well and fine tuning her performance of the caregiver role. She characterized her daughter's performance state as reflecting her growing into responsible independence in performing the tasks over several years.

I think probably in high school, she showed a little bit more of the responsible independence. Before then, in middle school I had to remind her more. And then in high school she's really become more independent and responsible.

In describing her adolescent's gradual evolution from dependent need to independent responsibility, the mother differentiated between her daughter's initial demonstration of readiness for independent task performance and her current capacity to engage in responsible independence, which the former progressed to during adolescence. Based on her and other parents descriptions of this phenomena, responsible independent care involves performing the regimen of diabetes care tasks independent of parent reminders. Thus, responsible independence seems to be a level of responsibility youth grow into the capacity to handle as they mature with age.

Most parents whose adolescent had reached 16 years old reported having transferred the decision-maker role to their adolescent. They also reported that they very infrequently provided aide to their adolescent making decisions. When parents did it, was at their adolescent's request to help them figure out insulin dosage adjustments to accommodate: an unfamiliar meal or food item; a peculiar incident of out of range blood sugar level; and an unusual experience of change in activity level.

All parents and adolescents believed that the healthcare systems manager role's responsibilities of ordering medications and supplies and dealing with insurance companies would be performed by the parent into the adolescent's early adulthood. One parent of a well adjusted 16 year old female who independently performs and makes decisions about her diabetes care described how they arrived at this point of parent acting as an as-needed helper and supply orderer.

It's just kind of been a really natural progression, but she does almost everything now, except like ordering supplies and stuff. I see myself ordering her supplies and such through college. I probably will do whatever I can do to help her because, it's just the daily grind of all you have to keep up with is just exhausting. And sometimes I know that she just hates doing what she already has to do.

Thus, the transition process gradually occurred from diagnosis through early adulthood with parents transferring the 3 main diabetes care roles (listed above in Table 8) progressively in an order based on the complexity and maturity of cognitive functioning they require to be consistently and effectively carried out. When, why, how and at what pace parents conducted this process is unique to each parent's readiness to conduct the transition. This study found that parents' readiness is in part dependent on their perception of their adolescent's readiness. The role of adolescent readiness in the occurrence of the transition process is addressed next in Results Chapter 5. The role of parent readiness is presented in Results Chapter 6.

Chapter 5

Results Part 2

Research Concept # 2 – Adolescent Readiness

Research Question #1: How does *adolescent readiness* for transitioning to independent diabetes self-care ***influence parent readiness***?

Research Question #2: What **adolescent factors inhibit** or **facilitate parent readiness for transitioning** adolescents to independent diabetes self care?

This chapter addresses research questions one and two by summarizing parents' descriptions of adolescents' characteristics that influenced parents' readiness for the transition process. This chapter also describes the findings about the influence of adolescents' readiness for the transition process on parents' approach to conducting the process. The following Table10 serves as an introduction to this chapter's content and guide to how it is presented. Table 10 summarily presents the major findings about this topic categorized according to themes and subthemes and related to research questions (both the original theory driven and data analysis derived ones), interview questions and questionnaires. For the rest of this chapter, the themes and subthemes will serve as the organizing element for the presentation of more detailed descriptions of the data.

Table 10

Organizational Guide for Themes of Chapter 5

Theory Driven	Theory Operationalized		Sections of Findings According to Themes	
Research Questions	Interview Questions for Adolescents and Parents	Question-naires Providing Collateral Data	Themes	Subthemes
1. How does adolescent readiness influence parent readiness? 2. What adolescent factors inhibit or facilitate parents' readiness for transitioning adolescents to independent, diabetes self care?	1. What factors inhibited or facilitated your readiness for transitioning (your adolescent) to independent, diabetes self care? 2. Tell me about what you do to take care of your (your adolescent's) diabetes. 3. Tell me about your (your adolescent's) involvement in transitioning (your adolescent) to caring for your (their) diabetes. **Probe:** What was your role when it started? **Probe:** How did it (your role) occur (come to be)?	2. Helping for Health Inventory (HHI) – a measure of miscarried helping 3. The adolescent and parent versions of the Diabetes-Specific Parental Support for Adolescents Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy developmen t	1.Determining Adolescents Readiness 2. Adolescents Characteristics that Facilitate the Transition Process. 3. Adolescents Characteristics that Inhibit the Transition Process 4. Parents Responsibility to Accurately Determine and Respond to their Adolescents Readiness 5. Parents Fitting their Approach to Accommodate Adolescent	1a. How Parents Assessed Adolescents' Characteristics. 1b. The Importance of Parents Making the Right Decision About Starting. 1c. Adolescents' Petition for Independence 2a. Characteristics that Demonstrate Capacity to Handle Responsibility. 2a1. Adolescents' Competence and Capability to Perform care tasks. 2a2. Adolescents' Temperament and Character Reflected Cognitive Maturity

Table 10 (cont'd)

	Probe: Did your role change? - Why or why not? - What influenced this? 4. Tell me how you feel about (your adolescent) taking more responsibility for your diabetes care. **Probe:** Now **Probe:** In the future **Probe:** What more do you think you (your adolescent) can do? Should do? 5. Tell me how you feel about your parent (you the parent) taking less responsibility for your (adolescent's) diabetes care. 6. Tell me about the impact of diabetes on your life.			3a. Characteristics that Suggest Inability to Handle Responsibility 3a1. Adolescents Stage-specific Development Factors 3a2. Adolescents Cognitive Functioning 3a3. Adolescents Behavior - Inconsistent Performance of Care Tasks. 3a4. Adolescents Preoccupation with social factors. 5a. Adolescents Temperament

This chapter summarizes parents' descriptions of adolescents' characteristics that facilitated or inhibited the transition process. Some characteristics were identified by parents when they were assessing their adolescent's readiness to start the transition process. Others were noticed by parents after they started and were progressing through

the process. There was variety among parents approach to assessing their adolescent's readiness in terms of what adolescent characteristics were taken into account and what method was employed to come to a conclusion. This resulted in there being variance in the extent of the thoroughness and potential for accuracy of the assessment methods parents employed.

Before describing the characteristics, in the following section I address two topics that are necessary to understand in order to grasp the important influence parents' assessment of their adolescent's readiness for the transition process had on how effectively they conducted it and thus, on their adolescents achievement of independence in caring for their diabetes. To accomplish this, first I describe how parents engaged in the process of identifying adolescents' readiness facilitating and inhibiting characteristics. Then, I explain the importance of parents' identifying and accurately interpreting characteristics as indicators of adolescents' readiness and using of them to inform their decisions about starting and progressing through the transition process.

Determining Adolescents' Readiness - How Parents Assessed Adolescents' Characteristics

Before starting the transition process, parents assessed their adolescent's readiness for taking on increasing levels of responsibility. To determine their adolescent's readiness, parents considered the characteristics of their adolescent's life that could have an effect on their ability to correctly perform, consistently adhere to and effectively manage their care protocol. When parents noticed characteristics that reflected their adolescent's maturity, reliability and competence they interpreted them as being indicators of readiness and felt confident starting the transition process. When parents noticed characteristics about their adolescent that could compromise their ability to take

on or handle increasing diabetes care responsibility, they questioned their adolescent's readiness for engaging in the transition process. Any characteristics that caused unresolvable concerns inhibited parents' readiness to start the transition process. The likelihood that parents would make the right decision about when to start the transition depended on the validity and accuracy of the things they considered when they assessed their adolescent's readiness. This included whether they chose characteristics that were accurate indicators of their adolescent's readiness for a change in responsibility; and whether they accurately indentified each characteristic as a potential facilitator or inhibitor. Parents agreed that the evidence of the correctness of their judgment was the quality of their adolescent's performance of their new responsibility, which was directly observable in their adolescent's actions and also reflected in their short-term health outcomes.

The Importance of Parents Making the Right Decision about Starting

Making parenting decisions regarding managing the diabetes care of adolescents presented unique challenges and pressures uncommon to managing the diabetes care of children. If it had not occurred in childhood, adolescence is the stage when parents felt it necessary to start the transition process. Since they conducted the transition, parents had the obligation to make sure it was effective in helping their adolescent progress towards achieving healthy and developmentally appropriate outcomes. Whether or not they conducted the transition in the best way and at the best point in time for their adolescent influenced how effective the transition was at achieving its goal. Thus, parents reported they felt pressure to choose the best fitting approach to conduct the process, beginning with making an accurate determination of when to start it.

Adolescents' Petition for Independence

For some parents, the pressure they felt to make an accurate determination of when it was best to start the transition was exacerbated by their adolescents' resistance to their involvement; which began or intensified during adolescence as the desire for autonomy grew. All parents agreed that their adolescents' requests for independence infiltrated their assessment and decision-making process regarding both when to start the transition process and when to give their adolescent charge over specific roles and ultimately their comprehensive diabetes care plan. In some cases (n=8) adolescents convinced their parents to start the transition process primarily by voicing their desire for and right to have more control over and independence in taking care of their diabetes. For parents who engaged in a more thorough approach to making the decision, their assessment process was complicated by their feeling the necessity to properly balance consideration of their adolescent's desire for independence against their knowledge of the quality and quantity of consistent care that is required to ensure that their adolescent would experience healthy short and long-term diabetes outcomes. So in determining when to start the transition parents felt pressure to both appease their adolescents' desire and meet their needs. Although difficult, parents' ability to accomplish this had vital implications for their adolescents' health and survival.

The following quote illuminates how in determining when it is best (in terms of their adolescent's readiness) to start the transition process, it is difficult for parents to resist adolescents' pressure for premature independence. It also reveals how not resisting can result in dangerous health consequences. A mother of a 14 year old female who was diagnosed at age 8 described her negative experience and outcomes of bowing to her daughter's pressure to be given more independence even though she was not ready to handle it.

I gave her shots and then, she wanted to take control, independence. She wanted to I guess feel like she was in control of diabetes, instead of the diabetes taking control of her. The doctor said when she turned 10 she could take her own shots for herself. Well then she wasn't doing them right: she wasn't giving herself enough insulin. She used to get ketones a lot when I used to let her do it herself. It got so bad where she kept getting ketones. We would get rid of them one day and the next day they would be back to large again. I'm like, "What is going on?" At that point, I took over all her shots no matter what she wanted. I'm like" I need to make sure that you're gettin' this insulin." So I took back taking and giving her shots. Then she was getting' more conscious of her body, I guess, even at age 11. She asked if she could start doing the shots herself again. I gave her another try and she was doing it a little bit better. I gave her back her independence probably around age 11. But she's struggled the past year because I've given her more independence than I probably should have.

As this example shows, giving an adolescent responsibility too soon can result in disastrous health outcomes for them. Based on parents' reports, I categorize situations in which being granted premature responsibility caused adolescents harm as those in which parents gave them: responsibility for their regimen before they were capable of consistently adhering to properly performing it; and authority to make decisions before they were cognitively capable of thorough and objective thought processing. In this study, when adolescents (n=4) were given responsibility they were not mature enough to handle properly their lives were in immediate jeopardy due to their error causing ketoacidosis. Ketoacidosis is a debilitating condition that occurs when diabetes that is not well managed even for a relatively short amount of time causes dangerously high

blood sugar, which the body's attempt to rectify results in dehydration and system failure. Its occurrence minimizes quality of life by causing compromised body functioning and incapacitation that requires medical care to treat. If not successfully treated, it has the great potential to quickly cause organ damage and even death. Thus, parents believed it was necessary to engage in deliberately cautious and thorough decision making in order to make the right determination of when their adolescent was ready for them to start the transition process.

Adolescents' Characteristics that Facilitated the Transition Process.

Following is a description of the adolescent characteristics that influenced parents' readiness to start the transition process. The characteristics are signs of maturity and competence and fit in the categories of temperament, behavioral and cognitive functioning. Parents unquestionably interpreted these characteristics to be indicators of their adolescent's readiness. Thus, parents consistently identified these as factors that facilitated their own readiness for and influenced their decision to start the transition process. I describe these factors and present parents quotes to illustrate them.

Characteristics that Demonstrate Capacity to Handle Responsibility.

Adolescents' competence and capability to perform tasks.

For some parents, when assessing their adolescents' readiness to start the transition, their adolescents' actions made the biggest impression on them and carried the greatest weight in their determination of when to start the transition. Even as the transition progressed, some parents continued to decide to transfer their control over performing and making decisions about the care protocol to their adolescent based on their adolescents' behavior-demonstrated competency. Some other parents considered

their adolescents' behavior along with, but giving it more weight than, their adolescents' declaration of their right to independence.

In some cases, the transition process started when adolescents first performed care task(s) immediately upon diagnoses. Their parents observed their capability and based on their performance and healthcare providers' suggestions entertained the idea of starting the process of making them independently responsible for their diabetes care. If adolescents (or at that point they may have been children) comfortably and competently performed their first task(s) parents decided to let that be the beginning of progressively giving them more responsibility as they demonstrated their ability to handle it. Thus, the transition was begun by the adolescents own action driven initiative. This situation is exemplified by the following quote, which shares the experience of the mother of a 14 year old female, who was diagnosed and initiated her progression towards independence at age eight.

> By the time she got home from the hospital, she was doing it all by herself. A lot of it was self-initiated. Her giving her injections were something she really wanted to do herself. She really wasn't comfortable having us give them to her, as much. She just really wanted to be able to do it herself. That was important and so I would say she did a lot of it on her own. I always felt very fortunate that she wanted to learn and to take that on herself._Every step she took we were very proud of her because we really feel like as parents, it's not only our job to take care of her but it's our job to educate her and encourage her to do everything she can for herself and not always rely on us.

As this mother indicates, in instances like this, parents followed their adolescent's performance based lead in determining what their own involvement should be. Once

given responsibility, when their adolescents showed they could be relied on to consistently, properly perform their diabetes tasks, the parents were assured that they had made the right decision. Thus, the adolescent's actions displayed their reliability and competency and earned them their parents' confidence and increased their parents' willingness to allow them to take on more independent control. One parent of a 16 year old male described her experience of this.

> I think the fact that he has become, he's so responsible made the transition easier. There's a lot of other aspects in his life he's not necessarily so responsible (laughs) but his diabetes, he has taken ownership of. He's been so independent in that way from pretty much the beginning; that's just helped the transition.

Adolescents' temperament and character reflected cognitive maturity.

Adolescents who took the initiative to immediately be involved in taking care of their diabetes and who and then consistently advanced towards independence by taking on more responsibility over time, engaged in goal directed behavior. The following quote of a 15 year old female diagnosed at age 9 reflecting on why she initiated her transition process within a week after diagnosis illuminates this behavior and, in this case, the intrinsic factors that provoked it.

> I just always felt comfortable with doing everything myself 'cause I was like, 'Oh, well I'm gonna [sic] have to do it anyway and I was already that type of independent person where it's like I can get things done myself. I guess just like anything else I just started trying to learn how to do it.

Based on parents' description of these adolescents' ways of being, I identified their goal directed behavior as reflecting their temperament traits of: optimism, self-

efficacy, persistence, self-control and determination. The mother of a 14 year old female who took on full responsibility for the caregiver role when she was diagnosed at age 8 describes her daughter in the following way.

> She does have a very positive attitude. She's a happy person. She just is determined to not let it get in her way. She's just determined to do everything she wants to do and diabetes is not going to tell her what she can do and can't do. And that was something she showed with her diabetes early on too.

One mother described how her 13 year old daughter's responsible nature and mature reliability led her to take responsibility for tasks early on that she was still performing well four years later. This adolescent's consistency fed her mother's confidence in and willingness to let her take increasing control over her diabetes care over the four years.

> She's just very responsible, really she's just a great kid, she really she is. I think because she's the kind of person that wants to please and wants it to be right and wants to do what's right; I think it makes it easier for her to manage her diabetes (laughs).

These examples imply that there is a connection between adolescents' temperament and their eagerness to take responsibility for taking care of their diabetes from the start. These early starters also seem to have a mature level of cognitive processing that sobered their eager desire for independence by coupling it with a confident willingness to first commit to properly learning how to perform their diabetes care tasks. This caused them to behaviorally follow through on their verbal push for independence by consistently and reliably performing the tasks they requested responsibility for. When parents observed

this combination of reliable and goal directed behavior and temperament traits, they felt encouraged that their adolescent was ready to handle diabetes care responsibilities. Thus, adolescents' behavior that reflected cognitive maturity and reliability facilitated parents' readiness to start and progress through the transition process.

Adolescent Characteristics that Inhibited the Transition Process. –

Characteristics that suggest inability to handle responsibility –

Some characteristics hindered the transition process because all parents interpreted them to be indicators that an adolescent was not able to handle taking on primary responsibility for diabetes care roles. Thus, when parents noticed them about their adolescent they were impelled to question their adolescents' readiness for the transition process, which caused parents to be concerned about the prudence of starting and progressing through the transition process. Based on the ways parents described them, all but one represent developmental stage influenced, psychosocial and cognitive ways of functioning. These fall within the realm of the oft idiosyncratic cognitive processing, emotions and behaviors that are byproducts of the characteristic psychosocial, hormonal and physical changes adolescents' experience. They caused adolescents to be inconsistent in performing the tasks they were responsible for and in adhering to their care regimen. The one that is a stable part of adolescents' personhood rather than a product of their adolescence changes is temperament. Temperament tendencies that caused adolescents to be extremely hesitant and cautious or be unconscientiously easy going challenged the transition process. They caused adolescents to be timid about or disinterested in taking on the care roles and thus inhibited the transition process. Following is a description of these transition challenging characteristics.

Adolescents' stage-specific development factors –

Adolescents cognitive functioning.

