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Transitioning Teens with Diabetes to Adult Healthcare

Rebecca Ann Meyer

University of Missouri-St. Louis

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TRANSITIONING TEENS WITH DIABETES TO ADULT HEALTHCARE

by

REBECCA A. MEYER

ASN, St. Louis Community College at Meramec, St. Louis
BSN, Barnes-Jewish College of Nursing and Allied Health, St. Louis
MSN, Goldfarb School of Nursing at Barnes-Jewish College, St. Louis

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Advisory Committee

Anne F. Fish, PhD, RN, FAHA

Chairperson

Kuei-Hsiang Hsueh, PhD, RN

Kimberly Allen, PhD

Wilma Calvert, PhD, RN

Neil White, MD

Abstract

Adolescents must enter adult health care services at age 18, yet most are not ready and have not mastered daily self management of their type 1 diabetes. The purpose of this study was to determine the feasibility of a transition planning intervention, focused on educating adolescent/parent dyads about diabetes self management in preparation for the transition from pediatric to adult health care, using a newly developed transition plan and framework. The setting was a diabetes endocrinology clinic where 95% of young type 1 diabetics in the metropolitan area are seen. The intervention included supporting the parent in the relinquishing of diabetes management responsibilities to the adolescent. This study measured the transition readiness and self management practices of the adolescent as well as the parents' ability to promote autonomy in their adolescents' transition to self management. In addition, this study sought to gain information from the dyads on the usefulness of this intervention.

The intervention consisted of four weekly sessions emphasizing a review of type 1 diabetes pathophysiology, daily living with type 1 diabetes, leaving the parental home, and reproductive health. A non-experimental, pre-post feasibility design was used and 11 adolescent/parent dyads consented to participate. Seven dyads completed the intervention. Using descriptive statistics, mean scores improved for transition readiness, diabetes care activities, problem solving, communication, and goals setting. Post intervention evaluations completed by participants were favorable. Most agreed or strongly agreed that the transition intervention was helpful in getting adolescents ready for transition and taking care of diabetes as a young adult. They would recommend this intervention to others.

Based on the findings of this study and evidence found in the literature, the intervention will soon be packaged into brief 15-minute teaching sessions presented during quarterly clinic

visits for all adolescents age 15-18 at the study site. If any adolescent remains in the clinic until age 19 or later, the intervention will continue quarterly until the adolescent transitions to adult health care. In addition, based on the responses given by the adolescent/parent dyads at completion of the sessions, this intervention contains useful information relevant to the adolescents' transition to adult health care.

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In memory of my brother who passed away at age 42 from complications of type 1 diabetes and who was a good friend. He took my daughter, Amy, under his wing when she was diagnosed with type 1 diabetes at age 6. He helped her to realize the importance of taking care of your body because of what he went through.

Table of Contents

Abstract.....	2
Acknowledgements.....	4
Table of Contents.....	5
List of Tables.....	10
List of Figures.....	12
List of Appendices.....	13
Chapter I	
Introduction.....	14
Statement of Problem.....	14
Background.....	17
Significance.....	20
Purpose-Feasibility.....	21
Associated Assumptions.....	22
Research Questions.....	22
Related Question.....	23
Chapter II	
Introduction.....	24
Transition Plan.....	24
Review of Literature on Transition Plan.....	25
Method.....	25
What is Known About Transition.....	26
Not Known About Transition.....	32

Factors Affecting Glucose Control.....	35
Carbohydrate Intake/Insulin Administration.....	35
Physical Activity.....	36
Blood Glucose Testing.....	36
Doctor Visits.....	37
Alcohol Use.....	37
Theory Related to Transition Readiness, Self Management, and Parental Support.	37
Transition.....	38
Developmental.....	40
Erikson's Stages of Psychosocial Development.....	40
Emerging Adulthood.....	42
Self-Efficacy.....	42
Mastery.....	45
Self Management.....	46
Health Belief Model.....	48
Parent Development Theory.....	49
Review of Instruments Related to Transition Readiness, Self Management, and	
Parental Support for Autonomy.....	51
Method.....	52
Results.....	52
Adolescent.....	54
Transition Readiness.....	54
Self Management.....	54

Support for Autonomy.....	55
Adolescent and Parent.....	55
Transition Readiness.....	55
Self Management.....	55
Support for Autonomy.....	56
Criteria for Instrument Inclusion.....	57
Summary	59
Chapter III	
Introduction.....	60
Research Questions.....	60
Related Question.....	61
Method.....	61
Design.....	61
Recruitment.....	62
Setting.....	62
Sample.....	62
Intervention.....	63
Data Collection Measures.....	64
Data Collection Procedures.....	66
Data Management and Analysis.....	67
Protection of Human Subjects.....	67
Chapter IV	
Introduction.....	70

Research Questions.....	70
Related Question.....	71
Results.....	71
Sample Characteristics.....	71
Missing Data.....	72
Findings Related to Research Questions and Related Question.....	72
Summary of Results.....	79

Chapter V

Introduction.....	81
Summary of the Problem.....	81
Summary of the Significance.....	83
Summary of the Purpose.....	84
Discussion of Results.....	85
Study Strengths.....	88
Study Limitations.....	89
Recruitment of Adolescents.....	90
Theoretical Considerations.....	91
Transition Theory.....	91
Erikson's Stages of Psychosocial Development and Emerging Adulthood.....	92
Self-Efficacy, Mastery, and Self Management Theories and Health	
Health Belief Model.....	92
Parent Development Theory.....	93
Implications for Practice.....	93

Implications for Future Research.....	95
Conclusions.....	96
Tables.....	97
Figures.....	112
References.....	114
Appendices.....	133

List of Tables

Table 1	Instruments Useful for Creating a Transition Plan in Adolescent with Type 1	
	Diabetes-Transition.....	97
Table 2	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes-Self Management.....	98
Table 3	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes-Support.....	99
Table 4	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes and Their Parent-Transition.....	100
Table 5	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes and Their Parent-Self Management.....	101
Table 6	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes and Their Parent-Self Management.....	102
Table 7	Instruments Useful for Creating a Transition Plan in Adolescents with Type 1	
	Diabetes and Their Parent-Support.....	104
Table 8	Criteria for Intervention Inclusion.....	105
Table 9	Recruitment Venues.....	106
Table 10	Data Collection Schedule.....	107