Some adolescent characteristics are obvious indicators of immature cognitive functioning, which, although is consistent with the adolescent stage's still developing brain and life skills set, is also an indicator of not being ready to handle increased responsibility for diabetes care. The cognitive and emotional maturity necessary to manage Type 1 diabetes does not immediately and automatically occur once a person reaches adolescence. Although for the average healthy functioning person it is evident by middle to late adolescence, there is no fixed age when it emerges or is fully accomplished. Instead, its onset and process of unfolding is unique to individual adolescents. In addition, a full dose of maturity is not bestowed in one fell swoop. It is developed and refined as an adolescent ages, learns from experiences, settles into their changing body and goes through a steadying of their hormone levels. Whether and at what age an adolescent achieved the level of cognitive maturity necessary to handle transitioning to independent responsibility for their diabetes care depended on their temperament, personality and how effectively supported they were by their family system. Until cognitive maturity occurred, some adolescents displayed certain ways of thinking, perceiving and behaving that caused them to be unreliable at consistently performing their tasks and adhering to their care protocol. Parents identified adolescents' inconsistent and improper adherence to their care regimen as causing them to question their adolescent's readiness for and to delay starting the transition.

Adolescents' Behavior

Inconsistent performance of care tasks

Based on parents' descriptions, adolescents' inconsistency was caused by one or more of the following stage-typical characteristics: laziness, perpetuated by both an under

developed sense of personal responsibility and an immature understanding of the danger of risk taking; and increased social activity and heightened self-consciousness, resulting from the new importance of spending time with and being accepted by peers. Following are examples of adolescents' displaying the characteristic of inconsistency in performing diabetes care tasks.

Inconsistency due to Laziness

Many parents found that regardless of their adolescents' adherence during childhood and their once professed interest in taking control of their diabetes, as they settled into adolescence they went through a phase in which they were lazy about properly adhering to their care regimen and protocol. A mother of a 15 year old male diagnosed at age 8 explained the complexity of managing diabetes when adolescence brings on the change of lack of commitment to consistent proper adherence.

> He had been pretty independent with it right away, but I was told since he was 5, that he would go backwards, you know take a step back and not be responsible or be I'd say self-dependent, and just may be lackadaisical about it. It started just this past year, for sure when he was14.

Another mother of a 14 year old male diagnosed at age 9 described how her son's initial interest in giving himself his insulin shots when he was first diagnosed quickly fizzled out, as it became a mundane part of his daily life.

> At first he wanted to do it, so he did give his shot at the hospital and for the first 3months or so. But then I think once the newness wore off he got tired of it. He

said I don't like doing it, my stomach tightens up or it tickles. He wanted us to do his arms.

Many parents believed that this adolescence emergent decline in commitment to consistently adhering reflected a stage related tendency to live in a poorly thought out way. This is corroborated by adolescents' accounts of their experiences and perspective about taking care of their diabetes. They reveal shallow understanding and thought processing that caused adolescents to undervalue being adherent to their regimen and underestimate the danger of inconsistently performing it. This mindset underlies adolescents' display of a fickle commitment to performing tasks, and lazy, slacking behavior.

In the following quote, this mother described her concern about her son's lack of motivation to regularly give himself his insulin shots. She also explained her theory that her son operated according to the adolescent mindset characteristics of a sense of invincibleness and an inability to grasp the grave implications of his actions.

> I guess I was worried that, you know, he wouldn't realize how serious this was for him, just because of his age and, even now, I don't think he realizes the complications that can come up. People tell him things but, unless you have those complications, I don't think kids take it seriously.

One mother of a 16 year old male provided the following description of and perspective about experiencing her son's challenging health outcomes that resulted from his lazy inconsistency in adhering to his treatment protocol. Like the aforementioned mother, this mother believed that her son's actions were a sign that he believed he was invincible.

> He's a little more lax {about taking his insulin on time}. That's frustrating for me, 'cause I want to get that A1C down 'cause, I worry about his future how it can affect him later. I don't think he quite grasps yet how it would affect him, 'cause I mean of course he's young and active. But he knows the complications are out there: all the things with your eyes or your kidneys and your amputations or any of that kind of stuff. But I just think he's still at that invincible stage.

A mother of a 14 year old female who had lobbied hard to get her mother to start the transition process described how, despite her daughter's fervent desire to be in control of her care regimen, once she emerged into middle adolescence, she was inconsistent in her performance of it.

> It's very difficult 'cause teenagers have their own mindset. They want to do what they want to do when they want to do it. I'm hoping she gets more of a handle on caring for her diabetes than she does right now because she struggles with taking care of it. It's more and more, she likes to do what she wants to do when she wants to. This started right before she turned 13. She just figured she was a teenager now, she was gonna have different boundaries and maybe I can do this and maybe I can do that. She wants to be a normal teenager: play on the computer, talk on the phone, be in her room and she still hasn't gotten a handle on the reality that diabetes is here to stay. Once in awhile she'll say, "I don't want to do this {take care of diabetes} anymore".

This example also highlights the role of adolescents' increased peer-focused socializing as an adolescence emergent hindrance to youth with Type 1 diabetes focus on and commitment to consistently adhering to their diabetes care regimen.

Adolescents' preoccupation with social factors.

Adolescents shift away from family and towards peer relationships as the main system they are interested in and influenced by was the sociobehavioral hindrance to the transition process by causing their inconsistency. Adolescents' preoccupation with being social led them to increase the time spent socializing with peers in person, or through electronic means. A busy social or extracurricular activity schedule caused them to forget to perform tasks and thus, inconsistently adhere to their regimens necessary schedule. A mother of a 15 year old male explained the complexity of managing diabetes in the midst of the challenges of adolescence.

> It's {managing diabetes} a 24/7, 365 job and thought process. Just when you think you've got it under control, then for him these years, puberty kicks in. Hormones, cell texting kick in. So he doesn't think to check his blood sugar.

Related to the increase in the importance and role of peers in adolescents' lives, adolescents desire to be accepted by and fit in with peers caused them to feel self consciousness about having to perform diabetes tasks around them. In an effort to prevent diabetes negatively affecting their peers' perception of them, some adolescents avoided doing tasks around them. Another mother described how after 3 years of properly managing her diabetes regimen since she was diagnosed, her 16 year old daughter had negative health consequences due to not wanting to be bogged or slowed down by taking care of her diabetes.

> This summer she kind of fell out of the pattern where she was supposed to keep writing down her numbers or keep on testing, things like that. I think it's an age thing. She's sixteen and she's got lots of friends. She wants to hang out with

everybody. She doesn't want her friends pegging or hindering her because she's got diabetes and she has to stop and test and she has to have her shot and things like that. I definitely think it will change with age.

When parents who based their decisions about starting the transition on their adolescent's functioning observed their adolescent displaying any or all of these characteristics they decided to delay the transition process. Uncertainty of their adolescent's ability to handle the responsibility of increased involvement in their diabetes care while going through these changes and displaying the resulting inconsistent ways of behaving and thinking, made these parents hesitant to start the transition process.

Adolescents' tendency to be inconsistent in adhering to their regimen may confound the positive influence of their competency and confidence on their health outcomes. This occurrence commonly reflected adolescent stage-specific hormonal changes and brain development related limitations in cognitive processing inducing their haphazard behaviors and choices. Some parents decided to start and progress through the transition process despite obvious indicators that their adolescent was not ready for increasing responsibility. One mother described how, despite her concerns about the consequences on her 15 year old son's health, she knew his stage and personality required her letting him learn the benefit of consistency and competency in his independence through natural consequences.

I'm nervous that he's going to just let it go to the way-side a little. I know deep down he wants to do the right things and he knows the right things about his body, he understands the consequences. I get nervous because I think he waits too long. I mean he's pushed it. He knows what his body will, and can't, will

allow him to do and what it won't allow him to do. I just I guess I get nervous as he goes into high school now, um, how he may just continue to push the limits to, "I'm having fun at the moment or I'm doing this activity or talking with a girl, so I'll skip going to check my blood so I know where I'm at. When's it going to kick in that I can confidently say, "He'll be just fine", I'm just not sure. I think it will take that frontal lobe connecting that's what the doctor says. I think he has to fail a few more times before it really hits him. Now, I hope to God failing doesn't mean we have to hospitalize him before it really hits him because we've been very lucky with that. I think we've been able to help him or surround him with enough people that he's been blessed enough to say, "I need to take care of myself, people care". So, I think it's just a little bit more time. He's someone when he wants something or some challenge is put in front of him, he will find a way to make it work. He will do it.

These examples of adolescents challenging characteristics highlight adolescents' competing desires to have independent control of their diabetes care and also to not be bogged down with responsibilities. The resulting feelings-driven inconsistency also attests to these adolescents' immature cognitive functioning. As challenging as it is for parents to experience, these ways of thinking and behaving reflect developmentally appropriate functioning. This stage typical way of being results in their displaying fickle dedication to acting in the responsible way that is required for them to take on primary responsibility for their diabetes care.

Parents Responsibility to Accurately Determine and Respond to their Adolescents Readiness

It is parents' responsibility to accommodate and reconcile this health compromising adolescent fickleness. It puts them in the unenviable position of struggling to balance fulfilling their oft competing responsibilities of being guardian of their adolescent's health and facilitators of their adolescent's growth towards competent independence, in preparation for their future healthy adulthood functioning. The former involves guaranteeing the successful implementation of the diabetes care plan, which requires parents to be involved to the degree that is necessary to ensure their adolescent's consistent and proper performance of the regimen. The later involves giving their adolescent increasing opportunities to practice independence and autonomy in caring for and making decisions about their diabetes care. One 16 year old adolescent eloquently described her perception of how and why adolescents can challenge their parents regarding caring for their diabetes. She also provides her opinion of how parents can best respond.

> "Teenagers are naturally rebellious against parents and the more you try to push yourselves on them, the more they are gonna want to start hiding things and stuff. It's like, if you punish them for not telling you their blood sugar or if you scold them every single time that they've gone high and they haven't known it or if you go low in the middle of the night and they are the ones who wake you up first before you wake up and then they're like "Well how come you didn't wake up or something." But, parents just need to make sure that they know that they can go to you for help and for consultation and stuff and to always be supportive. And if the child wants to start doing things on his own, let them do it. Maybe check up on them once in awhile but don't be like, I don't know, just start switching things over. If you've been doing things for them, start letting them do it or like if

they're the kind of kid who needs to wake up in the middle of the night to test, have them start waking up in the middle of the night to test themselves. Because they need to get into the habit of doing it in order to be independent. You know it's just, you need to teach them to get into the habit of taking care of their blood sugar, or testing regularly, taking insulin before you eat meals, counting carbs and eating healthy. Have them call the doctors about questions and just give them more and more responsibility, because they're going to need to deal with it sooner or later.

As this adolescent's suggestions to parents based on her experience of what she needed while transitioning reveal, balancing ensuring continued proper care performance and initiating a necessary change process are the challenging responsibilities of parents of adolescents with Type 1 diabetes. A mother of an almost 14 year old female diagnosed at age 8 and showing inconsistency when she turned 13 after pressuring her mother for responsibility at age 11 described the challenge of this situation.

Letting her go is the hardest part of watching her grow up with diabetes: Letting her go to be as independent as she wants to be. I'm not quite sure I want to let go of that responsibility of making sure that she's doing what she needs to be doing when she needs to be doing it. I'm still scared of that she's going to go back into her old ways and just want to do what she wants to do and not take care of her diabetes. She knows I'm worried about things 'cause, she knows what can happen if she doesn't take care of it. She'll get acid...she gets ketones, instantly, if she doesn't take her insulin. Soon as she eats, or soon after she gets done eating, I'll take a correction. If she misses her 24 hour insulin by 2 hours, her numbers are all messed up for at least 3 days. I'm always behind her, reminding her and she

feels like I'm not giving her the space that she needs to do it herself. But if I'm not there to remind her, she won't do it. It's kinda hard to explain to her because she's understanding more but she doesn't understand.

This parent's description of her experiences shows the challenges of parenting an adolescent in a way that protects their survival, nurtures their growth and accommodates their stage. There were instances in which parents ignored, dismissed, minimized the importance of or incorrectly interpreted a transition challenging characteristic. Their inaccurate assessment or faulty decision making resulted in negative consequences for the transition process. When parents dismissed these characteristics or decided to proceed with the transition process in spite of them, the transition process was plagued by missteps, setbacks, poor health, and parent-adolescent conflict. Thus, the transition process was marred by problems when parents did not recognize, properly interpret or give challenging adolescent characteristics the proper weight as indicators of their adolescent not being ready for the transition process.

When parents' who recognized and accepted their adolescents' inconsistency wanted to start the transition in spite of them, they considered ways to work around the characteristics that caused the inconsistency. Parents who continued effectively managing their adolescents' diabetes while initiating the transition process despite these challenges employed an approach that fulfilled their adolescents' physical and developmental needs. How well parents accomplish this has critical ramifications for their adolescents' immediate and life-long healthy functioning.

Parents Fitting their Approach (to Motivating their Adolescent to Start the Transition) to their Adolescent's Temperament

Following are examples of transition experiences in which parents used a good fitting approach to getting their easy-going or cautious/hesitant temperament adolescent to start their transition process. They came up with a fitting approach by matching their timing and pace of introducing new responsibilities and their methods of engaging with their adolescent to their adolescents' needs. To figure out a match, parents did the following: acknowledged their adolescents' transition process-challenging temperament; identified the best ways to get their adolescent to grow toward independence in spite of it; and then used that to inform their decision about when they should start the transition and about how to design a fitting approach to conducting the transition for their adolescent. This wise acknowledgement and consideration allowed parents to tailor their approach to their adolescents' temperament.

Adolescents' Temperament

One mother of a 16 year old son, diagnosed at age 8, was a late bloomer in getting involved in performing his health care tasks at age 14. His parents were pushed to encourage him to take on more responsibility by his healthcare team. When he had not taken on tasks by early adolescence, the team strongly encouraged his parents to follow a plan with set goal points for when he would take on tasks. Although they thought it unnecessary, the parents complied with the healthcare team's urgings and their son eventually assumed the primary caretaker and decision maker roles and quickly adapted to consistently performing them well.

> Even though he's not a little baby, you feel this responsibility to protect him and take care of him. He was probably in junior high [when he started getting involved with his diabetes care] and probably the first thing I remember him doing his own shots [which was] was a big deal. That was a long transition. I

don't know maybe a year. Just because we felt like we could take care of him. And we didn't understand why they [healthcare team] were pushing us to give him this independence and he didn't want it. But, we had a lot of respect for the team, and so we did it begrudgingly. [We felt] apprehensive. I don't say we were angry and we weren't confused, so just apprehensive. This is our little kid, you know. Why push him to know more then he really has to know. If he had wanted it, yeah, we probably would have felt different. I think if his personality was different maybe he would have been really eager to be more independent. I think it's part of the personality, where some kids would have just jumped at the responsibility.

Following is their son's perspective about his slow progression towards independent diabetes care.

I guess I never really thought about it. Because it's like I'd always had to wait for the nurse to come over. So, finally one day I just got tired of waiting and I did it. And then, it's just my parents were always there at home so it was never that waiting. So, I just, never saw any point. At first it was probably a little intimidating. But, now it's just like it's part of everyday life. Just something I do. I definitely think it gets easier because at first I never really understood it. Just sort of let them do everything. But, now I understand what's happening. I understand everything. I can take care of it. I'm not having to check in with them and have them sort of control everything. I need something I can get it. It's just like; I can take care of it.

Thus, a temperament-based slow to progress adolescent found that when allowed to progress at a pace that fit for him, he was able to eventually take on responsibility at a point in his development that fit him well.

One father of a 15 year old male diagnosed at age 10, described how his son's more relaxed nature was both a help and a hindrance to his adjustment to living with Type 1 diabetes. Their son's easy temperament served him well by allowing him to immediately accept diabetes and enjoy his childhood and adolescence despite the fact that having it made him different from his friends and that the care regimen often intruded on his busy social schedule. At the same time, his nature caused him to have a delayed and passive interest in progressing towards independent diabetes care. Following is the father's description of how he adjusted his approach to his son's temperament, in order to get him to start giving his shot and checking his blood sugar.

> The good thing about {son} is really, he's real easy-going and the bad thing about {son} is he's real easy-going. So as far as you know, you kind of have to be on him a little bit, to do what he needs to do. In the beginning we kind of did everything just to kind of make it a little easier for him. That didn't last too [long]. After a month or two, then you kind of get him starting to do some stuff. Well, you just, you're doing it so often, so eventually you just kind of, as far as checking goes, see that it is pretty easy for him to do after awhile so, you just get him to do it and remind him to do it and then, you get to the point you figure out how much he needs and get the shot ready for him to give himself.

One parent describes how she took a gently persistent approach to encouraging her daughter to take more responsibility for the primary caretaker and decision maker

roles. The parent based her approach on her daughter's cautious temperament which, in-spite of her mature cognitive functioning made her hesitant to move toward independence in taking care of her diabetes. The parent describes how she took her direction about when to start the transition from her daughter's cues.

> With being hesitant about giving her shots, I think she was just afraid that either she was gonna [sic] hurt herself, or she was gonna [sic] do it wrong or something. So we kept offering her the opportunity to do it but didn't force her. There are some things she's hesitant about and some things she doesn't question and just does.