Table 11 Diabetes Transition Demographics Pre Intervention (n=11).....	108
Table 12 Diabetes Transition HbA1c Table Pre Intervention (n=11).....	109
Table 13 Transition Readiness Assessment Questionnaire (TRAQ) Results (n=7).....	110
Table 14 Self Management of Type 1 Diabetes in Adolescents (SMOD-A) Results (n=7).....	110
Table 15 Diabetes Specific Parental Support for Adolescents Autonomy Scale Results (n=7).....	110
Table 16 Post Intervention Evaluations.....	111

List of Figures

Figure 1	Transition Plan from Pediatric to Adult Endocrinology Services for the Patient with Type 1 Diabetes.....	112
Figure 2	Theoretical Model of Transition from Pediatric Endocrinology Health Services to Adult Endocrinology Health Services.....	113

List of Appendices

Appendix A: Transition Readiness Assessment Questionnaire (TRAQ).....	133
Appendix B: Self Management of Type 1 Diabetes in the Adolescent (SMOD-A).....	134
Appendix C: Diabetes Specific Parental Support for Adolescents Autonomy Scale (DSPAAS).....	138
Appendix D: Institutional Review Board Approval Letter, Washington University.....	140
Appendix E: Recruitment Letter.....	141
Appendix F: Recruitment Flyer.....	142
Appendix G: Demographic Form.....	143
Appendix H: Phone Script.....	144
Appendix I: Website Post Registry.....	145
Appendix J: Facebook Post Registry.....	146
Appendix K: Centerwatch Post Registry.....	147
Appendix L: BJC Today Advertisement.....	148

CHAPTER I

Introduction

Chapter I contains specific detail regarding the statement of the problem for the current study. It includes a discussion of the background and significance of the study. This chapter concludes with associated assumptions and the research questions for this study.

Statement of the Problem

Type 1 diabetes is an autoimmune disorder that occurs when the body destroys its insulin-producing beta-cells leading to a lack of insulin production for proper carbohydrate metabolism. Medical expenditures among people diagnosed with type 1 diabetes in the United States are about nine times higher than for those without type 1 diabetes, and the total cost of type 1 diabetes per year is equal to \$14.9 billion (JDRF, 2011). It is estimated that one in every 400 to 500 youth has type 1 diabetes (Centers for Disease Control and Prevention [CDC], 2010). Macrovascular and microvascular complications arising from poor glucose control in those with type 1 diabetes are a continual threat. Serious complications of diabetes are imminent unless daily blood glucose is controlled and maintained over time. Fewer than 1 in 20 young adults with diabetes achieve target HbA1c levels and up to 37% already have, at a young age, serious complications as a result of poor glucose control (Balfe, 2009b; The Diabetes Control and Complications Trial Research Group [DCCT], 1993). Tight glucose control results in decreased rates of diabetes complications and premature mortality (Centers for Disease Control and Prevention [CDC], 2011; DCCT, 1993) therefore, preventing complications before they manifest, rather than attempting to reduce the effects of diabetes complications after they occur, is advantageous.

Research indicates that the adolescent to young adult period is a critical time for prevention of diabetes complications. Making poor choices in diabetes management can result in negative life-changing situations including poor metabolic control (an increase in HbA1c levels), feeling unwell, premature cardiovascular disease, and failure to reach desired life goals as an adult. Other sequelae are loss to medical follow-up, hospitalizations, and possibly premature death (Anderson & Wolpert, 2004; Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Bryden et al., 2001; Wolpert & Anderson, 2001). As adolescents age, they must take on more responsibility for diabetes management, however, they may not have adequate background information to manage type 1 diabetes well (American Diabetes Association [ADA] & Barclay, 2011; Anderson & Wolpert, 2004). At a young age at diagnosis, they were unable developmentally to comprehend the disease and the complexity of its management, and their parents received type 1 diabetes education in the hospital, typically an intensive two-day training session that *focuses solely on survival with diabetes* (B. Alseth, RN, Certified Diabetes Educator, personal communication, January, 24, 2012). As a result, adolescents receive information about diabetes management second hand from their parents (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP] & American College of Physicians-American Society of Internal Medicine [ACP], 2002; Bowen, Henske, & Potter 2010; Jameson, 2011; Rasmussen, Ward, Jenkins, King, & Dunning, 2011; Visentin, Koch, & Kralik, 2006).

Understanding the pathophysiology of type 1 diabetes and the rationale behind self management practices is vital to remain healthy (Anderson & Wolpert, 2004). Clinically, adolescents do receive ongoing coaching, preventive, and self management strategies during doctor visits and during diabetes emergencies such as hospitalization for diabetic ketoacidosis,

but instruction at these times tends to be reactive rather than proactive, and emergency visits are not ideal venues for learning and retention of knowledge (Surawy, 1989; Visentin et al., 2006).

Transitioning from adolescent to adult diabetes endocrine health care services at age 18, most adolescents are not ready and by that time have not mastered daily self management of their type 1 diabetes (ADA & Barclay, 2011; Anderson & Wolpert, 2004; Bryden et al., 2003; Bryden et al., 2001; Surawy, 1989; Visentin et al., 2006; Weissberg-Benchell, Wolpert, & Anderson, 2007; Wolpert & Anderson, 2001). This transition between services may be planned or abrupt depending upon the structures in place between these services (Lugasi, Achille, & Stevenson, 2011). Once the adolescent enters adult health care, they are viewed differently, as independent, self-reliant, and able to make decisions about treatment without parental help, which can be challenging for some 18-year olds (Bowen et al., 2010; Fleming, Carter, & Gillibrand, 2002; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Visentin et al.).