As exemplified by the examples, the cautious and easy-going types of temperament characteristics caused adolescents to be inconsistent in performing and cautious about taking on tasks. This caused a delay in the start of their transition process. In order to start and effectively conduct their transitions, their parents had to tailor their motivational approach to accommodate these characteristics. The accommodating approaches involved: gently persisting in encouraging adolescents with the hesitant/cautious temperament; and monitoring and reminding adolescents with easy-going temperaments and inconsistent behavior. This resulted in the process not being indefinitely delayed or avoided, but instead being effectively conducted at a slow but steady pace as the parents moved their adolescents towards the goal. Tailoring approaches to accommodate temperament needs allowed parents to effect successful outcomes and prevent themselves and their adolescents from feeling discouraged by and have conflict about the process being stagnant. In chapter 7, I describe and discuss participants' experiences of parents' use of approaches that caused them to effectively or ineffectively conduct the transition process.

Parents' readiness for and resultant commitment to using an approach to starting the transition that was tailored to their adolescent's needs influenced how effectively they transferred their roles. The adolescents' whose parents effectively trained them to perform their regimen properly, also experienced better diabetes related care behavior and health outcomes during adolescence with increased chances for continuation of these outcomes during adulthood. I describe these outcomes in Chapter 7. To facilitate complete understanding of those results, it is necessary that I describe the other factor that contributes to parents' readiness to start the transition process, their own differentiation, which I do next in chapter 6.

Chapter 6

Results Part 3

Research Concept # 2 – Parent Readiness

Research Question # 3: How does ***parent differentiation of self inhibit or facilitate*** **the transition *process*?**

This chapter summarizes the relationship between parents' differentiation and their readiness for and approach to conducting the transition process. I describe how parents' differentiation influenced their readiness to start and progress through the transition process by coloring their perception of their adolescent's readiness. Parents' perception of their adolescent's readiness then determined how they conducted the transition process in terms of their decisions about when was the best time and what was the best approach to start and progress though transferring their diabetes care roles to their adolescent. This study is driven by grounded theory qualitative approach but in addition to interviews, I also employed questionnaires as a secondary source of information. Along with the interviews, the questionnaires addressed research question # 2 by measuring parents' differentiation and behavioral and emotional support of their adolescent's growth towards independently caring for their diabetes. The information they acquired provided supplemental data that I compared to the interview data to corroborate it. Thus, they provided a way of checking and balancing the interview data to increase the validity and reliability of the study's findings. The study acquired an even more substantive data base than if they were not included

As an introduction to the content of this chapter, 11 summarily presents this study's major findings about its topic by categorizing them as themes and subthemes and relating them to interview questions and questionnaires. For the rest of this chapter, the themes and subthemes serve as the organizing element for the presentation of more detailed descriptions of the data. When possible I present descriptions of themes accompanied by an illustrative quote and table.

Table 11

Organizational Guide for Themes for Chapter 6

Theory Driven	Theory Operationalized		Sections of Findings According to Themes	
Research Questions	Interview Questions	Collateral Measure	Major Themes	Subthemes
How does parent differentiation of self inhibit or facilitate the transition process?	**Question:** Tell me about the impact of diabetes on your life. **Question:** Tell me how you felt then and now about (your adolescent) taking more responsibility for you (their) diabetes care. **Question:** Tell me how you felt then and now about (your parent) taking less responsibility for your adolescent's (you) diabetes care.	1) Bowen Differentiation of Self Measure (DSR) 2 & 4) Diabetes-Specific Parental Support for Adolescents **Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy development.** 3). Helping for Health Inventory (HHI) - A measure of miscarried helping.	1) Parents' Differentiation	1a) Types 1b) Influence on Perception of Diabetes and of their Ability to Control it 1c) Influence on their Perception of Adolescents Need for Parent to be Involved 1d) Influence on Parents Readiness to Conduct Transition 1e) Influence on Parents Approach to Conducting Transition

Table 11 (cont'd)

	Question: Tell me about your (your parent's) involvement in transitioning (your adolescent) to caring for your (their) diabetes. **Probe:** What was your role when it started? **Probe:** How did you come to play that role? **Probe:** Did your role change? - Why or why not? - When?			1e1) Support of Adolescents Autonomy 1e2) Miscarried Helping.

Parents Differentiation

Differentiation is an indicator of a person's ability to objectively manage anxiety. It reflects the extent to which a person allows their anxiety level to be determined or affected by another person or situation. A person's level of differentiation can range on a continuum from high, well to poor. Parents completed the Differentiation of Self Inventory for the purpose of determining their level of differentiation.

Types of differentiation.

A well differentiated parent independently manages any anxiety they may experience related to their adolescent's diabetes and negative health experiences. They do not allow themselves to avoid helping their adolescent care for or learn to independently manage their diabetes in order to avoid stress. Nor do they use their

control over their adolescent's diabetes to wallow in or handle emotional distress. Instead, they take charge of any anxiety they feel and resolve it using healthy self-reliant methods that do not involve manipulating their role in their adolescent's diabetes care.

A poorly differentiated parent does not manage their anxiety in healthy, self-reliant ways. Instead, they need and depend on emotional involvement or connectedness with others to manage their anxiety. Thus rather than directly confront and control any anxiety about their adolescent having diabetes, they use their caregiver relationship with their adolescent to attempt to manage it. They respond to diabetes related anxiety in one of two relationship threatening ways: avoid dealing with or consume them self with dealing with it. Poorly differentiated parents may avoid feeling anxious about their adolescent's anxiety by withdrawing from responsibility for it. They do this by giving up responsibility for any care roles to their adolescent, regardless of their adolescent's readiness for them. These parents then eschew responsibility for properly monitoring their adolescents' care of their diabetes. This causes them to be absent in their relationship with and abandon their responsibility to care for their adolescent. They neither take care of their adolescent, nor engage them in a transition process that would properly prepare them to be successfully independent. Thus, in some cases, poorly differentiated parents disconnect from their parenting healthcare responsibility in order to manage anxiety that comes from dealing with their adolescent's diabetes.

The other way poorly differentiated parents respond to anxiety about their adolescent's diabetes is to create or manipulate situations to cause the adolescent to need and thus stay connected with them through dependency. They hold on to controlling their adolescent's diabetes care to make their adolescent stay connected to them. The dependency relationship their adolescents have with them is based on their need to have

their diabetes cared for. These poorly differentiated parents are resistant to starting the transition process because they perceive it as taking away their control and connection. Because these are the ways they manage their anxiety, they find reasons to avoid or delay starting the transition. They use the distraction of being occupied with caring for their adolescents' diabetes to avoid and thus, by default manage their anxiety. Some adolescents go along with avoiding the transition because they believe they need to stay dependent on their parents in order to receive the care they need to stay alive. In cases when their adolescents do desire independence and feel capable of managing it well, they accept their parents' pressure to feel responsible to let them take care of them.

Negative Emotional Outcome of Parents' Poor Differentiation Caused Ill-fitting Approach.

Supported by this mom's careful oversight, the daughter has managed her diabetes well enough to maintain good metabolic control since she diagnosed at age 13. However, this daughter reported feeling exasperated by what she perceives as her mother paying excessive, anxiety-driven attention to her diabetes.

> My mom has become more extreme and my dad has become less extreme. It's like just from my mom's nerves all the time she's always stressed out and she's always trying to do more than she needs to. Like after the first year she just had this like stressful feeling about her. And it's become more instead of like "How is your day?" it's like "How is your blood sugar?" I think it comes out of worry and concern or something. She's kind of like, always going to the extreme being like, "What if I didn't check your blood sugar level when you are sleeping and you died, what would that be like?" And I'd be like, "Well I don't know, I'd be dead."

(Laughs). Whenever I go low she made this rule that I have to tell her. And like if I don't then she's like "Oh my God she's not going to tell me the next time and then she's going to go even lower and die." I don't know, she's just like the type of person who comes up with like situations like, "What if's?" and then she starts thinking about those all the time. I kind of like compromise with her. I think that's more of the way that it is. Like she checks up on me all the time and otherwise, I'm the one like checking my blood sugars. And I have to check in with her before I drive anywhere and like tell her like what my blood sugar is because it's just another rule that she made up (laughs). Um, I kind of like compromise with her. I think that's more of the way that it is. Like she checks up on me all the time and otherwise, I'm the one like checking my blood sugars. I think what she's doing like it's more extreme here than what I would have normally done it.

However, they act out it out poorly differentiated parents depend on their adolescents to manage their own anxiety about their adolescents' diabetes. These parents passively or aggressively manipulate their adolescents into dependency relationships so they extract relief from clinging to or avoiding their emotional connectedness.

Influence on perceptions of Type 1 diabetes and their control over it.

In this study, parents' level of differentiation, that is the extent of their ability and tendency to manage their anxiety in emotionally healthy, self reliant ways, was associated with: the intensity of their fear about and sense of being personally responsible for their adolescent's health outcomes; and their resultant need to control their adolescent's diabetes care. The following Table 12 illustrates the mindset of parents who had

different levels of differentiation by presenting parents differentiation score with a quote of their feelings about the impact of their adolescent having Type 1 diabetes on their lives.

Table 12

Comparison of Parents' Differentiation Scores and Descriptions of the Impact of Diabetes on their Lives

Highest Differentiation = 5.5	• It hasn't had a huge impact. Other than lack of sleep occasionally because you're concerned about if he's low or something.
High Differentiation – 5.2	• It's getting easier the older he gets and that he's taking more responsibility.
High Differentiation – 4.8	• It's become such a part of our lives, I mean I don't know what it would be like without it.
High Differentiation = 4.7	• It's there but so be it. It's not the worst thing that could happen to her. • It is what it is and you can't change it and so you take it for what it is and move on. We've just adapted.
Moderate Differentiation = 4.3	• Day to day it's fine as long as you have the tools that you need to work with then it works out o.k. You get into the routine. In the short-term, it's pretty manageable. We're lucky enough to have the resources that you get all the stuff we need to do it.
Moderate Differentiation = 4.2	You get used to living with it.
Moderate Differentiation = 4.0	• It kind of becomes a day-to-day lifestyle. Sometimes everything's going good you don't think that much of it, and then when things kind of happen.
Low Differentiation = 3.7	• It has been a constant concern, throughout the last 16 years. • Keeping track of everything, it's a lot on my plate
Lowest Differentiation = 3.4	• It changes as you roll with and get kind of used to it and as he changes too from being a 10 year old to a 15 year old things change.

The table shows that parents with high differentiation used words to describe the impact of diabetes that reflect more self-efficacy about taking care of diabetes and better acceptance of and adjustment to their child having diabetes than parents with low differentiation.

More than well differentiated parents, poorly differentiated parents reported experiencing anxiety about their adolescent having Type 1 diabetes and about the possible resulting negative health and life outcomes their adolescent may experience. In the interviews, compared to parents who were well differentiated parents who were poorly differentiated negatively expressed more feelings of anxiety about their adolescent being diagnosed with diabetes, and their ability to adhere to and properly perform the regimen. A poorly differentiated mother describes her anxiety about her 15 year old son's performance of the caretaker role for his diabetes care.

> I usually don't sleep. I go in and check on him, when he doesn't realize it. Um, but, I'm also letting him know that there's times now, especially as he gets ready for driving, as he gets beyond and he talks about going to college. These are the additional anxiety things that I have saying: Is he going to get it now so that he doesn't forget about it when there's nobody hovering, nobody watching, nobody reminding?

In keeping with Bowen's theory of differentiation of the self, poorly differentiated parents did not manage their anxiety well. This is evidenced by their adolescents' reports of observing and being negatively affected by these parents' anxiety. Their adolescents also described these parents as being over involved with their diabetes care in a smothering or obsessive way, which also provides evidence of their being poorly

differentiated. Compared with well differentiated parents, poorly differentiated parents expressed greater feelings of personal responsibility for their adolescent's health outcomes. They described experiences and expressed feelings that reflect a belief that their parenting actions were the locus of control for their adolescent's diabetes outcomes. Thus, they personally owned and emotionally felt the weight of the onus of responsibility for their adolescent's well-being and survival.

One such parent, a mother of a 16 year old male who had been performing most of his diabetes tasks, since he was diagnosed 4 years prior described her sense of feeling ultimately responsible for the consequences her son experienced due to demonstrating the adolescent stage-specific tendency to not optimally adhere to the care protocol.

> We just struggle with the more of, he'll eat, and then he doesn't give his insulin right away, so then his A1C's aren't right where we want them to be. I feel I'm still responsible for that 'cause then I'm the one who's trying to explain his blood sugars to the doctor.

Influence on parents' perception of their adolescents' need for their involvement and therefore adolescents' readiness to start transition

Consistent with prevailing findings of previous research that there is a relationship between lack of parental involvement and adolescents' poor metabolic control, parents believed that ensuring their adolescent's optimal diabetes control required their continued engagement in caretaking and decision-making. They also agreed that their involvement was required to help move their adolescent to the next developmental level of adopting these roles from them. Parents' determination of their adolescent's readiness for being taught and given opportunities to practice the roles is the

preliminary step to actually starting the transition process. In order to determine an adolescent's readiness to take on increasing responsibility in preparation for independent control, the following aspects of their cognitive and behavioral functioning should be evaluated as they are considered indicators of the maturity that reflects readiness: capability to physically perform tasks; cognitive capacity to make care decisions; and desire for and ability to consistently and reliably handle perform the regimen

This study found that while parents' assessment of their adolescent's readiness indicating characteristics informed their perception of their adolescents' readiness for the transition process, parents' differentiation also influenced it. Parent's description of their decision-making process revealed that, whether they were consciously aware of it at the time or not, differentiation was the factor besides their adolescent's needs indicators that prominently weighed in their assessment of how much continued help their adolescent needed from them. Thus, parents' differentiation influenced their decision about when it was appropriate to start the transition.

In contrast to well differentiated parents, poorly differentiated parents need for connectedness to manage their anxiety about possible negative outcomes of their adolescent's diabetes care performance clouded the clarity of their perception of their adolescent's developmental needs and capability. This tainted the accuracy of their assessment of their adolescent's readiness. In some cases, regardless of whether adolescents displayed pro or con indicators of readiness, parents' differentiation superseded the influence of this evidence on parents' decision making about starting the transition. These parents own readiness to transfer their role as primary responsibility-holder for their adolescents' diabetes management and care influenced their determination of the specific type and amount of involvement they believed their

adolescent needed from them. The result was that these parents' differentiation was the primary influence on and determinant of the approach they employed to engage with their adolescent regarding caring for their diabetes as well as their approach to conducting the transition.

Parents' level of differentiation seemed to be related to their philosophy about the necessary approach to parenting an adolescent with Type 1 diabetes and guiding them through the transition process.

The following Table 13 presents some of the parenting philosophies of parents with high differentiation. I present their parenting philosophies as an indication of parents' perspective about how they approach raising their kids to deal with and adjust to life in spite of a stressor like diabetes. Thus, their philosophy reveals the foundation of what they teach and model for their kids about managing diabetes. Pairing parents' differentiation score with their philosophy informs us of what parents' internal anxiety managing and coping capability level is that also guides their parenting behavior when engaging in the transition.

Table 13

Comparison of Parents Philosophy about How to Effectively Parent a Child with Type 1 diabetes and Parents Differentiation

Philosophy Quote	**Differentiation**
• I think right from the start we knew that it's a life-long thing and that he just needed to incorporate it in his life. We just kind of pushed that way from the beginning. I think it's really important to start younger making them responsible and understanding it. So that the parent can let go a little bit and let the kids be responsible and have a fairly normal life. • I know that's not easy for every kid, but let them start right from the beginning managing themselves or at least understanding why they're doing things. Because if they know why then they'd be more likely to make corrections the right way.	5.5/6

Table 13 (cont'd)

• I know it's got to be her deal and me trying to make her do it my way, will only make her want to not do it at all so, that's not going to be the best thing. • I'm constantly needing to adapt to that [letting her take on responsibility]. If I'm constantly doing for her, then she can't learn to do it for herself. • It's always been my attitude that the growth that your children experience, you have to make room for it. And actually if you make room a little ahead of time, then the growth happens a little more naturally. And if I look at it as progress for them, then it's not as sad for me to lose these things. I always look at it as a positive event. That's my parenting philosophy so it works into how we deal with her diabetes. It makes it easier for both of us to adjust.	5.2/6
• I want her to have a healthy life as an adult as well and I just hope and pray always that it, [having Type 1 diabetes] doesn't hurt her physically in any way. I just want her to have a healthy adult life, when she's not here [living with parents] anymore. I want desperately for her to have the use of every limb and just be healthy.	4.8/6
• My philosophy is: if I'm not with her and something happens, she needs to be able to take care of herself. I'm a firm believer in, yeah, she needs to be a child but, she needs to know how to take care of herself.	4.7/6
• Be patient and never give up. It's your job as a parent to be the expert. So, don't think it's not your responsibility. Draw on your resources and find out. You need to read. You need to go to things. You need to learn about the different growth and developmental stages adolescents go through and how diabetes impacts that. You need to know. • Never do for them what they can do themselves. Take a time and step back a little and be busy, so they have to do some of their own self-care. When they have times that they're coping really well with things, and you're not having to struggle and try with things, always give a little bit more responsibility to them. Just step away from that responsibility in periodic things. And then kind of evaluate how your child is doing and then just step away more. It's just kind of been a really natural progression [doing this with her daughter].	4.6/6
• The more that they can learn along the way, so that when they're wanting that independence, you're ready to give it to them and you feel good about that they can do that. I think that's for us has been really helpful and good. Whatever they're capable for their age and personality.	4.6/6
• She'll tell you that I've been a police mother sometimes and that's just how it goes. I feel ultimately responsible for her health. I always tell her, "I'm in charge of your organs being in good shape, so that one day when you want to have babies, you can have babies. So, you can be angry with me if you want.	4.6/6

Table 13 Continued

• I guess I've always been one of them determined people that's always trying to make sure we're doing what we're supposed to be doing, the right thing. I'm trying to help keep them educated and understanding why they're doing what they're doing. And not just because I'm trying to be the nag (laughs) or the mom that's always on their case.	4.0/6
• My kids have always come first.	3.7/6

Parents' philosophy incorporates and reveals their: efficacy regarding controlling their adolescent's diabetes; perception of their adolescents' diabetes care efficacy and; belief about the necessity of the transition and how they should conduct it. I propose that parents' philosophy articulates their beliefs, which direct their choices that then guide their behavior. Regarding their adolescent's diabetes care, their behavior is exemplified by the approach they employed to carry out their main functions in the process.