Much of the literature on adolescent transition between pediatric and adult diabetes health care services uses focus groups, interviews, or non-validated surveys as a means to study transition in adolescents to adult health care, concentrating on discrepancies between the services. Observational and descriptive studies on non-structured transition programs showed them to be less than effective, with poor outcomes related to clinic attendance and early onset of diabetes complications (Anderson & Wolpert, 2004; Bowen et al., 2010; Daneman & Nakhla, 2011; Fleming et al., 2002; Frank, 1992; Garvey et al., 2012; Garvey & Wolpert, 2011; Hanna & Guthrie, 2000; Keough, Sullivan-Bolyai, Crawford, Schilling, & Dixon, 2011; Kipps et al., 2002; LoCasale-Crouch & Johnson, 2005; Logan et al., 2008; Lotstein, McPherson, Strickland, & Newacheck, 2005; Pacaud & Yale, 2005; Pacaud, Yale, Stephure, Trussell, & Davies, 2005; Perry, Steinbeck, Dunbabin, & Lowe, 2010; Rapley & Davidson, 2010; Rasmussen et al., 2011;

Scal & Ireland, 2005; Scal, Evans, Blozis, Okinow, & Blum, 1999; Scott, Vallis, Charette, Murray, & Latta, 2005; Van Wallegghem, MacDonald, & Dean, 2008; Van Wallegghem, MacDonald, & Dean, 2006; Visentin et al., 2006; Wolpert & Anderson, 2001). Studies with structured transition plans measured clinic attendance, hospitalizations, severe hypoglycemia, diabetes complications, and barriers to accessing care (Cadario et al., 2009; Nakhla, Daneman, To, Paradis, & Guttmann, 2009; Orr, Fineberg, & Gray, 1996), yet none focused on these important factors: transition readiness or self management practices before and after the implementation of a transition plan, smoking, alcohol, or drug consumption that may affect daily management of type 1 diabetes, reproductive health, or involvement of parents in the process. No published randomized controlled studies of type 1 diabetes transition plans from pediatric to adult health care were found.

Background

Long-term survival of those with type 1 diabetes has dramatically improved after results of the The Diabetes Control and Complications Trial Research Group (DCCT) (1993) were published and intensive glucose management became the standard of care for type 1 diabetes (National Institute of Health, 2011). The DCCT demonstrated that intensive treatment with the goal of maintaining blood glucose concentrations as close to the normal range as possible effectively delays the onset, reduces the incidence, and slows the progression of micro and macrovascular complications of type 1 diabetes, specifically, diabetic retinopathy by 76%, nephropathy by 50%, and neuropathy by 50% (DCCT, 1993; The National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2008). In addition, the DCCT established that any sustained lowering of blood glucose helps reduce diabetes complications even if the person has a history of prior poor glucose control (NIDDK, 2008). A follow-up study, Epidemiology of

Diabetes Interventions and Complications, showed a 42% reduction in cardiovascular events and a 57% reduced risk of nonfatal heart attack, stroke, or death from cardiovascular causes when blood glucose is maintained at or near the normal range (NIDDK, 2008). As a result of enhanced blood glucose control, increasing numbers of those with type 1 diabetes are surviving into adulthood without severe complications and transitioning from pediatric to adult endocrinology health services (adult health care) at increasing rates (AAP et al., 2002; ADA & Barclay, 2011; Bowen et al., 2010; Fleming et al., 2002; LoCasale-Crouch & Johnson, 2005; Lotstein et al., 2005; Orr et al., 1996; Rapley & Davidson, 2010; Scal & Ireland, 2005; Scal et al., 1999).

As the child grows and matures he or she transitions from a role of dependence upon parents to independence in managing their disease, as they will no longer be under the constant supervision of parents. Many potential barriers exist that may prevent a successful transition to adult health care. First, this stage in the adolescent's life can be chaotic and unpredictable due to moving out of the parental home to go to college, living on their own, or entering the workforce at a job with variable hours. The established routine previously experienced while living at home under the care of parents is gone and there is reduced parental involvement in diabetes management (ADA & Barclay, 2011; Keough et al., 2011; Peveler, Davies, Mayou, Fairburn, & Mann, 1993; Strachan, MacCuish, & Frier, 2000; VanWalleghem et al., 2008; Van Walleghem et al., 2006; Wdowik, Kendall, & Harris, 1997; Wilson, 2010). Second, the long-term, comfortable relationship with the pediatric endocrinologist, where care is family-focused and visits include both the patient and the parent, is not the norm with adult health care. Pediatric health care has been described as nurturing whereas adult health care can be less family focused, as adult health care visits tend to be more disease focused (Bowen et al., 2010; Fleming et al., 2002; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Rapley & Davidson, 2010; Visentin et al., 2006).

Third, adult physicians, while capable of caring for young adults with chronic diseases, may not be as adept as pediatric endocrinologists at handling developmental and psychosocial issues that coincide with this age group and disease chronicity (Cadario et al., 2009; Lotstein et al., 2005; Orr et al., 1996). Fourth, navigating health insurance and the process for obtaining diabetes supplies can be overwhelming for the newly independent adolescent (Frank, 1992; Jameson, 2011; LoCasale-Crouch & Johnson; Lugasi et al., 2011; Peters, Laffel, & The American Diabetes Transitions Working Group, 2011). Finally, adolescents may not have an adequate educational background on the management of diabetes due to old information from parents, or independent management was not permitted (Surawy, 1989; Visentin et al.).

The transition to independent management of type 1 diabetes must be a gradual process of the parent releasing responsibility while the adolescent gradually increases his or her responsibility in diabetes management. Communication between the adolescent and parent is important during this transition. Parents' relinquishing control over diabetes management may manifest as nagging, over-questioning about self management, giving orders, and strictness that can become a source of conflict. Adolescents view this as intrusive (Dashiff, Hardeman, & McClain, 2008; Hanna, Dashiff, Stump, & Weaver, 2012; Hanna & Guthrie, 2000). However, feelings of loss of control and worry over future complications may be the motive behind parental behaviors and must be considered during the transition of diabetes management responsibilities. In addition, parents may perceive that their adolescent's diabetes self management practices are unsatisfactory, or the adolescent may feel as though their parents do not trust their judgment in self management decisions. Parental support and trust in adolescent decision making is necessary for the adolescent to successfully transition from pediatric to adult

health care and independent living (Chaney et al., 2011; Hanna, 2012; Surawy, 1989; Visentin et al, 2006).

Significance

Transitioning from pediatric to adult health care is not an automatic process for the adolescent with type 1 diabetes or their parent. The adolescent needs time to transition to independent diabetes self management while at the same time the parent needs time to relinquish diabetes management responsibilities to the adolescent. Adolescents need a review of basic type 1 diabetes pathophysiology, insulin action, nutrition, exercise and glucose management in addition to the mechanisms of diabetes complications and problem solving related to hypoglycemia and hyperglycemia episodes. Additionally, the adolescent needs to know the effects of smoking, alcohol use, and drug use on glucose control as well as overall health. Other aspects of daily living with type 1 diabetes including determining and procuring needed supplies, phoning the doctor, gaining employment, moving out of the parental home, obtaining Individual Education Plans (IEP) or a 504 plan in preparation for college entrance exams, and disclosing to others that the adolescent has diabetes are skills that take time to learn. Lastly, information on pregnancy and how diabetes affects the mother, fetus, and infant post delivery are essential for the female adolescent to know for future family planning. While the effects of type 1 diabetes on male reproductive health are generally not apparent until adult years, adolescent males should receive information on normal reproductive health and preventative health measures.

Transitioning the adolescent with type 1 diabetes from pediatric to adult health care must be a planned, gradual process to ensure both the adolescent and the parent are adequately prepared for the change in diabetes management responsibilities. This process could take up to four years, or the entire period of time the adolescent is in high school. This study facilitates the

education of adolescents on diabetes self management in preparation for the transition from pediatric to adult health care. This study also includes support for the parent in the relinquishing of diabetes management responsibilities to the adolescent.

Purpose-Feasibility

Extensive work has been done on what transition planning interventions should provide to the adolescent getting ready to move to adult health care. These interventions should be comprehensive, interactive, collaborative, and proactive to optimize health and meet the complex developmental and psychosocial needs of the adolescent in a structured format. In addition, the interventions should contain diabetes coaching, preventive, and self management strategies for adolescents with type 1 diabetes (AAP et al., 2002; Anderson & Wolpert, 2004; Bowen et al., 2010; Daneman & Nakhla, 2011; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Lotstein et al., 2005; Nakhla et al., 2009; Rapley & Davidson, 2010; Rosen et al., 2003; Scal & Ireland, 2005; Scal et al., 1999; Scott et al., 2005; Van Wallegghem et al., 2008; Van Wallegghem 2006; Visentin et al., 2006). Though these interventions have been described, they have not been systematically studied. A feasibility study, using the framework described by Bowen (2009), is a sound approach to investigate whether the intervention can be implemented and to determine the usefulness of a transition planning intervention to adolescents and their parents. The purpose of this study was to determine the feasibility of a transition planning intervention, focused on educating adolescent/parent dyads about diabetes self management in preparation for the transition from pediatric to adult health care, using a newly developed transition plan and framework. Transition readiness, diabetes self management practices, and parental support for autonomy in adolescent decision making from the adolescent and parent point of view were examined.

Associated Assumptions

The first assumption is that adolescents are not adequately prepared for the transition from pediatric to adult health care. The second assumption is that adolescents need to become more independent in the self management of their disease by acquiring more autonomy. The third assumption is that parents' actions and behaviors may be counterproductive to adolescents becoming more autonomous in type 1 diabetes self management; parents and adolescents should work together to contribute to a successful transition.

Research Questions

The research questions for this study were:

Research Question 1: Will transition readiness in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 2: Will self management practices (collaboration with parents, diabetes care activities, diabetes problem-solving, diabetes communication, and goal setting) in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 3: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 4: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from the parent of adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 5: Is this intervention useful to help with getting ready to transition the child's care to adult medical health care providers?

Research Question 6: Does this intervention provide important information about how to take care of the child's diabetes as a young adult?

Research Question 7: Would adolescents and parents recommend this intervention to other families with teenagers and young adults with diabetes?

Research Question 8: What parts of the intervention were most useful?

Research Question 9: What parts of the intervention were least useful?

Research Question 10: Are there ways the intervention can be improved?

Related Question

Related Question: Does the Diabetes Specific Parental Support for Autonomy in Adolescents Scale (DSPAAS) function in determining parental support for autonomy in adolescents age 15-19 after participation in a transition planning intervention?

CHAPTER II

Introduction

Chapter II contains 4 sections. The first section of this chapter introduces the transition plan followed by a review of the literature on transition plans. The second section presents factors affecting glucose control in the adolescent. The third section contains theories related to transition readiness, self management and parental support, and their application to the adolescent with type 1 diabetes. The final section includes a review of instruments that measure transition readiness, self management practices of the adolescent, and parents' ability to promote autonomy in their adolescents' transition to diabetes self management. In addition, a synthesis of instruments measuring these concepts with a determination of those instruments most suitable for this study is included in the final section.

Transition Plan

The adolescent transitioning into adult health care has many needs. To assist with a smooth transition from pediatric to adult health care, a transition plan is proposed (Figure 1). The Transition Plan from Pediatric to Adult Endocrinology Services for the Patient with Type 1 Diabetes has a developmental foundation using Erikson's Psychosocial Stages of Development and Arnett's Emerging Adulthood, and is for those adolescents aged 15 to age 19. Through fieldwork, it became apparent that some 14 year-old adolescents were not developmentally ready to start the transition process, so age 15, as opposed to age 14 or start of high school, was chosen to begin the plan. At age 15, the adolescent is beginning to drive a car, becoming more independent, and thinking about plans for post-high school therefore, the 15 year-old was deemed more developmentally ready to start the transition process. As the adolescent grows and

matures, life becomes more complex for the individual and diabetes management takes a backseat to other life distractions.