Relationship between Parents' Differentiation and their Approach to Guiding the Transition Process.

An approach consists of: the strategy a parent uses to conduct the gradual transfer of responsibility for the diabetes care roles to their adolescent; and the pace of progressing through this process. Parents' approach was illustrated by the way the engaged with their adolescent to conduct the transition process. Parents' results on the Helping for Health (HHI) and parents and their adolescents' results for the Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS) show that there were different ways parents engaged with their adolescent that reflected their differentiation. The approaches differed in terms of the extent to which they were helpful and supportive of adolescents' diabetes specific autonomy or not. In this study, parents'

support of their adolescent's autonomy is an indicator of the encouragement and support they give their adolescent to become independent in caring for their diabetes.

Each approach is associated with a certain level of differentiation. Comparisons of parents HHI, parents and adolescents versions of the DPSAAS and parents Differentiation of Self (DSR) assessments results, revealed a relationship between parents' level of differentiation and the helpfulness of their healthcare directed behavior and their support for their adolescent's diabetes care specific autonomy. Figure 3 below presents a conceptual map of this proposed relationship between parents' differentiation related belief about and approach to the transition process.

Figure 3. Conceptual Map of Relationship Between Parents Differentiation and Parents Approach to Engaging in Transition

Miscarried Helping as Part of Parents Differentiation Influenced Approach

The Helping for Health Inventory (HHI) assesses parents' tendency to engage in miscarried helping. Miscarried helping means providing help to one's adolescent regarding their health care in ways or amounts that they do not solicit, consider necessary or helpful. In this study, we proposed that a parent's emotion management reflective characteristic of level of differentiation would be displayed by their acting out the health-related, helping behavior of miscarried helping. Comparison of the Differentiation of Self and Health for Helping (HHI) Inventories indicated a relationship between parents' level of differentiation and their miscarried helping behavior. The results of the questionnaires supported this study's hypothesis that poorly differentiated parents engage in more miscarried helping than highly differentiated parents do. Data from the HHI corroborate the descriptions of adolescents' of poorly differentiated parents that their parents engaged in unsolicited and unwanted over-involvement in their diabetes care. Following is a quote from a parent who was poorly differentiated and engaged in miscarried helping to ease her anxiety about diabetes overcoming her daughter if she the parent was not hyper-vigilant in monitoring her 16 year old daughter's care, since she was diagnosed at age 13.

> For me it felt like I had a 2 year old again. I mean from 'cause her mood changes and my keeping on it as far as the tracking it. Every night at bedtime when she'd take her Lantus shot we'd decide again if we had to change her medication. At first they would answer my calls right away and they'd help me change it. And then they'd answer it less and less frequently and pretty soon it'd be 48 hours and they wouldn't call me back. So we started making our own decisions about changing the medication levels. So, what we started out was she tests you know 6

to 10 times a day depending on her activity level and how it's going and then every night before bed I check in with her about stuff. And then I also make sure that she's had protein food during the day, stuff like that. I still feel like I'm saving her life you know, a lot. I'm her guardian angel.

The following Tables 14 and 15 present a comparison of parents' differentiation scores and the fit of their approach.

Table 14

Comparisons of Approaches and Miscarried Helping Scores of Parents with Highest Differentiation Scores

Differentiation and HIH #	**Parent's Current Form of Caregiver Role**	**Fit of Parent's Approach**	**Adolescent's Descriptors**	**Age of Participation Diagnosis and Task Performance**
Differentiation = 5.5/6 HIH = 2.06/5	Supervisor Manager	Fits with adolescent Parent pays attention to child's uniqueness and cues of readiness for increased responsibility. Parent strongly believes in and encourages adolescent's growth towards autonomy.	Male Healthy Optimistic Ready to Try tasks	Participated in study at age 13 Diagnosed at age 9 Started tasks at age 9
Differentiation = 5.3/6 HIH= 2.4/5	Supervisor Manager	Fits with adolescent's interest in technology and encourages adolescent's practicing autonomy. Parent uses text messaging to check on adolescent during daytime. Parent has meetings with adolescent where they make collaborative decisions.	Male Healthy Happy and Self Assured	Participated in study at age 14 Diagnosed at age 4 Started tasks at 8-9

Table 14 (cont'd)

Differentiation = 5.2/6 HIH = 2.66/5	CEO-Consultant	Approach is not a good fit for adolescent's stage of maturity or level of competency: Adolescent was given too much responsibility before he was capable to handle it. Approach is reactive and situation-centered.	Male Presents as quiet, inquisitive and confident. Adolescent is physically sick (has had ketoacidosis many times). Was given too much responsibility too soon, subsequently, was hospitalized a lot.	Participated in study at age 14 Diagnosed at age 9 Started tasks at age 9
Differentiation = 5.2/6 HIH = 2.5/5	Manager to CEO	Fits with adolescent's needs and way of being. Parent pays attention to and parents according to adolescent's developmental changes, temperament and personality.	Female Polite, respectful and confident. Artistic (goes to dramatic arts high school). Can be absent minded and improving in forgetfulness.	Participated in study at age 16 Diagnosed at age 7 Started tasks at age 7
Differentiation = 5/6 HIH = 2/5	Boss	Poor fit for promoting adolescent's healthy growth and development. Parent coddled adolescent based on own needs to be involved and adolescent's timidity. Parent is frustrated. Ready for child to grow up, but still accommodating adolescent's dependency requests. Admits having created and assuaged adolescent's dependency. Now feels irritated and stifled by adolescent's dependency	Female Emotionally dependent and developmental responsibility delayed. Acknowledges and laughs about being coddled by parent. Acts sarcastic but may have low self-efficacy and fear of independence.	Participated in study at age 16 Diagnosed at age 11 Started tasks at age 11

Table 14 (Cont'd)

Differentiation = 4.9/6 HIH = 3.13/5 **HIGHEST Most frustrated child	Boss	Original approach did not fit adolescent's developmental capability. Current approach was mandated by physician and fits adolescent's developmental needs and keeps her healthy. Parent is ready to allow child independence but tried it and child got sick, so had to take over care again. Parent made child mad, but child is now doing tasks with heavy parent involvement	Female Experienced consistent poor diabetes health. Emotionally sad (sees therapist) and fragile. Frustrated by need to have parent involved. Doesn't feel believed in or understood by parent and medical team. Has body image issues. Wants what she can't handle and doesn't understand that.	Participated in study at age 13 Diagnosed at age 8 Started tasks at age 10

Table 15

Comparison of Approaches and Miscarried Helping Scores of Parents with Lowest* Differentiation

Transition Experience	**Differentia-tion and HIH #**	**Parent's Current Form of Caregiver Role**	**Fit of Parent's Approach**	**Adolescent's Descriptors**	**Age of Participation Diagnosis and Task Performance**
Stressful health transition	Differentiation = 3.7/6 HIH = 1.73/5	CEO Consultant	Poor Fit – Situation and child driven. Adolescent is not responsible and can't cognitively see that – invincible behavior effects health. Needs more input and monitoring BUT is strong-willed..	Female Fair health. Confident, independent and strong-willed. Goes away to her father's when mother challenges her. Not aware of danger of poor adherence.	Participated in study at age 16 Diagnosed at age 13 Started tasks at age 13.

Table 15 (cont'd)

Enmeshed with independent child Parent stressed and stresses child but too scared to give up.	Differentiation = 3.5/6 HIH = 2.8/5	Supervisor Manager	Poor Fit – overzealous mom. Too much insistence on direct monitoring and performance of care tasks. Ease (child's mental health is effected) Parent anxiety driven. Covert checks of blood sugar logs when child is sleeping; rarely leaves daughter; phone check-ins when daughter is away from her. Allows daughter to be active and social.	Female Good Health Confident, self-assured, active, funny; frustrated with mom's over-worrying – saw therapist.	Participated in study at age 16 Diagnosed at age 12 Started tasks at age 12
Lowest Differentiation	Differentiation = 3.4/6 HIH = 2.8/5	Supervisor	Good fit for adolescent's age. Soft reminders; Covert checks of blood sugar logs when adolescent is sleeping. Lot of masked (from child) worrying.	Male Good Health Gentile, respectful, articulate; a people pleaser	Participated in study at age 14 Diagnosed at age 5 Started tasks at age 6

Note. Differentiation #'s below 4: Range 3.7-3.4 from most to least

Parents Differentiation's Influence on their Approach to Starting Transition

Well differentiated parents' readiness to initiate and progress through the transition process was largely influenced by their: perception of their adolescents' desire,

need and capability to successfully handle independence in performing and managing the regimen. Parents who were well differentiated reported they were driven to start the transition process by a desire to equip their child with the skills, competence and comfortableness with performing and making decisions about their regimen so that parents ensured that their child had the wherewithal to take independent care of themselves if and when it was necessary. The following quote is from a mother of a 14 year old male diagnosed at age 9.

> I think right from the start we knew that it's a life-long thing and that he just needed to incorporate it in his life. And we just kind of pushed that way from the beginning. I think it's really important to start younger making them responsible and understanding so that the parent can let go a little bit and let the kids you know be responsible, have a fairly normal life.

This mother and her son reported that he responded well to her having employed a "start them early" approach and was currently effectively performing the primary caregiver role at age 14. Another mother of a 13 year old female diagnosed at age 8 also promoted using a "start them early" approach to ensuring that youth with Type 1 diabetes consistently progress at a developmentally appropriate pace towards independent responsibility for their diabetes care.

> I know it's not easy for every kid, but let them start right from the beginning managing themselves or at least understanding why they're doing things, 'cause if they know why then they'd be more likely to make corrections the right way.

These parents' words reveal that they espouse and have based their approach to engaging in the transition process on parenting philosophies that emphasize the

importance of children's early involvement in taking care of their Type 1 diabetes for their achieving the transition goal during adolescence. For these parents, the best transition and most efficient experiences with the most effective outcomes occurred when their adolescents also desired to and were capable of starting or progressing to new levels of responsibility throughout the transition process. A mother of a 14 year old female diagnosed at age 5 explained how she started getting her adolescent to do tasks at a very young age and why.

> You know, we started encouraging her to start doing tasks right off the bat. The first 4 or 5 months was really hard for her at age 6. It still is hard for her at times but, you know just, "Here, do you want to test to make it a little easier, you test". So it just progressively happened. It's her body, it's her life and she needs to know how to guide it.

These well differentiated parents description of how they guided the process indicates that they accommodated the way they communicated their own motivation to their adolescent's indicators of readiness. Another mother of a 14 year old female diagnosed and performing her first task at age 9 described how she and her husband took charge of moving their cautious child past her hesitancy to get involved in performing her diabetes care tasks by making it nonnegotiable.

> I think just from the beginning we said, "You will do this. This is your responsibility." It wasn't a negotiation or anything. "If you're gonna [sic] go back to school, you need to do this."

Parent's Differentiation Influenced Approach's Influence on Progression of Transition

Parents' perception of their adolescent's readiness also determined the way the transition process started and the way and pace at which it progressed. Throughout the transition, well differentiated parents determined how involved they would be in managing and caring for their adolescent's diabetes, based on assessing their adolescents need for direct care, assistance and guidance in order to control their diabetes and stay healthy. Subsequently, well differentiated parents based their decisions about conducting the transition process (including when to start it and what approach and pace to take) on their adolescents needs rather than on an anxiety-driven need for controlling their adolescents' diabetes care.

Well differentiated parents did not start transferring the decision maker and healthcare systems manager roles until after the adolescent showed competency and consistency in performing the caregiver role. To move the transition process along towards the end goal of adolescents' independent self care, well differentiated parents guided the transfer of roles to occur in a way that fit the needs and capabilities of their adolescent. In order for their adolescent to take more control over their diabetes, well differentiated parents also gradually gave up their responsibilities to their adolescents so they could eventually shed the roles for their adolescents to occupy them. When assessing their need to move into roles that had decreasing amounts of control and responsibility in order to bring about and accommodate their adolescent taking on roles with greater amounts of responsibility, these parents verified their adolescent's readiness for the new level of responsibility the role involved. Determining this required observation and assessment of the following characteristics about their adolescent: developmental-stage influenced emotional and cognitive functioning, dependability, cognitive diabetes-specific competency and decision-making ability.

Table 16 below presents well differentiated parents descriptions of how they progressed through these forms of the primary caregiver role to move out of it as their adolescent moved into it.

Table 16

Parent Quotes About How to Transition Adolescents into Primary Caregiver Role

Parent's Role Changes From Task Performer to Monitor – **Progression of change in parent's role from starting with doing care tasks, to monitoring adolescent doing tasks by hovering and giving verbal commentary, to stepping back and visually monitoring.** So, it was probably by the time he was 10 if not sooner that he didn't want us do the site change. He refuses to let the adult do it because he wants the control of when it's coming into him. So it was already when he was I'd say 9 or 10 that he kind of said, "I want to do this." For several years he has actually done all the tasks. We do kind of the hover over him and make sure, "Did you go change out, did you check your blood? How do you feel?", probably, every day. We may not do it all day, like we've done in the past. It's more that we are just watching from a distance but maybe not saying anything out loud. Kind of making sure he is still doing what we need him to do or what he should be doing. Occasionally if he sits down and he starts eating, we may still need to say, "I didn't see you check your blood." But I think what changed is that he kind of got that attitude, pushed back like, "I know, I know, I got it, I got it." We noticed that and we decided to sort of step back and just do more, you know, visual observation than verbal.
Parent as Supervisor – Parent plays Supervisor role due to being afraid that adolescent will return to poor management and have ketoacidosis again Letting her go. Letting her go to be as independent as she wants to be; I'm still scared of that she's going to go back into her old ways and just want to do what she wants to do and not take care of her diabetes. I'm not quite sure I want to let go of that responsibility of making sure that she's doing it when she needs to be doing it. I ask her every day, and it drives her crazy. "Yes mom, I did it. I took my shot, I took the correction. Alright, I'm just askin' [sic]. And the next day I'll ask her "How are your blood sugars today? Did you do this, did you do that?" "Yes, mom, I did that," And it drives her crazy. I don't take over her shots anymore. I let her do those because she still, she's not testing, and she needs to do her shots by herself and I don't want to take that independence away from her. So I do every hour, I'll if I'm at work, I'll call her or if she's at school I'll call school "um, she's had trouble for the past couple days, can you have her check her blood a little bit more today to make sure her numbers are good?" So it's more of a checking and then double checking and then triple checking if she's done it.
Parent's Role Changes from Supervisor to Overseer -Trust in adolescent helped mom move past hovering to being an Overseer It was probably harder for me than it was for him, letting go, and not nagging him. There was a time when I'd be right watching over him, making sure he was doing everything right and now I know I can trust him.
Overseer – Dad can perform Overseer role because adolescent performs Cargiver Role well. I oversee the, I am the scheduler of appointments. I download her pump onto the Care link and print that off for the doctor. I'm in charge of learning new things, investigating things, insurance, ordering, that kind of thing, and she does um, she takes care of checking her sugar, eating when she needs to eat, taking her insulin.

Table 16 (cont'd)

Healthcare Systems Manager - Mom makes projections about her tenure as Healthcare Manager.
I see myself ordering her supplies and such through college (laughs). You know, I probably will do whatever I can do to help her because, the daily grind of all you have to keep up with is just exhausting. And sometimes I know that she just hates doing what she already has to do. So, if I can, I do anything that would help her.

When parents' perception was colored by their own emotional need for connectedness to soothe their anxiety, adolescent's experience of the transition and achievement of the goal of independence was subject to their parents' differentiation influenced readiness for and approach to starting and progressing through the transition process. Poorly differentiated parents involvement in their adolescents' diabetes care and their readiness to transition out of responsibility for it was driven by their fear of the consequences of their adolescent's performance of diabetes tasks. They felt comforted by being performing or directly overseeing their adolescent's performance of care tasks. The more heavily involved they were the less prone they were to worrying about the possible negative outcomes of diabetes for their adolescent, especially when they were in control of all aspects of the diabetes care. Thus, their poor differentiation caused them to hang onto their roles as primary caregiver, decision maker and systems manager or when pressured to start the transition, engage in a more intense and involved forms of being the monitor, supervisor and overseer to their adolescents. Poorly differentiated parents had transition experiences that were more difficult and that progressed more slowly than were well differentiated parents. The way parents expressed their anxiety affected the efficiency of the process by stalling the start and slowing the pace of the transition process. This prevented the transition from progressing efficiently as is considered by their health professionals' expectations of what is developmentally appropriate progress for adolescents' movement towards independent self care.

This chapter presented the relationship between parents' differentiation and their readiness to conduct the transition process. I also discussed the relationship between adolescents' readiness and parents' differentiation and its influence on parents' decision making about and approach to conducting the transition. I also presented a conceptualization of the way parents' differentiation determined the fit of their approach. Lastly, in chapter 7, I relate all of the results sections together to discuss the relationship between the fit of parents' differentiation influenced approach and adolescents' transition experiences and outcomes. Chapter 7 is an extension of this chapter because, I describe how parents' differentiation influenced readiness determined the adolescent specific and developmentally appropriate fit of their approach to and pace of the transition process. This in turn influenced parents and adolescents perception of the ease of their experience; and parent's effectiveness in training adolescents to assume the primary caregiver, decision maker and manager roles.