Reading the transition plan (Figure 1), the left column of the plan depicts the progression of the adolescent and family throughout the transition process whereas the right column depicts the responsibilities of the diabetes healthcare provider. As the adolescent matures, he or she becomes more responsible for their diabetes management with less dependence upon the parent. Also, as the adolescent matures, he or she may become less dependent on the parent and healthcare provider for routine, daily management, and focuses more on the overall picture of glucose control and the prevention of diabetes complications. The diabetes healthcare provider may spend less time devoted to therapy adherence and more time educating the adolescent on psychosocial and healthy lifestyle habits. The newly developed transition plan is multidisciplinary and is designed to be used in the clinic setting over a three-four year period. However, for purposes of completing this study, and after discussion with clinic personnel, the decision was made for the current study to be focused on educating the adolescent and parent on type 1 diabetes pathophysiology and daily living skills.

Review of Literature of Transition Plans

Method

A comprehensive review of the literature related to transition, diabetes self management, and parental support for adolescents' autonomy was conducted through a computerized search of Academic Search Elite, Academic Search Premier, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychArticles, PsychInfo, PubMed, and reference lists of research articles. Search terms included adolescent, diabetes mellitus type 1, self management, transition, and parental support for adolescents' autonomy. One hundred and twenty articles were

obtained. The literature on transition focuses on problems adolescents encountered during transition and discrepancies between pediatric and adult health care using focus or support groups, patient interviews, or surveys (Anderson & Wolpert, 2004; Bowen et al., 2010; Daneman & Nakhla, 2011; Fleming et al.; Frank, 1992; Garvey et al., 2012; Garvey & Wolpert, 2011; LoCasale-Crouch & Johnson, 2005; Logan et al., 2008; Lowes, 2008; Markowitz & Laffel, 2012; Pacaud & Yale, 2005; Pacaud et al., 2005; Perry et al., 2010; Peters et al., 2011; Rapley & Davidson, 2010; Rasmussen et al., 2011; Sawyer, Blair, & Bowes, 1997; Scal et al., 1999; Scott et al., 2005; VanWallegghem et al., 2008; Van Wallegghem et al., 2006; Visentin et al., 2006; Watson, Parr, Joyce, May, & Le Couteur, 2011; Wolpert & Anderson, 2001). No published randomized controlled studies of transition plans with evidence-based interventions were found.

What is Known About Transition

A significant problem associated with the transition from pediatric to adult health care is a decrease in clinic or office visit attendance or complete loss to follow-up (Allen & Gregory, 2009; ADA & Barclay, 2011; Bowen et al., 2010; Cadario et al., 2009; Fleming et al., 2002; Garvey et al., 2012; Hanna & Woodward, 2013; Johnston, Bell, Tennet, & Carson, 2006; Lewis & Hermayer, 2013; Logan et al., 2008; Lugasi et al., 2011; Markowitz & Laffel, 2012; Masding et al., 2010; Orr et al., 1996; Pacaud & Yale, 2005; Pai & Ostendorf, 2011; Perry et al., 2010; Peveler et al., 1993; Rapley & Davidson, 2010; Scott et al., 2005; Strachan et al., 2000; Vanelli et al., 2004; VanWallegghem et al., 2008; Van Wallegghem et al., 2006; Wdowik et al., 1997). Identified barriers to clinic attendance include anxiety over leaving the pediatric service and attending the adult health care clinic due to lack of trust and or confidence in the adult healthcare provider (Allen & Gregory, 2009; Anderson & Wolpert, 2004; Fernandez et al., 2014; Fleming et al., 2002; Hanna & Woodward; Harris, Freeman, & Duke, 2011; LoCasale-Crouch & Johnson,

2005; Lowes, 2008; Lugasi et al.; Markowitz & Laffel; Nakhla et al., 2009; Pacaud & Yale, 2005; Rapley & Davidson; Scott et al.). In addition, negative perceptions of adult health care providers may be relayed to the patient by the pediatric endocrinology services or the parent (Harris et al.; Lowes).

Some pediatric endocrinology services do not want to “let go” of their patients due to the belief that adult health care providers are unfamiliar with psychosocial aspects of this age range and therefore may not provide adequate care (Anderson & Wolpert, 2004; Fleming et al., 2002; Harris et al., 2011; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Rapley & Davidson, 2010; Sawyer et al., 1997; Weissberg-Benchell et al., 2007). Additionally, waiting rooms of adult health care providers’ offices may have older adults with diabetes complications such as amputations, which can be frightening as the adolescents’ mortality is threatened (Lowes, 2008). Adolescents perceive that their regimen may change with the transition to adult health care and are reluctant to make a switch in their routine. They may not have the inclination to rewrite their health history for the adult health care provider, or they feel they do not have the time owing to competing demands to maintain a schedule of appointments with the healthcare provider. This results in relegation of diabetes self management to a lower priority due to lack of coordination and communication between adult health care providers (Bowen et al., 2010; Garvey & Wolpert, 2011; Harris et al.; Lowes; Markowitz & Laffel, 2012; Peters et al., 2011; Rapley & Davidson; Rasmussen et al., 2011; Wolpert & Anderson, 2001).

Successful self management of diabetes is a means to healthy living and avoiding complications but many factors can interfere. First, daily management and attention to diabetes can be overwhelming and demanding, leading to burnout from the stress of continuous monitoring or psychosocial issues such as depression and anxiety when glucose control is not as

expected (AAP, 2002; Anderson & Wolpert, 2004; Fleming et al., 2002; Frank, 1992; Gelder, 2009; Hanna, 2012; Lewis & Hermayer, 2013; LoCasale-Crouch & Johnson, 2005; Logan et al., 2008; Lotstein et al., 2005; Pacaud & Yale, 2005; Rapley & Davidson, 2010; Scal et al., 1999; Trigwell & Jawad, 2010; VanWallegghem et al., 2008; Van Wallegghem et al., 2006; Weissberg-Benchell et al., 2007; Wolpert & Anderson, 2001). Second, delayed psychosocial development may be a factor, as shown by high uptake of psychological services in adolescents (Logan et al.; Pacaud & Yale; Surridge et al., 1984; Weissberg-Benchell et al.). This trend is especially found in females with eating disorders leading to poor glucose control and subsequent development of diabetes complications (Weissberg-Benchell et al.). Pre-DCCT (pre-intensive management) studies on psychosocial maturation in older adolescents with diabetes revealed significant psychosocial development delay. However, more recent studies depict those with type 1 diabetes as having similar psychosocial development as those without type 1 diabetes (Gillibrand & Stevenson, 2006; Pacaud et al., 2007; Pacaud & Yale; Weissberg-Benchell et al.).

Other barriers related to self management include fear of hypoglycemia (Anderson & Wolpert, 2004; Balfe, 2009; Balfe, 2009b; Bowen et al., 2010; Eaton, Williams, & Bodansky, 2001; Frank, 1992; Garvey & Wolpert, 2011; Hanna, 2012), dietary and weight control issues (Anderson & Wolpert; Balfe, 2009; Balfe, 2009b; Balfe, 2007; Bowen et al., 2010; Frank; Garvey & Wolpert; Hanna; Lewis & Hermayer, 2013; Rapley & Davidson, 2010; Hillege, Beale, & McMaster, 2008; Weissberg-Benchell et al., 2007; Wdowik et al., 1997; Wilson, 2010; Wolpert & Anderson, 2001), sexuality and pregnancy (Balfe, 2009; Bowen et al., 2010; Fernandez et al., 2014; Frank, 1992; Lewis & Hermayer, 2013; Logan et al., 2008), and lastly smoking, drug and alcohol use (Balfe, 2009; Balfe, 2007; Bowen et al., 2010; Eaton et al.; Hanna; Lewis & Hermayer, 2013; Miller-Hagan & Janas, 2002; Perry et al., 2010; Ramchandani

et al., 2000; Wdowik et al.; Wilson). The adolescent along with the diabetes healthcare team must take a proactive stance to manage these problems; thus preventing the development of bad habits in self management and promoting high-quality decision making related to diabetes management.

Aspects interfering with self management include lack of finances, ignorance of insurance benefits, and navigation of the insurance system (Bowen et al., 2010; Daneman & Nakhla, 2011; Garvey & Wolpert, 2011; Jameson, 2011; Peters et al., 2011; VanWallegghem et al., 2008; Van Wallegghem et al. 2006; Weissberg-Benchell et al., 2007). Many older adolescents may not have insurance coverage due to part time work status or they are attending college. These individuals may still be covered under their parent's insurance plans so the parents take on negotiating insurance claims and finances related to diabetes management.

One study evaluated diabetes outcomes related to the transition process. This study examined the duration of diabetes and HbA1c pre and post transition to adult health care among young adults aged 23-25. Females had poorer glucose control overall. Duration of diabetes diagnosis did not have an effect on HbA1c levels pre or post transition in this group. This study was not successful in lowering HbA1c levels in both males and females (Orr et al., 1996).

The synthesis of the literature of transition plans without structure show different approaches to the transition process and provide an appreciation of the need for a well-constructed progression from pediatric to adult health care (Lotstein et al., 2005; Scal et al., 1999; Trigwell & Jawad, 2010). Few studies report a gradual introduction of adult health services with even less proposing highly structured transition models. Pediatric diabetes healthcare providers without transition plans may or may not end their involvement with the adolescent at age 18. However, by the time the adolescent with type 1 diabetes reaches the age of

22, most have been released to the care of an adult diabetes health care provider. Transition occurring without planning generally produces poor clinic attendance with subsequent early onset of diabetes complications (Allen & Gregory, 2009; Anderson & Wolpert, 2004; Bowen et al., 2010; Cadario et al., 2009; Daneman & Nakhla, 2011; Frank, 1992; Garvey & Wolpert, 2011; Gelder, 2009; Jameson, 2011; Kipps et al., 2002; Lewis & Hermayer, 2013; LoCasale-Crouch & Johnson, 2005; Logan et al., 2008; Lotstein et al., 2005; Lowes, 2008; Lugasi et al., 2011; Nakhla et al., 2009; Pacaud & Yale, 2005; Pacaud et al., 2005; Pai & Ostendorf, 2011; Rapley & Davidson, 2010; VanWallegghem et al., 2008; Van Wallegghem et al., 2006; Visentin et al., 2006).

To assist the adolescent during the transition, a structured process appears to contribute to better diabetes outcomes. Studies have measured clinic attendance rates (Cadario et al., 2009; Holmes-Walker, Llewellyn, & Farrell, 2007; Kipps et al., 2002; Logan, 2008; Masding et al., 2010; Orr et al., 1996; Van Wallegghem et al., 2006), number of hospitalizations (Cadario et al.; Nakhla et al., 2009; Van Wallegghem et al.), severe hypoglycemic reactions (VanWallegghem et al., 2008; Van Wallegghem et al., 2006), diabetes complications (Logan et al.; Nakhla et al.; VanWallegghem et al., 2008; Van Wallegghem et al., 2006), and barriers to accessing care (Cadario et al.; Nakhla et al.; VanWallegghem et al., 2008; Van Wallegghem et al., 2006) between a structured and a non-structured transition process. Clinic attendance rates decreased significantly among all groups, however, those with a non-structured transition process showed significantly higher non-attendance rates with resulting worsening of glucose control as evidenced by higher HbA1c levels (Cadario et al.; Kipps et al.; Lugasi et al., 2011; Masding et al.). This is especially evident for those living in rural areas (Perry et al., 2010). However, those

that met the adult diabetes healthcare provider prior to transition had higher rates of clinic attendance (Cadario et al.; Kipps et al.).

Diabetes complications occurred in both structured and non-structured transition programs. However, those in non-structured programs fared worse with significantly higher rates of diabetic retinopathy (Nakhla et al., 2009), hospitalizations for diabetic ketoacidosis (DKA; Perry et al., 2010; VanWallegghem et al., 2008; Van Wallegghem et al., 2006), severe hypoglycemia (Perry et al.; VanWallegghem et al., 2008; Van Wallegghem et al., 2006), as well as amputations and death secondary to DKA (VanWallegghem et al., 2008; Van Wallegghem et al., 2006). Among structured transition groups, participants experienced less frustration with scheduling appointments, developing relationships with the new healthcare team, or feelings of being “lost in the shuffle” (Cadario et al., 2009; Harris et al., 2011; Lewis & Hermayer, 2013; Lugasi et al., 2011; Nakhla et al.; VanWallegghem et al., 2008; Van Wallegghem et al., 2006).