Chapter 7

Results Part 4

Outcome of Adolescent and Differentiation Influenced Approaches Parents Used

This chapter concludes the results section because it summarily pulls together all of this study's findings presented in the previous 3 results chapters and shows how they connect to explain parents role in influencing adolescents experience and outcome. I describe how parents' approaches to engaging their adolescent in the transition process contributed to how both parents and adolescents characterized their transition process in terms of the following: what the experience has been like and how has it effected in their emotional well being and relationship; and how it has progressed adolescents towards being independently responsible for their diabetes care. The following Table 17 describes the findings according to themes and subthemes and shows how they connect to research questions, by interview questions and questionnaires.

Table 17

Organizational Guide for Themes for Chapter 7

Theory Driven	Theory Operationalized		Sections of Findings according to Themes		
Research Questions	Interview Questions for Adolescents and Parents	Questionnaire	Major Themes	Sub-Themes	Relation-ship to other Major Themes*
How do parents and adolescents experience it?	**Question:** Describe how it felt to experience the transfer of roles and responsibility. **Probe:** Before it started, how did you feel about it occurring?	1. Diabetes-Specific Parental Support for Adolescents Autonomy Scale (DPSAAS)			

Table 17 Continued

	Probe: How did you feel when it started? **Probe:** How did you feel about its progression? - As it has progressed, did you like and feel comfortable with the process, pace and ease of it? **Probe:** How do you feel about its outcome so far? **Question:** Tell me about what you do to take care of diabetes. **Question:** When will the transition be complete? **Probe:** What will indicate that? **Probe:** When do you think that will occur? **Probe:** What do you think you can you do to make it occur?	2. Helping for Health Inventory (HIH) - a measure of miscarried helping.	1. Match of Parents' Approach to Adolescents Needs 2. Outcomes of Approaches	2a. Ease of Experience Relational and Individual Distress 2a. Effective-ness of Experience 2b. Efficiency of Experience	Miscarried Helping

Participants' answers to interview questions and questionnaires provide data showing that both parents and adolescents perception of the ease of their transition experience vary according to how its start and pace fit their readiness for the process and the fit of parents approach to engaging their adolescent in inversing their diabetes care roles. Thus, the ease and efficiency with which adolescents evolve to transition from parent-dependent to independent responsibility for their diabetes care is influenced by parents' differentiation influenced readiness and assessment of and response to their adolescent's readiness. Below Figure 4 presents a conceptual map of this.

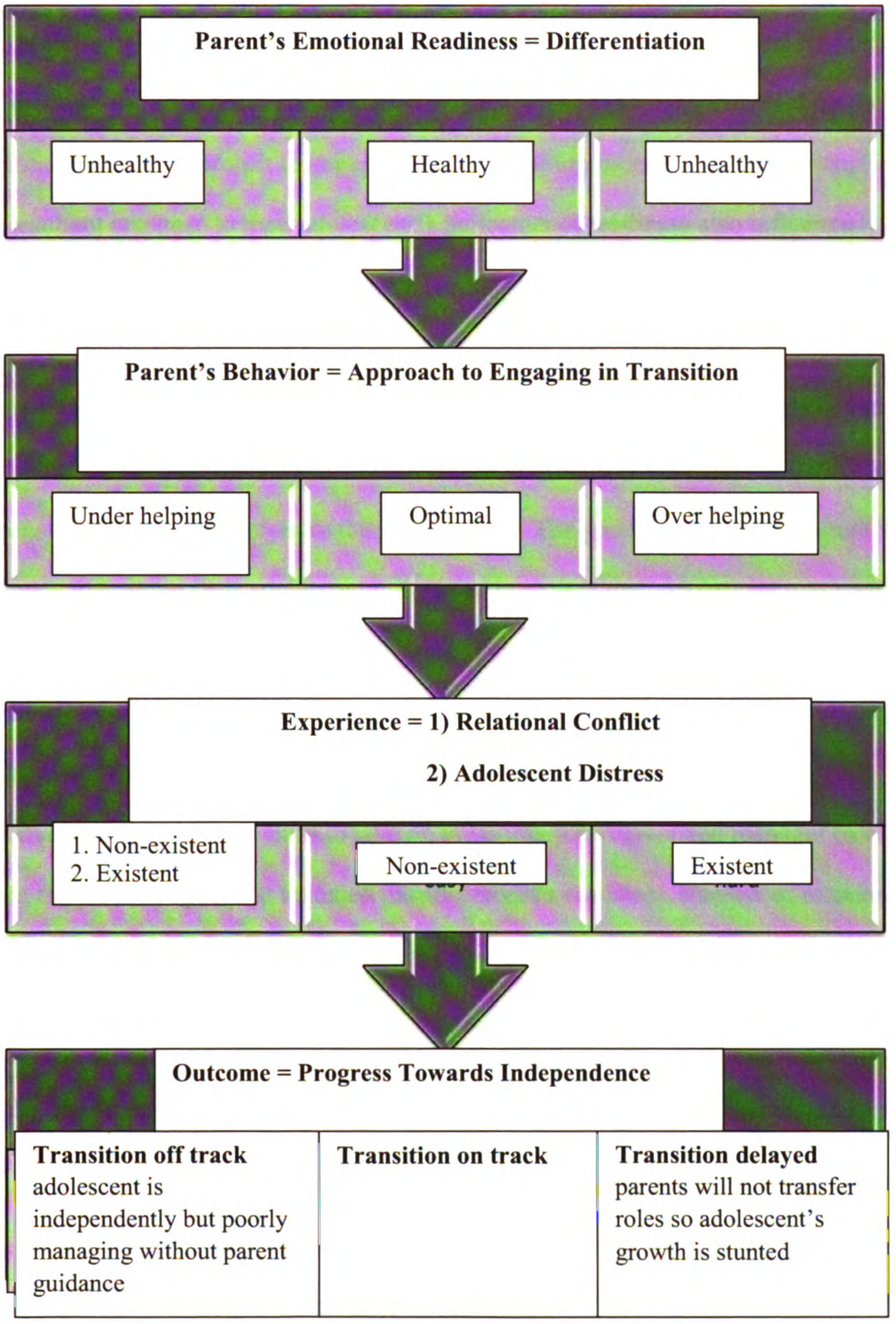

Figure 4. Conceptual Map of Relationship between Parents Differentiation and Transition

Experiences

Parents' differentiation influenced readiness and perception of their adolescent's readiness for the adolescent's move toward independence in taking care of their diabetes influenced parents approach to engaging in the transition process. Parents perception of and resultant response to their adolescent's indicators of readiness also influenced how effectively they prepared their adolescent to competently perform the primary caretaker role, decision maker and manager roles. Adolescents who competently performed their regimen tasks as they were given responsibility for them, had parents who took their cues from their adolescent (n=7) about when and how they should facilitate the transition of responsibility from themselves to their adolescent. The goodness of fit of a parent's approach to training their adolescent influenced how well their adolescent was equipped to gradually take on managing their diabetes. Parents who were engaged in their child's life and committed to their healthy development chose to employ a strategy that they believed had the best potential for making the process an optimal experience while effectively equipping their child to take on the primary caregiver and manager roles. When the parent's approach matched the adolescent's readiness, transfer of responsibility for the healthcare regimen occurred in an easier and more efficient manner than when they were mismatched.

Match of Parents' Approach to Adolescent's Needs

This study found that the goodness of fit of the approach a parent used influenced the ease, efficiency of the experience and the effectiveness of the process. A goodness of fit approach seeks to help adolescents evolve in ways and pacing that accommodate the adolescent's characteristics to the diabetes professional's developmental guidelines for age-appropriate involvement in diabetes care. This involves the parent expecting,

encouraging and requiring their child to take on responsibility in ways that take into consideration their child's temperament, personality and capability as compared to developmental standards of the diabetes tasks one can reasonably be expected to perform and make decisions about at their age. Thus, as their adolescent aged, parents adjusted their support and involvement based on balancing their adolescent's current readiness against their future needs. This involved encouragement techniques and timing that fit with their adolescent's personality. In these cases, the parents gave emotional support and actively shaped the course of their adolescents' transition to independent responsibility. The parents made sure to do this in a way and timing that was appropriate for their children's developmental stage in life. They accomplished this by using a goodness of fit model of shaping their adolescent's evolution into independent responsibility for their diabetes.

Given the life threatening stakes of their adolescent not properly learning how to care for their diabetes through the transition process, even once they started the transition process, parents had to continue to soberly pace the transition's progress according to their adolescent's maturity or temperament. Parents had to approach conducting the transition such that when giving their adolescent responsibility they did not allow them (influenced by their inconsistency causing characteristics) to sabotage the success of their treatment protocol and compromise their health. Assuring their adolescents' good health during the transition required parents to continue, even if at increasingly distant levels, monitoring their adolescent's performance to make sure proper adherence occurred until the adolescent displayed consistent optimal performance. Parents who focused on their adolescent's readiness to determine the pace continued to consistently observe their adolescent's performance of the tasks they gave them and take this into consideration,

along with their temperament, to determine when they were ready take on more responsibility. To do this effectively, parents put in place safeguards that allowed them to provide their adolescent's need for well controlled care and invest in the priority of equipping them with the skills they need to develop the competency necessary to survive in the future. That is parents who successfully prepared their adolescent to be their own primary caregiver equipped them to be able to perform the responsibilities of the role.

Parents who used a fitting approach matched their readiness to their adolescent's readiness and also accommodated for changes in their adolescent's developmental competency. The process started at initial diagnosis when most parents perform and made decisions about the care regimen. Then, as their child demonstrated readiness (determined by their child's age, demonstrated capability or request) parents performed less of the regimen tasks as they taught and allow their adolescent to try performing more tasks. They then supervised their child's performance of the task for a period of time, monitoring their effective and efficiency progress to determine when their child was ready for increasing levels of independence in performing the tasks. Once their child could independently perform a task, parents removed themselves from directly supervising the performance of the task. They then focused more on making sure that their adolescent consistently performed the task by checking-in directly by asking their adolescent or indirectly by checking their electronic or written log. If necessary, they then reminded their adolescent to perform tasks and to complete their regimen. As adolescents' demonstrated consistency in performing their regimen, their parents become their consultants regarding making changes to their regimen and decisions about their diabetes care. As consultants, parents shared their opinions, advice and problem solving skills at their adolescent's requests.

A fitting approach adequately prepared their adolescent to be able to independently manage their diabetes by late adolescence. This was first evidenced by adolescents' health outcomes when they were given various levels of self-care responsibility during the transition. This was further evidenced by adolescents' good diabetes health outcomes once they have responsibility for performing the complete regimen.

Outcomes of Approach in terms of Ease, Efficiency and Effectiveness of Transition

Analyses of the interviews illuminated three categories of features that I conceptualize as characterizing participants' experience of the transition: ease, efficiency and effectiveness. An easy transition had minimal conflict between parent and adolescent regarding diabetes care and management. An efficient transition involved the adolescent assuming responsibility for their diabetes care within a developmentally fitting time-frame. An effective transition means the adolescent performed competently at each level of responsibility they took on as they moved toward independence in taking care of their diabetes. The approach a parent employed to transfer their primary roles to their adolescent and to help them prepare to successfully handle inheriting them determined the ease, efficiency and effectiveness of the transition experience.

Figure 5 below presents a visual illustration of my conceptualization of how different types of parent and adolescent factors influence different ways the transition process is experienced in terms of the ease, and efficiency of it.

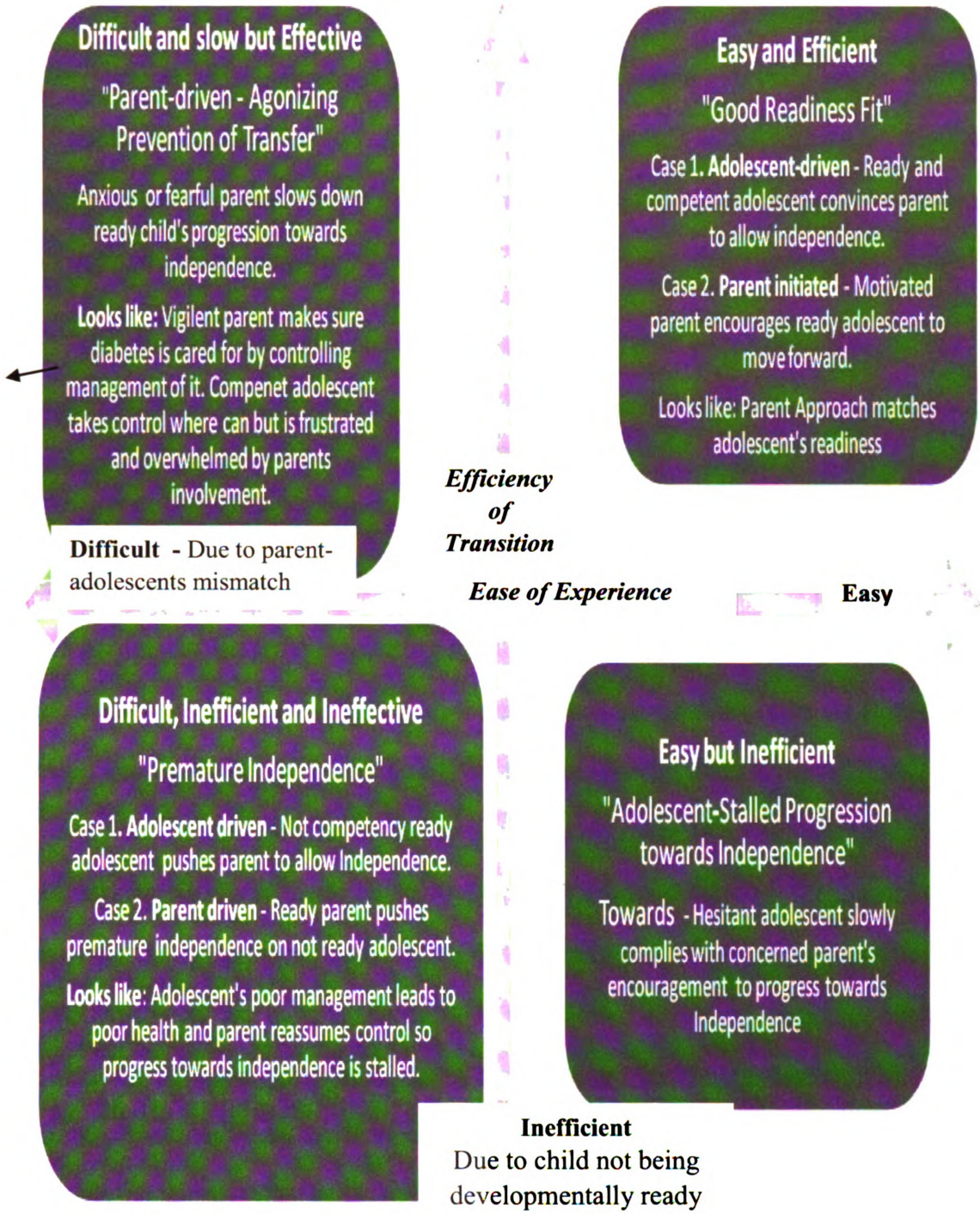

Figure 5. Descriptions of Conceptualization of Different Types of Transition Experiences

To facilitate a thorough understanding the content of Figure 5, the following section presents participants accounts of their real life transition experiences. Each of the 4 categories of experiences identified in Figure 5 is illustrated by a summary description of the experiences of and a quote from a single parent or adolescent participant or quotes from a parent-adolescent pair.

Participants' memories and perceptions of going through the transition process reveal a spectrum of ways parents and adolescents with different readiness characteristics experience the process. The most constructive transition experience was cooperative, efficient (progressed at a developmentally appropriate pace) and effective (resulted in adolescent being able to perform caretaker, decision maker and manager roles) due to a match between adolescents needs and parent's approach to engaging in the process. The least constructive transition experiences were difficult (parent-adolescent conflict, stressed individual member's wellbeing), inefficient (slowed, stalled, remedial pace of progress), and ineffective (adolescent did not demonstrate progressive growth towards ability to successfully and independently perform the roles involved in taking care of their diabetes) due to unresolved differences that result in a mismatch between an adolescent's needs and parents approach. In the following section I present excerpts of adolescent-parent participant pairs descriptions of their transition process and show how I conceptualize the way the major themes fit together to explain why they had the types of transition experiences they had.

Easy Experience and Efficient Transitions that were Parent-driven AND based on Parent Meeting Child Factors

For adolescents whose emotional desire for control matched their cognitive capacity to handle increased levels of caretaking and decision making responsibility, the most *efficient* transition occurred when parents acknowledged their readiness and started engaging them in the transition process. The approach to conducting the transition process can either facilitate or inhibit the developmentally appropriate timing of the occurrence of the transition process. Adolescents described how opportunities to perform their care regimen's tasks built-up their confidence in their caretaking ability and fueled their appetite for more consistent independence and autonomy in their diabetes care. By effectively training their adolescent to engage in the various forms of the caregiving role, parents equipped their adolescents with the tools they needed to successfully function as primary caregiver and manager which supported their continued growth towards achieving independence by adulthood.

One mother explained the benefit to her 16 year old daughter's growth, towards taking ownership of her diabetes care, of the parent stifling her concern driven desire to direct and suggest how her daughter should care for her diabetes.