Overall, research suggests that in the transition from pediatric to adult health care there should be a comprehensive transition planning intervention that addresses all aspects of diabetes self management. The transition planning intervention should support the adolescent in their progression from dependence on parents to independent self management while maintaining health, and should be collaborative including the adolescent, their family, and both the pediatric and adult diabetes healthcare providers (AAP et al., 2002; ADA & Barclay, 2011; Anderson & Wolpert, 2004; Bowen et al., 2010; Cuttell, 2004; Daneman & Nakhla, 2011; Gelder, 2009; Hanna & Woodward, 2013; Hanna et al., 2012; Harris et al., 2011; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Lotstein et al., 2005; Rapley & Davidson, 2010; Scal & Ireland, 2005; Scal et al., 1999; Scott et al., 2005; Van Wallegghem et al., 2008; Van Wallegghem et al., 2006; Visentin et al., 2006). A program coordinator is recommended to provide continuity and

familiarity during the process (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP] and American College of Physicians [ACP], Transitions Clinical Report Authoring Group, 2011; Bowen et al., 2010; Cuttell; Holmes-Walker et al., 2007; Logan et al., 2008; Michaud, Suris, & Viner, 2004; Peters et al., 2011; Rapley & Davidson; Sawyer et al., 1997; Scal et al., 1999).

Not Known About Transition

Transition planning must begin at an early age with a written, well-thought, structured process with clear goals and strategies (AAP et al., 2002; ADA & Barclay, 2011; Anderson & Wolpert, 2004; Bowen et al., 2010; Cuttell, 2004; Frank, 1992; Harris et al., 2011; Pacaud et al., 2005; Peters et al., 2011; Rapley & Davidson, 2010; Scal & Ireland, 2005; Scal et al., 1999; Scott et al., 2005; VanWalleghem et al., 2008; Van Walleghem et al., 2006; Visentin et al., 2006). Transition planning interventions in the literature did not address developmental issues or psychosocial barriers to self management (Allen & Gregory, 2009; AAP, AAFP and ACP, & Transitions Clinical Report Authoring Group, 2011; ADA & Barclay; Anderson & Wolpert; Gelder, 2009; Harris et al., 2011; Logan et al., 2008; Lotstein et al., 2005; Lowes, 2008; Lugasi et al., 2011; Pacaud & Yale, 2005; Pai & Ostendorf, 2011; Rapley & Davidson, 2010; Scal & Ireland; Scal et al.; Trigwell & Jawad, 2010; Weissberg-Benchell et al., 2007). Transition planning interventions did not include supporting the parent in their relinquishing of diabetes management responsibilities to their adolescent. Adolescents should be allowed separate time to speak with the diabetes healthcare provider in private as well as together with their parent throughout the transition planning period, which was not found in the literature (AAP, AAFP and ACP, & Transitions Clinical Report Authoring Group; ADA & Barclay; Anderson & Wolpert; Peters et al.; Harris et al.; VanWalleghem et al., 2008; Van Walleghem et al., 2006). Separate

time in a non-judgmental, respectful environment where caregivers are empathetic to this age group's life circumstances enhances communication and is key to the development of a trusting relationship with the healthcare provider (Allen & Gregory; AAP et al., 2002; Anderson & Wolpert; Lowes, 2008; Harris et al., 2011; Lewis & Hermayer, 2013; Pai & Ostendorf, 2011; Peters et al.; Price et al., 2011; VanWallegghem et al., 2008; Van Wallegghem et al., 2006; Visentin et al., 2006).

The adolescent is commonly managing diabetes with second-hand knowledge. Diabetes is a childhood onset disease and often, at the time of diagnosis, the patient is extremely young and not developmentally ready to learn or perform self management. Therefore, the parent is taught diabetes pathophysiology and tasks associated with monitoring the disease (AAP et al., 2002; Bowen et al., 2010; Gelder, 2009; Jameson, 2011; Lowes, 2008; Rasmussen et al., 2011; Visentin et al., 2006). For this reason, education sessions related to diabetes self management are essential within the transition planning intervention and no interventions were found in the literature that included a diabetes pathophysiology review. Education focusing on diabetes pathophysiology and complications, monitoring trends in glucose, adjusting insulin dosage, and recognizing body cues are the basis for further development of much needed critical thinking and problem-solving skills (Allen & Gregory, 2009; ADA & Barclay, 2011; Bowen et al., 2010; Garvey et al., 2012; Garvey & Wolpert, 2011; Gelder, 2009; Jameson, 2011; LoCasale-Crouch & Johnson, 2005; Logan et al., 2008; Rasmussen et al., 2011; Visentin et al.; Weissberg-Benchell et al., 2007). Also not found in the literature was the provision of information on navigating insurance and obtaining diabetes supplies or how to obtain a Section 504 Diabetes Management Plan that allows for diabetes care in the classroom. Section 504 plans also can and should be used during college entrance examinations to allow the adolescent to stop the clock to test blood

glucose and treat hypoglycemia or hyperglycemia episodes (Anderson & Wolpert, 2004; Bowen et al.; Garvey & Wolpert; Jameson; Scal et al., 1999).

In addition to specific disease management instruction, those in the transition process require education regarding living a physically and emotionally healthy life. Diabetes management skills not found in the transition readiness literature include how to prepare a balanced diet incorporating weight control, recognize eating disorders, manage exercise and hypoglycemia, manage diabetes when living away from the parental home, monitor blood glucose while driving a car, and information on reproductive health and implications of pregnancy for both the mother with diabetes and the unborn child (AAP, AAFP and ACP, & Transitions Clinical Report Authoring Group, 2011; ADA & Barclay, 2011; Anderson & Wolpert, 2004; Bowen et al., 2010; Charron-Prochownik, Ferons-Hannan, Sereika, & Becker, 2008; Charron-Prochownik et al., 2001; Fernandez et al., 2014; Garvey et al., 2012; Garvey & Wolpert, 2011; Harris et al., 2011; Jameson, 2011; Lewis & Hermayer, 2013; Pai & Ostendorf, 2011; Rapley & Davidson, 2010; Scal et al., 1999; Weissberg-Benchell et al., 2007). Also not found as part of transition planning interventions in the literature was teaching on smoking, drug, and alcohol use and the effects these have on the adolescent with type 1 diabetes (Balfe, 2009; Balfe, 2007; Bowen et al.; Eaton et al., 2001; Hanna, 2012; Lewis & Hermayer, 2013; Miller-Hagan & Janas, 2002; Perry et al., 2010; Ramchandani et al., 2000; Wdowik et al., 1997; Wilson, 2010). Finally, stress management and coping techniques to deal with the burnout from the stress of daily diabetes self management were not found in the literature on transition planning interventions (AAP, AAFP and ACP, & Transitions Clinical Report Authoring Group; ADA & Barclay; Fleming et al., 2002; Gelder, 2009; LoCasale-Crouch & Johnson, 2005; Pacaud et al., 2007; Rapley & Davidson; Scal et al.; Trigwell & Jawad, 2010; Weissberg-Benchell et al.).