> *Oh, I worry about her taking on more responsibility.* I mean, I also appreciate it. I know it's her, it's got to be her deal and me trying to make her do it my way, will only make her want to not do it at all. When I have been too attentive to it, she resists more, and she will be more secretive about it. Then if she has trouble, she won't come to me. So, it's much better if I just let the mistakes happen and we just talk about it and try. I think she feels a tremendous amount of guilt about it anyway when things get out of control.

This statement exemplifies the parent's understanding of the necessity to support growth towards independence and ensure good healthcare behavior. Her words suggest she works to fit her parenting approach to her child's uniqueness. She demonstrates attentive parenting by knowing her daughter's adolescent-stage idiosyncrasies and personality traits. She demonstrates conscientious parenting by recognizing that the way she engages her daughter about her diabetes care affects her comfortableness with continued parent involvement. The parent recognizes that her adolescent needs continued parental guidance to make good decisions about her diabetes care. The parent also recognizes that her adolescent's desire for independence makes her resistant to her parent being overly involved and causes her to avoid her parents counsel. This would compromise the adolescent's proper diabetes management which has repercussions for her health. Given that her daughter's health is of the optimum importance, the parent sacrifices her urge to have more input than the adolescent desires in order to have access to being involved even if at the adolescent's discretion. The parent realizes that her response to her daughter's way could jeopardize her most important goal of ensuring her daughter's good health. By fitting her approach to her daughter's temperament, the parent engages with her daughter to fulfill both her parenting responsibilities and her daughter's transition goals. She allows her daughter to take on responsibility for performing tasks. The parent also monitors her daughter in a way that is not controlling but that allows her to observe her performance and be assured that it does not compromise her good health. This approach allowed her to facilitate an easy and efficient transition.

Easy Experience but Inefficient Transition

Some parents used a goodness of fit approach to accommodate the hesitant personality of their adolescent. This resulted in an easy transition process because the parent tailored their encouragement of their adolescent's progression to their adolescent's more hesitant, cautious or easy-going manner. It was, in fact, this manner that actually made the process progress at a slower than typical pace according to healthcare providers standards. However, because the parents started the transition and encouraged their adolescent's progress while allowing it to gradually unfold at a pace that was comfortable for them, parents conducted an effective transition process. Following is an example of the process occurring at a gradual pace because it fit with what the adolescent was comfortable. One 16 year old female diagnosed and performing her first task at age 10 described how her parents used scaffolding to move her from dependence to independence in performing her regimen.

> I was diagnosed when I was ten and I just remember I couldn't really go anywhere at first 'cause I was so new to it. And I didn't really know what to do to control it, and stuff. I wouldn't give my own shots. My parents helped a lot, so I think that kind of helped me to get worked up to doing it myself. Yes, it kind of like gave me my own time to do my own stuff until I kind of got comfortable with it. When I first gave my shot I felt proud that I did it myself; it wasn't half as bad as I thought it would be. When I got a pump, my dad always filled the pump reservoir for me for a little while. But then I started doing it. But he still used to do [change] my sites for awhile, until I kind of got used to doing it. My mom helped me with carb. counting at first. But, then after a little bit, I kind of got the hang of it and just did it myself after I had it for about a year and a half. She would check it and double check it. When I was 11, almost 12, I wasn't doing all

of it myself, but I kind of got the hang of things. I started doing everything on my own, probably, around 2 years ago when I was 14. It just kind of happened. I'm not really sure how. My mom would make me do some of the stuff more and she'd try to hand it off I guess kind of, I'd have to do it myself. I would do it, and I would just, yeah, I would probably just do it. I probably got more confident. I wanted to start doing stuff after a little while. It got a little annoying, because I thought I could do it myself after that. So, I asked them if I could start doing things myself. I think my parents were probably scared that I'd mess up but they were supportive about it.

Easy Experience but Inefficient Transition due to child's personality - hesitant child

Some parent's willingness to match their approach to their adolescent's readiness cues led to an easy yet inefficient progression through the transition process. One mother of a 14 year old male diagnosed at age 5 described how she and her husband adapted their approach to his temperament. They accepted the slow pace of their adolescent's transition based on perceiving and responding to his hesitancy to move towards performing tasks.

Yeah, we approach encouraging him to take on more responsibility based on his personality. I mean, he's just a very easy going kid. It's kind of good, kind of bad. It's good that he's not stressed by it, but there's sometimes I wish he was a little more stressed, you know, 'because I worry about his kidneys in the future. But he sure doesn't, he doesn't spend any time worrying about it. He doesn't view it as this terribly negative thing and he really never has. I mean, the other side of it is my husband and I are both statisticians, so we're numbers people, so

> we used to look at the numbers a lot, you know, and early on we were very interested in all that. So, there's a potential for that too. He doesn't get wrapped up in it, he doesn't feel, you know, we don't have a lot of judgment about good number, bad number [number representing his glucose level after testing blood sugar]. It's all just a number and we deal with it.

Following is their son's perspective about his parents approach to helping him transition towards independent diabetes self care. It reveals that he experienced their parenting approach as fitting his needs.

> I think they've supported it. It's like they've been helping me gain independence. If I needed help like, if I wasn't sure what to do for insulin, they would help me try and figure out the dose. Like help me remember to test. So it's like sort of giving me independence, but at the same time, not just sort of shoving it on me. I think they've always been like half sort of like letting me go at my own pace, but at the same time, sort of pushing me to keep taking independence and taking control of it.

Easy Experience yet Inefficient Transition due to parent and child comfortable with child's complacency – their arrangement worked.

One 16 year old male, diagnosed at age 8 was a late bloomer in getting involved in performing his health care tasks at age 14. His parents were pushed to encourage him to take on more responsibility by his healthcare team who even forced them to follow a plan with set goal points when he would take on tasks. Although they thought it unnecessary, the parents complied with the healthcare team's urgings and their son

eventually assumed the primary caretaker and decision maker roles and quickly adapted to consistently performing them well.

> Even though, you know I mean, he's not a little baby, but, you know, you feel this responsibility to protect him and take care of him. He was probably in junior high [when he started getting involved with his diabetes care] and probably the first thing I remember him doing his own shots [which was] was a big deal. That was a long transition. I don't know maybe a year? Just because we felt like we could take care of him. And we didn't understand why they [healthcare team] were pushing us to give him this independence and he didn't want it. But, we had a lot of respect for the team, and so we did it begrudgingly. [We felt] apprehensive. I don't say we were angry and we weren't confused, so just apprehensive. This is our little kid, you know. Why push him to know more then he really has to know. If he had wanted it, yeah, we probably would have felt different. I think if his personality was different maybe he would have been really eager to be more independent. I think it's part of the personality, where some kids would have just jumped at the responsibility.

Following is their son's perspective about his slow progression towards independent diabetes care.

> I guess I never really thought about it. Because it's like I'd always had to like wait for the nurse to come over. So, it's just like finally one day I just got tired of waiting and I did it. And then, it's just my parents were always there at home so it was never that waiting. So, I just, never saw any point. At first it was probably a little intimidating. But, now it's just like it's part of everyday life. Just something I do. I definitely think it gets easier because like at first I never really

understood it. Just sort of let them do everything. But, now it's like I understand what's happening. I understand everything. It's like I can take care of it. Yeah. It's like I'm not having to check in with them and have them sort of control everything. Like if I need something I can get it. It's just like; I can take care of it.

Thus, a temperament-based slow to progress adolescent found that when allowed to progress at a pace that fit for him, he was able to eventually take on responsibility at a point in his development that fit him well.

One father of a 15 year old male diagnosed at age 10, described how his son's more relaxed nature was both a help and a hindrance to his adjustment to living with Type 1 diabetes. Their son's easy temperament served him well by allowing him to immediately accept diabetes and enjoy his childhood and adolescence despite the fact that having it made him different from his friends and that the care regimen often intruded on his busy social schedule. At the same time his nature caused him to have a delayed and passive interest in progressing towards independent diabetes care. Following is the father's description of how he adjusted his approach to his son's temperament, in order to get him to start giving his shot and checking his blood sugar.

Well, you know that's the other thing. I mean the good thing about {son} is really, he's real easy-going and the bad thing about {son} is he's real easy-going. So as far as you know, you kind of have to be on him a little bit, to do what he needs to do. In the beginning um, we kind of did everything, um just too kind of make it a little easier for him. That didn't last too [long], you know, after a month or 2, you know then you kind of get him starting to do some stuff. Well, you just,

> you're doing it so often, so eventually you just kind of, as far as checking goes, see that it is pretty easy for him to do after awhile so, you just get him to do it and remind him to do it and then, you get to the point you figure out how much he needs and get the shot ready for him to give himself.

This led to the parents engaging in their current role of being monitors and reminders.

> We just pretty much remind him. Right now it's in the mode of I'll remind him. Well I think he kind of knows that someone's got to do it and he doesn't really want to do it. You know he's, like I said, he's kind of, off doing other things and thinking about other things so.

These participants' transition experience was moderately easy. There were times when the son's easy-going temperament resulted in his forgetting to check blood sugar level and give shots before eating. This caused the process to be inefficient in its pace.

Conclusions about Transition Process:

Parents approach to conducting the transition process was effective when they tailored it to their adolescent's needs, which was evident in their way of being and their developmental challenges. Parents could only employ an effective approach if they knew what their adolescent's needs were (which was determined by accurately observing and assessing their adolescent's characteristics to understand them) and tailored their parenting to fit who their adolescent was at the point in time. When parents designed and then employed a fitting approach to meet their adolescents' needs, they were better equipped to start and conduct an effective and easy transition process, which is one in

which parents protect adolescents' health while promoting their healthy progression towards independence

which parents protect adolescents' health while promoting their healthy progression towards independence

Chapter 8

Conclusion

Purpose Re-visited

The purpose of this study was to use grounded theory approach to gain a better understanding of parents and adolescents experiences transitioning adolescents with Type 1 diabetes to independent, self care of their diabetes. The semi-structured interview method was employed to yield data illustrating real-life experiences that reflect the parent-adolescent relationship dynamics surrounding parents' readiness to transfer diabetes responsibilities to their adolescents and adolescents' transition to self-management. This study proposed that adolescents' ability to take over responsibility for their diabetes care and management from their parents could be better understood if explored in terms of both adolescents' developmental readiness and parents' emotional readiness. It was more specifically proposed that a goodness of fit between parent and adolescent readiness for the transition would allow them to engage in a relationship that facilitates a cooperative role transfer and efficient and effective transition.

Emerged Theory

Following is the substantive, conceptual theory about the transition process that emerged from this study's findings. The ease and efficiency of the transition experience for both parents and their adolescents and the effectiveness of parents guiding role in the process is influenced by parents tailoring their approach to their adolescents unique needs (which is indicated by an adolescent's personality and their fluid indicators of competency and developmental readiness to grow in the depth and amount of their participation in caring for their diabetes). The type and fit of the approach parents

employ is influenced by their differentiation influenced readiness to transition their adolescent to independent diabetes self-care. Figure 6 depicts the emerged theory.

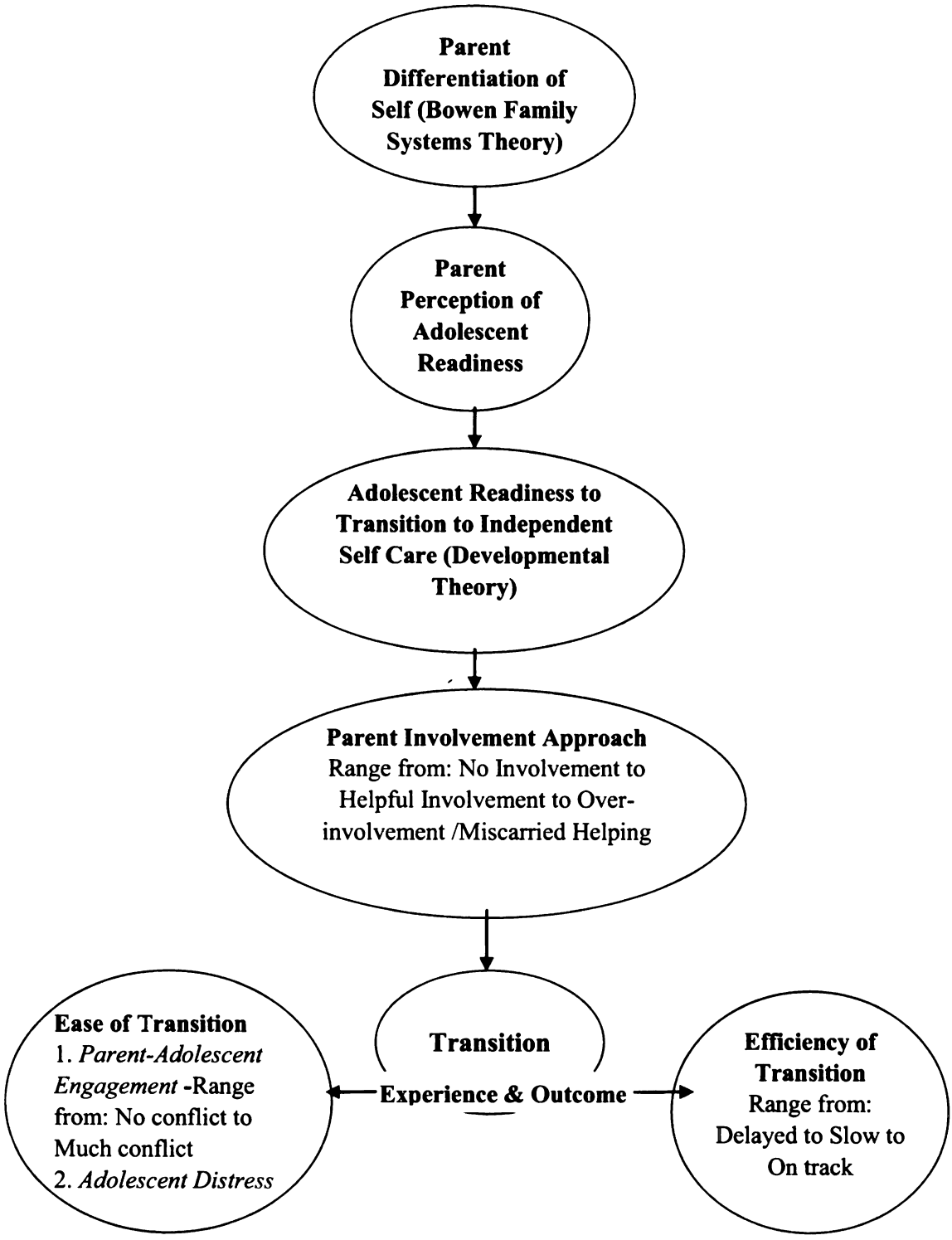

Figure 6. Map of Emerged Theory

A goodness of fit between parent and adolescent readiness for and approach to engaging in the transition process allows them to engage in a relationship that facilitates a cooperative role transfer process and successful transition. The fit of parents' approach to adolescents' personality, readiness and developmental needs influences how effectively parents guide the role transfer process and prepare their adolescents to handle the primary caregiver and manager roles.

Findings Regarding Research Concepts and Questions

This study also found support for its proposition that miscarried helping underlies the conflict associated with the parent-adolescent relationships of diabetics with poor metabolic control. Further, this study found support for its proposition that parents' lack of readiness to transition their adolescents into the primary management role can lead parents to engage in behaviors that represent miscarried helping. Parents' readiness to transition their adolescent to the primary diabetes caregiver and manager roles they occupy influence the efficiency of the transition process and the ease of parents and adolescents experience of it. Specifically, parents lack of readiness to prepare, transfer responsibility to and allow their adolescent to assume the primary diabetes manager role leads parents to engage in behaviors that represent miscarried helping. When adolescents are developmentally ready (i.e., show a level of competence, capability and maturity necessary to handle) to be trained for and given responsibility that progresses them towards independence in taking care of their diabetes, parent over-involvement is experienced as miscarried helping. Miscarried helping comes from parent's personal readiness factors (differentiation and perception of adolescent's readiness) and is influenced by adolescents' display of readiness factors. Put reference to article here.

Miscarried helping interferes with normal adolescent development by stalling their progression towards independence and autonomy in caring for their diabetes. Stalling may stunt healthy adolescent development and handicap their ability to care for themselves, further perpetuating dependency on their parent to manage their diabetes. When adolescents desire and are ready to assume responsibility, miscarried helping causes them to feel stifled and controlled, which spurs parent-adolescent conflict. When adolescents are not ready, to assume responsibility, parent over-involvement helps them maintain proper management and control over their diabetes while also allowing the adolescent to avoid maturing into developmentally appropriate readiness for caring for their diabetes. Figure 7 presented below shows this relationship.

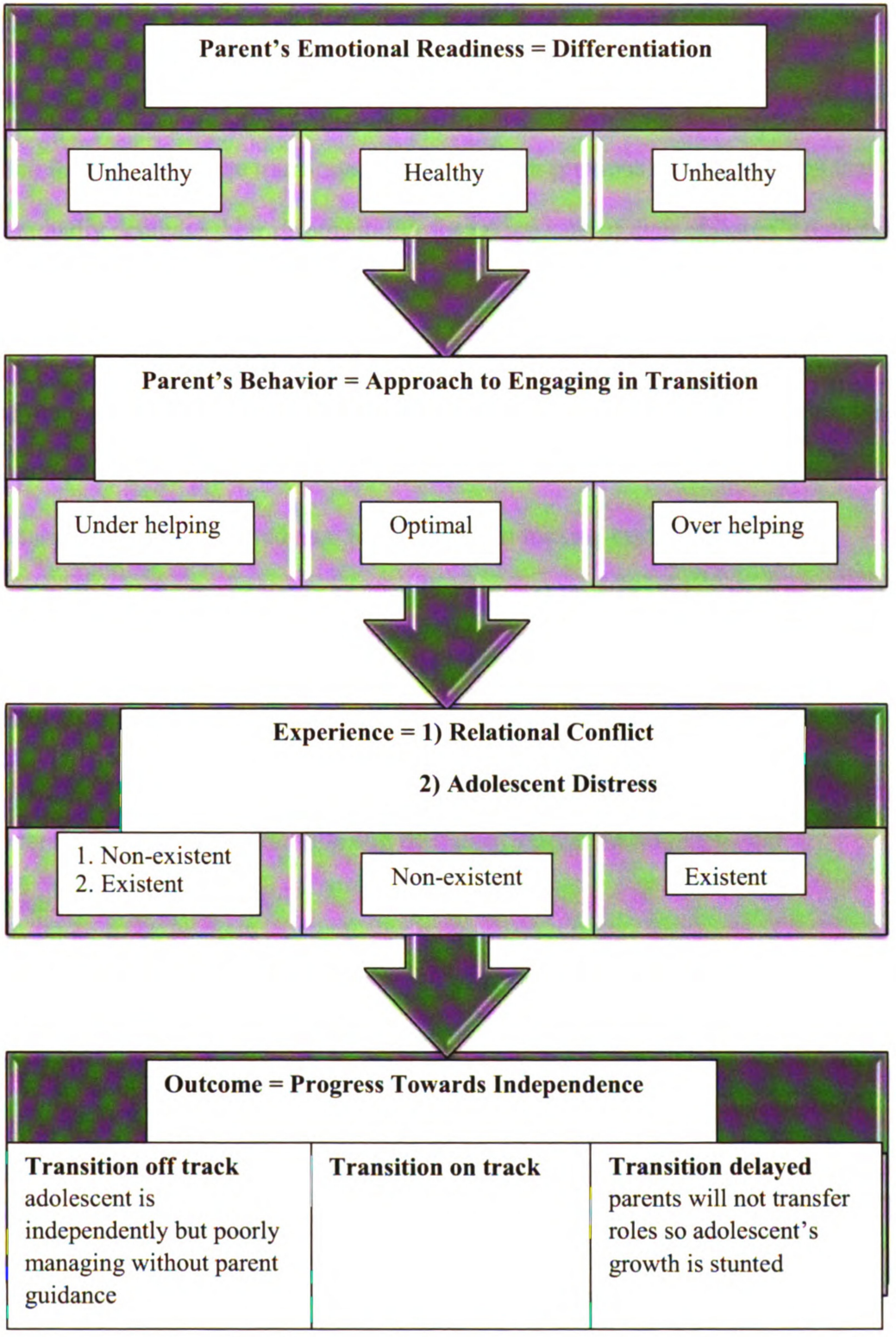

Figure 7. Relationship Between Parent Differentiation, Parent Involvement and Transition Experience and Outcomes

Relating this Study's Findings to Previous Research

Emerged Concept: Transition Process

The findings about the transition process confirm previous studies findings that parents gradually decrease their responsibility for taking care of their children's diabetes during the adolescent years (Drotar & Evers, 1994; Hanna and Guthrie, 2003; Schreiner, Brow, & Phillips, 2000; Steinburg, 1999). At the beginning of adolescence, youth increased the amount of care tasks they performed until they took full responsibility for the caregiver role, while parents continued to make decisions about and manage the overall treatment plan Parents reduced involvement in making decisions about the regimen and role as an infrequently sought out consultant by mid adolescence is consistent with the results of Hanna, Juarez, Lenss and Guthrie's (2003) study. Their study found: the amount of communication between parents and adolescents decreased from early to mid-adolescence; and adolescents behaviors of seeking and receiving support increased from early to middle and then decreased from middle to late adolescence.

Research Concepts One and Two: Adolescent Characteristics and Parent Readiness

The findings that adolescents' readiness for the transition influenced parents' readiness to start it are consistent with Palmer and associates (2004) findings about how pubertal status and autonomy relate to decreases in maternal involvement in diabetes management, and the effect on metabolic control. Adolescents' autonomy and pubertal status partially mediated the effect of age on maternal involvement in diabetes management. Mothers reported that their reasons for transferring responsibility included:

responding to their adolescents' diabetes care competence; promoting adolescents' competence and maturity; and minimizing hassles and conflict with their adolescents associated with their involvement in diabetes care. In terms of the findings that it is important to start the transition after adolescents' readiness has been confirmed, this study's results were consistent with the Palmer's results. In this study delays, parent-adolescent conflict and poor adolescent health occurred when parents started the transition despite their adolescents' display of indicators that they were not ready nor did they want to be consistently responsible for their diabetes care. Similarly, in Palmer's study, adolescents who assumed responsibility for diabetes management without being ready (i.e., autonomy and puberty status) had poor metabolic control. Parents' hesitancy to start the transition due to observing adolescent indicators of irresponsibility is consistent with the findings of several studies. (Buckloh et al., 2008; Marshall, Carter & Rose, 2006)

This study's findings that adolescents' temperament characteristic of self-efficacy facilitated the transition process is consistent with findings of previous research investigating the influences on and outcomes of adolescent's with Type 1 diabetes self-efficacy. Wall (2004) found that adolescents with diabetes who showed self-reliance also pushed for their parents to allow them to have general behavioral autonomy and diabetes-specific autonomy. Greater adolescent self-efficacy predicted their better adherence to the diabetes care regimen and better metabolic control. Steinburg (1999) found that self-efficacy, age, level of diabetes responsibility and an interaction between adolescents' self-efficacy and family environment significantly predicted diabetes-specific parent-child conflict. These results are consistent with this study's findings that when

adolescents' characteristics and parents' approaches are dissimilar, conflict regarding diabetes care and the transition process occurs.

The findings that cognitively mature and optimistic temperament adolescents gained their parents confidence and thus facilitated their readiness to start the transition are consistent with Salonius-Pasternak (2004) findings regarding the psychosocial characteristics that predict adolescents with Type 1 diabetes resilience in young adulthood. Resilient adolescents were closer to and experienced less conflict with their parents than poorly functioning adolescents. Resilient adolescents also demonstrated better ability to be flexible in managing their illness and other aspects of their lives. These results also corroborate this study's findings that certain positive temperament characteristics are associated with adolescents' readiness for and potential to be successful at taking on responsibility for their diabetes care.

Research Concept Three: Parent Differentiation

This study's findings that well differentiated parents' approach of being involved to the extent that adolescents needed allowed adolescents apply their self-efficacy and engage in self care. Parents who were poorly differentiated did not let their self-efficacious adolescent take on the responsibility they were capable of and ready for. These findings are consistent with Cant's (2003) about the factors that influence the self caretaking of youth identified as being the age and autonomy level indicative of readiness for self care. Cant employed the stage of change model as a developmental framework to assess the relationship between adolescents' self-efficacy, adolescents' families' responsibility for their diabetes care, and adolescents' self-care behaviors. Regression analyses indicated that parents' reports of family responsibility for diabetes care moderated the relationship between adolescents' self-efficacy and self-care.

The findings about parents' differentiation are consistent with the Liakopoulou and associates (2001) findings that mother's high expressed emotion along with its specific component of emotional overinvolvement and excessive detail, was related adolescents' poor metabolic control. The parents saw relief from burden and knowledge, and pride in their adolescents' abilities as their benefits of adolescents' diabetes self-management. They identified freedom, independence, and control as what they perceived as benefits to their adolescents.

This study corroborates Wall's (2004) findings about how the process of autonomy development hinders or facilitates adolescents' adherence to their diabetes care regimen and good metabolic control. Wall found that adolescents' early push for behavioral autonomy was associated with increased conflict and mothers' emotional maladjustment. Emotional autonomy was related to both better adolescent emotional adjustment and greater diabetes self-efficacy. In terms of the parent-adolescent relationship, better emotional autonomy was related to parental warmth and less conflict. Longitudinally, push for autonomy predicted negative outcomes, including: parent-child conflict; and differences in mother-adolescent expectations for autonomy predicting worse adherence

The finding that poor parent differentiation causes parents engagement in miscarried helping corroborates the findings of a study conducted by Hanna and Guthrie (2000). Their findings revealed that parents identified concerns about losing control and supervision as their barriers to letting their adolescents take responsibility for managing their diabetes. This study's finding that adolescents' inconsistency caused parents to delay the start of the transition corroborates Hanna and Guthrie's finding that parents saw the burden of responsibility as their children's barrier to taking on responsibility for

managing their diabetes. Well differentiated parents adapted to the transition process by changing their role based on their adolescents needs. These findings corroborate Hanna and Guthrie's (2001) finding that parents and adolescents agreed that parents' provision of directive guidance and tangible assistance was helpful depending on parents' directness and adolescents' perceived need for help.

This study's found that adolescents feel distressed by and engage in conflict with their parents when parents' poor differentiation causes parents to engage in miscarried helping behavior. This is consistent with the findings of a study conducted by Weinger, O'Donnell, and Ritholz (2001). Their study found that adolescents perceived parental worry, intrusive behaviors, lack of understanding, blaming behaviors, and focus on the future verses adolescents' focus on the present as sources of diabetes-related conflict with their parents. The adolescents found parents understanding of the demands of diabetes and reassurance about their illness and normative functioning as sources of parental support.

Theoretical Application

Bronfenbrenner and Bowen's Theories reflected in the Differentiation Influenced Inter-Family System Exchange of the Transition Process.

The results reflect Bronfenbrenner's Ecological theory in that adolescent's transition process involved their interaction with several primarily the parental subsystem and secondarily the healthcare system of their ecology. In order for the adolescents to reach the goal of independent self care of their diabetes, the parent and adolescent subsystems had to engage in a dynamic, dyadic process. The process was guided by parents but required both parents and adolescents to engage in inversely exchanging their

amounts and roles of involvement in the adolescent's diabetes care. Following I summarize the roles parents and adolescents played in and how their characteristics influenced this systems exchange process. In doing this, I also explain how Bowen's theory is also represented in the results.

As the residing manager of their child's diabetes care, parents directed and commandeered the occurrence of the transition process. Thus, the effectiveness of the transition in achieving the outcome of moving their adolescent toward confident and competent independent self care is their responsibility. The key to accomplishing this outcome is making sure that the transition process, including the approach and pace, are a good fit for the adolescent. A good fitting approach is tailored to an adolescent's needs and thus, specifically designed to help them achieve the transition's goal. The necessary preliminary step to designing a good fitting approach is accurately determining an adolescent's readiness to be engaged in the transition process.

Parents' differentiation influenced the accuracy of their perception of their adolescents needs. Well differentiated parents based making their decisions about when and how to start and conduct the progression of the transition process on the results of their assessment of these factors. They were then able to base their approach to conducting the transition process on what best fit their adolescent's needs. If their assessment of these adolescent characteristics yielded evidence that their adolescent was not ready to effectively handle a change in responsibility, these parents adjusted the pace to accommodate their need for continued parental involvement and support. Well differentiated parents also considered their adolescent's characteristics when deciding what approach to use to conduct the transition process. Engaging in this thorough processing gave well differentiated parents the opportunity to identify a transition pace

and method that best fit and addressed their adolescent's needs. Finding and implementing a fitting pace and approach increased the probability that they would be able to aide their adolescent in accomplishing the goal of independent self care.

Poorly differentiated parents need for their adolescent's dependency to control their anxiety about the possible outcomes of diabetes was the primary determinant of how they assessed their adolescents' readiness for starting and progressing through the transition process. Poorly differentiated parents' perception of their adolescent's need for continued parent involvement was not based on their engaging in unbiased consideration of adolescents readiness Thus, poorly differentiated parents' dependency on controlling their adolescents' diabetes care influenced their ability to accurately perceive and accommodate their adolescent's need for and ability to handle transitioning to independent self care. They engaged in miscarried helping to manage their anxiety. This led their adolescents to find their parents' involvement smothering and their opportunity to learn how to be in control of their diabetes care stifled. In fact, their need for their adolescent to stay dependent on them caused them to delay starting and stall progressing through the process of transferring the diabetes care roles to their responsibility. For adolescents who wanted independence, their differences with their parent regarding perception of their readiness caused conflict. Thus, poorly differentiated parents compromised their ability to conduct a transition that was easy, efficient and effective.

Since parents controlled the transition process, their readiness for the process determined the success of the way it occurred. Parents' readiness for the transition process was influenced by their differentiation, which is their ability to manage their anxiety about their adolescent having diabetes. Parent's differentiation influenced their perspective about when their adolescent was ready for it to occur. Ultimately, parents'

differentiation was the primary determinant of the transition process effecting participants' experience of and adolescents' outcomes of engaging in it. By effecting the ease of the experience, efficiency of the process' pace it influenced how effective the process was at preparing adolescents to take on independent control of performing, making decisions about and managing their diabetes care.

This is what parents who had easy transition experiences with effective outcomes described as the process they engaged their adolescent in. When first performing a care task, the adolescent needed direct instruction and direct assistance. While they are becoming comfortable with the task, they needed heavy guidance and monitoring. Once they showed proficiency, they needed general supervision and intermittent monitoring that may have included parents giving them suggestions and answering their inquiries. Once adolescents demonstrated consistency in proficiently, accurately and adherently performing the tasks of their care regimen, the parent only needed to provide emotional support and occasionally participate in brainstorming solutions to challenging (i.e., too high or low blood sugar levels or sick) days when the adolescent solicited their input or consulted with them. Parent and adolescent pairs whose adolescent was starting to emerge into independent diabetes care described the adolescents desired parent involvement as including providing the friendship characteristics of emotional support, and encouragement.

Some parents' descriptions of their experiences with their adolescents maturing into being more responsible for caring for their diabetes reflected the process of Operant Conditioning occurring. These parents described their adolescents as being more consistent in performing the tasks they were responsible for after they experienced the natural benefits of consistent, proper diabetes care. Through this conditioning process,

parents saw evidence gradually emerge of their adolescents learning the necessity of responsible independence. Adolescents had to be cognitively mature enough to perceive the immediate benefit of responsible care for themselves and consider it worth the effort. Thus, when they were cognitively cable of making the work-reward association, they learned the lesson of good care equals good health equals feeling good equals being able to do more of the things I want to do, and more independence from my parents in caring for my diabetes. It suggested that experience with the rewards of proper care is necessary but has its maximum benefit when adolescents are cognitively mature enough to perceive it and responsible enough to institute the behavior regularly to gain the benefits occurrence until proper, daily care became a habit.

Adolescent Learning by Outcomes of Experience

One parent of a 14 year old male who was diagnosed at age 5 described how she go against her own desire to control her son's diabetes based on knowing that his personality type dictates the need for her to pull back and allow him to have independence and even learn from his mistakes. Being an attentive and perceptive parent allows her to understand how to parent in a way that fits both his personality and developmental need for independence and autonomy. Desiring to encourage his healthy development of diabetes self-management, this parent forgoes controlling how he administers his regimen even when it means less than desirable immediate health consequences. She acknowledges that giving him room to make his own choice to not properly adhere to his regimen yields consequences that are challenging for her as a parent to observe and not prevent because it makes him physically miserable. However, she perceives her not interfering in even his unhealthy choices is necessary for his personality type to be conditioned to properly manage his diabetes. This reflects her understanding how her son

best learn through classical conditioning and thus, she allows it to occur with the hope that it will cause him to develop healthy diabetes care habits.

Implications

Implications for MFT

The findings highlight the weight of parents' responsibility to help make the transition happen in an easy, efficient and effective way. However, in addition to their leadership, the experience and effectiveness of the transition is also a function of the quality of parent and adolescent engagement. In the following section, I address implications for family therapists, healthcare providers and parents.

Implications for Parents:

Parents have more of the onus of responsibility for the ease and outcome of the transition because they serve their adolescent in this process. As the adult serving as the primary caretaker and manager of the diabetes, parents are responsible for effectively transferring these roles to their adolescent. This requires parents to relinquish their control over the diabetes care and equip their adolescent with the knowledge and skills necessary to take it by assuming the 3 care roles. The goal of the transition process is adolescents healthy development, demonstrated by their being able to progress towards independently manage their diabetes.

A parents approach is effective if it is tailored to their adolescent's needs, which are reflected in their way of being and the developmental challenges they present. Parents can only employ an effective approach if they: know what their adolescent's needs (which is based on accurately assessing who the adolescent is) are; and they tailor

their parenting to fit them in ways that promote their healthy progression towards independence. Easy, efficient and effective transitions involve approaches that accommodate parents' and adolescents' readiness needs.

Suggestions for Practical Application:

Parents highlighted the importance of gingerly and deliberately considering adolescents' readiness for the transition process before starting to engage them in it. Careful determination of readiness is required because the responsibilities involved in caring for Type 1 diabetes are numerous, intense and complicated. Although it starts with giving adolescents responsibility to perform tasks of the caregiver role, the transition process is a comprehensive, multifaceted endeavor to undertake. As was described in Chapter 4's Results Part 1, it is the process through which parents transfer responsibility to their child for all 3 of the main roles involved in controlling diabetes. Taking on the roles and consistently and properly performing them requires a level of cognitive functioning and emotional maturity that does not begin to emerge until adolescence. Properly and consistently fulfilling them is necessary to prevent negative health outcomes, which are debilitating and life threatening. Therefore, many parents waited until their child was entering into or in adolescence to move them beyond responsibility for performing one or a few tasks. They intentionally initiated the process of consecutively transferring the roles. Similarly, for instances when adolescents motivated their parents to consider initiating the process, they did so when they were emerging into adolescence.

Determining an adolescent's readiness requires consideration and assessment of their characteristics that can influence their capability to handle the necessary

responsibility. These were found to be adolescents': desire for responsibility; demonstration of reliable and consistent adherence to care protocol; proficiency of diabetes care skills; competency about diabetes and their particular care protocol; and mature decision making skills. Parents should be knowledgeable of these characteristics and other adolescence stage triggered emotional and cognitive functioning nuances that may compromise their adolescent's performance of the diabetes care roles.

To increase the chances of the transition being easy and effective, in preparation for it, parents should engage in the following process. Examine oneself and adolescent to identify factors that may hinder or facilitate an easy, efficient and effective process. Parents' personal readiness factors include: understanding the transition process and parents role in it; and being willing and emotionally ready to engage in the transition process. Parents personal transition hindering or facilitating factors are ways of emotionally and cognitively functioning that compromise the effectiveness of their approach to engaging in the transition process. They include: worrying; being needy; denying child's need for growth and independence; having poor differentiation; and inaccurately perceiving and judging adolescent's readiness. There are also ways of behaving, influenced by the aforementioned ways of emotionally and cognitively functioning, that compromise the ease, efficiency and effectiveness of the transition process. These ways of behaving include: miscarried helping; controlling diabetes care; avoiding and stalling the transition process; and prematurely transferring responsibility to the adolescent. Parents can prevent these negative factors from inhibiting the transition process by being willing to resolve, improve, change or control emotional, cognitive or behavioral factors that render their approach ineffective and compromise the ease, efficiency and outcome of the transition process.

Adolescents inhibit the transition process by acting in ways that prevent the ease and efficiency of the transition experience and the effectiveness of its outcome. Characteristics that cause adolescents to inhibit the process include their: personality or temperament; stage specific developmental idiosyncrasies; incomplete ways of cognitive functioning; and psychosocial needs.

Parents can help prevent adolescent and parent factors from inhibiting the transition process by engaging in the following transition, safe guarding process. Identify ways to match their readiness and parenting approach to the readiness, characteristics and needs of their adolescent (as revealed by the results of this study). At the beginning of the process, implement a good fitting approach. Maintain a good fitting approach throughout the transition process by continuously assessing whether it meets their adolescent's changing developmental needs and promotes their progress towards increasing levels of successful independence.

Implications for Healthcare Providers

As their patient, adolescents are health care providers, primary person of interest. Their focus is on achieving the clinical goal of adolescents maintaining optimal metabolic control. In order to aide adolescents in achieving this goal, health care providers have to intervene at the family system's level. This is because optimal control is the function of adherence to the prescribed health care regimen and protocol; which, during adolescence more often occurs when parents are involved in overseeing adolescents' performance of it. Adolescents' performance of and growth towards independently controlling their diabetes care is connected to and influenced by their parents' involvement. Based on the

findings of this study, following is a suggested guide for health care providers aimed at effecting adolescents' growth towards responsible and independent care of their diabetes

Identify the family system's and parent-child relational factors that hinder or promote an adolescent's age appropriate responsibility for managing their diabetes. This study's findings suggest that positive change in parents' differentiation leads to positive change in the ways they interact with their adolescent being developmentally appropriate. Developmentally appropriate parenting of adolescents involves preparing them for and encouraging their growth towards independence. Positive parenting also involves addressing adolescents' needs. Employing these ways of parenting allows parents to employ a goodness of fit approach to transferring responsibility from themselves to their adolescent. This study hypothesizes that creating a goodness of fit model will facilitate effective transfer (evidenced by ease of transfer and adolescent preparedness) of responsibility for diabetes management from parent to adolescent. The goodness of fit model is the study's conceptual basis for the creation of an assessment tool and guide to facilitating the transition process. Health care providers can use this guide parents in identifying an effective transfer approach that is the appropriate fit for a particular family at any stage of adolescent readiness. The following Figure 8 presents this assessment tool.

- **Assessment Tool –**
  - **Parent and Adolescent Readiness** – Where they are on a readiness continuum.
    - **Parent and Adolescent Needs** - What they need to either initiate readiness or move to the next level of transfer.
  - Parents' = fears, beliefs, differentiation
    - Adolescents' = age, maturity {emotional – differentiation and cognitive – LOC and recognition of need for and repercussions of not engaging in proper self-care}, interest/desire, cognitive {diabetes care knowledge} and behavioral capability{diabetes care skill})
      - **Needs Match Guide** - After the identifying step, using a guide for reconciling parents and adolescents' readiness factors and needs.
      - **Responsibility Guide** - Using a guide to determine, delineate and negotiate responsibility for daily diabetes management behaviors.
      - A model that provides a tool for determining the nature of parent and adolescent's diabetes readiness and guides for reconciling their readiness needs and determining personally fitting responsibilities will facilitate effective/appropriate transfer of diabetes management responsibility from parent to adolescent (evidenced by ease [less conflict] and preparedness).

This should facilitate optimal management and good metabolic control.

Figure 8. Assessment Tool for Healthcare Providers to Create a Goodness of Fit Model

Summary

I conducted this study to identify the parent and adolescent readiness factors that contribute to the way parents engage in the process of transitioning adolescents from dependent to independent care of their Type 1 diabetes. The following premise was my motivation for conducting this study: When parents properly prepare their adolescents to take on independent responsibility for their Type 1 diabetes, they equip them with the

skills necessary to gainfully invest in their immediate and long-term health. This study's results show that parents accomplish this through the transition process during which they engage in: teaching and giving adolescents opportunities to practice and hone critical diabetes care skills. Parents then gradually transfer to their adolescent responsibility for performing the roles that are necessary for controlling and surviving Type 1 diabetes for the rest of their lives. I more specifically designed the study to identify how parents' emotional readiness to transfer control of their adolescents' diabetes care influences: the way they engage with their adolescents in the transition process; and subsequently what their adolescents' transition experience and outcome is.

The overriding theme of the findings is: a parent's approach to engaging with their adolescent during the transition process is influenced by their emotional well-being and in turn influences their adolescent's experience and outcome of the transition process. Parents play an important and nuanced role in adolescents' experience of the transition as a healthy, development stimulating, and emotional wellbeing enriching process that prepares them to be independently responsible for their diabetes. Positive experiences and successful outcomes occurred when parents tailored their approach to guiding the process to their adolescent's unique ways of being. That is, both parent and adolescent participants reported having easy and positive transition experiences when parents guided their adolescent through the process using an approach that was individualized to fit their adolescent's personality and developmental maturity level.

This tailor-to-individuality approach worked because it matched parents' and adolescents' ways of relating by fitting parents' transition process leadership style to their adolescent's personhood. Consequently, the approach facilitated parents and adolescents ease of interaction. Easier interactions prevented a potentially complicated dyadic

process from resulting in parent-adolescent relational conflict and individual distress. Parents who used such an approach had a clear understanding of: who their adolescents were in terms of their personality and temperament; and how they functioned in terms of their cognitive development and maturity.

Also contributing to the ease and effectiveness of the transition process was parents' attention to their adolescent's developmental maturity as an indicator of when they were ready to take on increased responsibility. This allowed parents to make the pace of the process of transferring responsibilities individually appropriate for their adolescents' capability to handle them. This individualized pacing increased the probability that adolescents would be able to handle each level of responsibility when given it. It also allowed parents to help their adolescents gradually build their capability to handle full responsibility. According to the individualized pacing approach, this was given when an adolescent was ready for it. Thus, the goodness of fit of parents approach determined the ease of the experience for adolescents, which in turn influenced how effective and efficient parents where in preparing their adolescent to achieve the late adolescence milestone of being capable independent managers of their diabetes care.

Appendices

Appendix A

Interview Guide

Concepts	Research Questions	Interview Questions	Collateral Data
Adolescent Readiness	1. How does adolescent readiness influence parent readiness? 2. What adolescent factors inhibit or facilitate parents' readiness for transitioning adolescents to independent, diabetes self care?	1. Tell me about your experiences taking care of diabetes. 2. Tell me about what you do to take care of your (your adolescents') diabetes. 3. Tell me how you feel about taking (your adolescent taking) more responsibility for diabetes care. 4. Tell me about the impact of diabetes on your life.	
1. Differentiation of self 2. Miscarried Helping 3. Parents' Involvement in the Transition Process.	3. How does parent differentiation of self inhibit or facilitate the transition process?	1. Tell me about your (and your parent or adolescents') involvement in transitioning you (your adolescent) to caring for diabetes. **Probe:** How did it occur? **Probe:** What was the experience like?	1. Bowen Differentiation of Self Measure 2. Helping for Health Inventory (HIH) 3. Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS) - a measure of parental guidance for autonomy development

Appendix B

DSR – R

These are questions concerning your thoughts and feelings about yourself and relationships with others. Please read each statement carefully and decide how much the statement is *generally true* of you on a 1 (not at all true) to 6 (very true) scale. If you believe that an item does not pertain to you (e.g., you are not currently married or in a committed relationship, or one or both of the your parents are deceased), please answer the item according to your best guess about what your thoughts and feelings would be in that situation (perhaps with someone very close to you). There are NO right or wrong answers. *Be sure to answer every item and try to be as honest and accurate as possible in your responses.*

	NOT AT ALL TRUE OF ME					VERY TRUE OF ME
1. People have remarked that I'm overly emotional.	1	2	3	4	5	6
2. I have difficulty expressing my feelings to people I care for.	1	2	3	4	5	6
3. I often feel inhibited around my family.	1	2	3	4	5	6
4. I tend to remain pretty calm even under stress.	1	2	3	4	5	6
5. I usually need a lot of encouragement from others when starting a big job or task.	1	2	3	4	5	6
6. When someone close to me disappoints me, I withdraw from him/her for a time.	1	2	3	4	5	6
7. No matter what happens in my life, I know that I'll never lose my sense of who I am.	1	2	3	4	5	6
8. I tend to distance myself when people get too close to me.	1	2	3	4	5	6

9. I want to live up to my parents' expectations of me.	1	2	3	4	5	6
10. I wish that I weren't so emotional.	1	2	3	4	5	6
11. I usually do not change my behavior simply to please another person.	1	2	3	4	5	6
12. My spouse/partner could not tolerate it if I were to express to him/her my true feelings about some things.	1	2	3	4	5	6
13. When my spouse/partner criticizes me, it bothers me for days.	1	2	3	4	5	6
14. At times my feelings get the best of me and I have trouble thinking clearly.	1	2	3	4	5	6
15. When I am having an argument with someone, I can separate my thoughts about the issue from my feelings about the person.	1	2	3	4	5	6
16. I'm often uncomfortable when people get too close to me.	1	2	3	4	5	6
17. I feel a need for approval from virtually everyone in my life.	1	2	3	4	5	6
18. At times I feel as if I'm riding an emotional roller-coaster.	1	2	3	4	5	6
19. There's no point in getting upset about things I cannot change.	1	2	3	4	5	6

20. I'm concerned about losing my independence in intimate relationships.	1	2	3	4	5	6
21. I'm overly sensitive to criticism.	1	2	3	4	5	6
22. I try to live up to my parents' expectations.	1	2	3	4	5	6
23. I'm fairly self-accepting.	1	2	3	4	5	6
24. I often feel that my spouse/partner wants too much from me.	1	2	3	4	5	6
25. I often agree with others just to appease them.	1	2	3	4	5	6
26. If I have had an argument with my spouse/partner, I tend to think about it all day.	1	2	3	4	5	6
27. I am able to say "no" to others even when I feel pressured by them.	1	2	3	4	5	6
28. When one of my relationships becomes very intense, I feel the urge to run away from it.	1	2	3	4	5	6
29. Arguments with my parent(s) or sibling(s) can still make me feel awful.	1	2	3	4	5	6
30. If someone is upset with me, I can't seem to let it go easily.	1	2	3	4	5	6
31. I'm less concerned that others approve of me than I am in doing what I think is right.	1	2	3	4	5	6
32. I would never consider turning to any of my family members for emotional support.	1	2	3	4	5	6

33. I often feel unsure when others are not around to help me make a decision.	1	2	3	4	5	6
34. I'm very sensitive to being hurt by others.	1	2	3	4	5	6
35. My self-esteem really depends on how others think of me.	1	2	3	4	5	6
36. When I'm with my spouse/partner, I often feel smothered.	1	2	3	4	5	6
37. When making decisions, I seldom worry about what others will think.	1	2	3	4	5	6
38. I often wonder about the kind of impression I create.	1	2	3	4	5	6
39. When things go wrong, talking about them usually makes it worse.	1	2	3	4	5	6
40. I feel things more intensely than others do.	1	2	3	4	5	6
41. I usually do what I believe is right regardless of what others say.	1	2	3	4	5	6
42. Our relationship might be better if my spouse/partner would give me the space I need.	1	2	3	4	5	6
43. I tend to feel pretty stable under stress.	1	2	3	4	5	6
44. Sometimes I feel sick after arguing with my spouse/partner.	1	2	3	4	5	6

Appendix C

Parents Helping for Health Inventory (HHI)
For each item, circle the number that describes how often the following occur.

1. My child resists my involvement in his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
2. I find that the more I try to help my child with his/her chronic illness, the more he/ she resists my involvement.	1 = Rarely 2 3 4 5 = Always
3. I get upset with myself when my child's health doesn't improve.	1 = Rarely 2 3 4 5 = Always
4. When my child doesn't take my advice or direction in managing his/her health, I do it or want to do it myself.	1 = Rarely 2 3 4 5 = Always
5. I get upset with my child when his/her health doesn't improve.	1 = Rarely 2 3 4 5 = Always
6. My child and I argue about my helping him/her with managing his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
7. I feel like the more I try to help my child with his/her chronic illness, the worse things get between us.	1 = Rarely 2 3 4 5 = Always
8. My child says I "nag" him/her about managing his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
9. I feel there is no limit to what I can do as a parent in helping my child manage his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
10. When my child's health does not improve, I feel like I have not been a good parent.	1 = Rarely 2 3 4 5 = Always
11. I feel responsible for my child having a chronic illness.	1 = Rarely 2 3 4 5 = Always

12. I believe that if I do the right thing, my child's health will improve.	1 = Rarely 2 3 4 5 = Always
13. I want to be a "good" helper when it comes to helping my child manage his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
14. I feel that I "nag" my child about how he/she manages his/her chronic illness.	1 = Rarely 2 3 4 5 = Always
15. When my child has health setbacks, I feel that he/she is not trying hard enough.	1 = Rarely 2 3 4 5 = Always

Appendix D

Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS)

Parents' Version:

Parents Help with Diabetes Care: Think about the things that you have done to help your son or daughter be responsible for diabetes care in the *past 3 months*.

1. First, *circle the number* that best describes *how often you did the following things.*
2. Then for the things you have done, *circle the number* that describes *how helpful these things were*. Note: Give insulin means pump or injection.
3. There are NO right or wrong answers.

In the past 3 months:	**How often have you:**					**How helpful was it when you:**				
	None of the time				**All of the time**	**Not at all Helpful**				**Very Helpful**
Asked him/her "what do you think needs to done about your insulin."	0	1	2	3	4	0	1	2	3	4
Showed him/her how to figure insulin dose.	0	1	2	3	4	0	1	2	3	4
Suggested that he/she give insulin before telling him/her to do it.	0	1	2	3	4	0	1	2	3	4
Answered his/her questions about figuring insulin dose.	0	1	2	3	4	0	1	2	3	4

Appendix E

Diabetes-Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS)

Adolescents' Version:

Teens' Perceptions of Parents' Help with Diabetes Care: Think about the things that your parents have done to help you be responsible for your diabetes care in the *past 3 months*.

1. First, *circle the number* that describes *how often your parents did the following things.*
2. Then for the things they have done, *circle the number* that describes *how helpful these things were.* Note: Give insulin means pump or injection.
3. There is NO right or wrong answers.

In the past 3 months:	How often have your parent(s):						How helpful was it when your parent(s):				
	None of the the time				All of time		Not at all Helpful				Very Helpful
Asked you "what do you think needs to done about your insulin."	0	1	2	3	4		0	1	2	3	4
Showed you how to figure insulin dose.	0	1	2	3	4		0	1	2	3	4
Suggested that you give insulin before telling you to do it.	0	1	2	3	4		0	1	2	3	4
Answered your questions about figuring insulin dose.	0	1	2	3	4		0	1	2	3	4

Appendix F

Adolescent Demographic Questionnaire

Directions: Please clearly print the answers to all of the questions you are comfortable answering.

Gender ____Male ____Female

Ethnicity _____

Age _____

Grade level in school _____

Age when you were diagnosed with Type 1 diabetes _____

Age when you started performing diabetes tasks _____

What was the task?

_____

_____

What is the hardest thing about having diabetes?

_____

_____

Grade Point Average in School _____/_____

Grade point/out of possible

Appendix G

Code _____

Parent Demographic Questionnaire

Directions: Please legibly print the answers to all of the questions you are comfortable answering.

Your Age _____

Ethnicity _____

Parent Type

_____ Mother _____ Father

Marital Status: ____Single ____ Married ___Separated ____Divorced ____Widowed

Occupation

_____

Highest level of Education Completed

- *Please mark the line associated with the **highest level of school you started (S) or completed (C).***

____ High School ____ Some College _____ Junior College (Associate's Degree)

____ College (Bachelor's Degree) ____ Graduate (Master' Degree) ____ (PhD/Law/Medical)

Gender of child diagnosed with Type 1 diabetes ____Male ____ Female

- Age of child when he/she was diagnosed with Type 1 diabetes _____
- Current age of child _____
- Age when child started performing diabetes tasks _____
- What was the task? _____

Are you raising other children? ____ Yes ____ No

If yes, what are the ages of your other child(ren)?

_____

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