Factors Affecting Glucose Control

Maintaining glucose control during the adolescent to young adult years is critical to prevent or limit the severity of diabetes complications and reduce premature mortality (Weissberg-Benchell et al., 2007). This requires a continuous and intensive regimen of healthy lifestyle habits, most importantly a balance of diet, insulin administration, and physical activity (American Diabetes Association [ADA], 2014). However, obtaining consistent glucose control is particularly challenging for adolescents with type 1 diabetes because they often engage in unhealthy behaviors such as poor eating habits, sedentary lifestyles, and alcohol consumption (Balfe, 2009; Miller-Hagan & Janas, 2002). For those adolescents who did not manage their disease well before transition to young adulthood, beginning a healthy lifestyle to manage their diabetes in young adulthood is likely to be especially challenging (Balfe, 2009).

The time to establish healthy habits and halt the progression to diabetes complications is in adolescence, but at the same time, a multitude of factors get in the way of optimal glucose control. An understanding of the factors involved in glucose control in adolescents with type 1 diabetes is necessary.

Carbohydrate Intake/Insulin Administration

Carbohydrate intake and insulin administration as prescribed is required for facilitating glucose control for the adolescent with type 1 diabetes and may be viewed as the most important concepts in obtaining excellent glucose control. Carbohydrate intake is prescribed jointly with insulin administration in a ratio of units of insulin to grams of carbohydrate. The degree that the insulin to carbohydrate ratio is followed as prescribed positively affects glucose control by reducing the likelihood of wide swings in glucose levels (ADA, 2014; Smart, Aslander-van Eliet, & Wladron, 2009; DCCT, 1993).

Physical Activity

Physical activity can also affect the extent to which glucose levels are within acceptable limits. The degree to which physical activity affects glucose is highly individualized, as some adolescents experience hyperglycemia post-exercise while others experience hypoglycemia (Jimenez et al., 2007; Smart et al., 2009). Because insulin levels are not regulated by the pancreas in type 1 diabetes and there is possible impairment of glucose counter-regulatory hormones to stimulate gluconeogenesis due to the disease, the adolescent must take care to consume adequate amounts of protein, fats, and carbohydrate throughout physical activity and several hours later to prevent hypoglycemia. Furthermore, physical activity increases muscle sensitivity to insulin post physical activity so the adolescent with type 1 diabetes must take extra care to monitor blood glucose levels for several hours post activity (ADA, 2014; International Society for Pediatric and Adolescent Diabetes [ISPAD], 2009; Jimenez et al.). Hypoglycemia post physical activity is more of a threat to health and well-being for the adolescent than post-physical activity hyperglycemia, though hyperglycemia post-physical activity can be frustrating.

Blood Glucose Testing

The greater amounts of blood glucose testing completed as prescribed positively affects glucose levels: the more the adolescent performs blood glucose testing, the greater the extent to which glucose levels may be within acceptable limits, giving rise to HbA1c levels within acceptable limits. Frequent blood glucose testing provides more information and feedback to the adolescent enabling better decision making for insulin administration (ADA, 2014; DCCT, 1993; Wdowik et al., 1997).

Doctor Visits

The number of doctor visits attended is associated with glucose control. The more the adolescent attends doctor visits as prescribed, the more his or her glucose control may be within normal limits. During doctor visits, glucose readings, insulin administration, and patterns of hypoglycemia and hyperglycemia are reviewed with recommendations on adjusting carbohydrate intake and insulin administration may be given. Patients that have infrequent follow-up with the doctor tend to have higher HbA1c levels and are at greater risk of developing diabetes complications. In addition, these patients may feel disconnected from the healthcare provider and have poor attitudes toward patient-physician interactions (Jacobson, Adler, Derby, Anderson, & Wolsdorf, 1991).

Alcohol Use

The extent of alcohol use affects glucose levels by paradoxically causing a dramatic lowering of blood glucose with potentially negative effects of dangerous hypoglycemia resulting in seizures, coma, and possibly death (Hanna, 2012; Miller-Hagan & Janas, 2002; National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2007). In addition, the adolescent with type 1 diabetes who is experiencing hypoglycemia may appear drunk to others and may not receive the assistance needed to correct the hypoglycemia in a timely manner. In summary, vigilance regarding alcohol and all of these factors is necessary for the adolescent to maintain adequate glucose control.

Theory Related to Transition Readiness, Self Management, and Parental Support

Theoretical frameworks are the foundation for research and ultimately application to practice. This theoretical framework includes theories or models about transition, developmental theories, self-efficacy, mastery, self management, health beliefs model, and parent development.

Specific parts of each are applicable to transition in diabetes management from adolescence to young adulthood (Figure 2). For the adolescent in transition from pediatric to adult health care, there must be a shift in self management practices. Transition and self management ability depend on the developmental stage of the adolescent in order to achieve mastery in the medical, role, and emotional aspects of diabetes self management. Also influencing this transition is self-efficacy, or the adolescent's belief and expectations in their capability to self manage, as well as their perceived susceptibility and severity of diabetes complications. Furthermore, the adolescent must identify cues to action necessitating a change in management, plus perceive the benefits and identify barriers that may hinder their ability to follow the prescribed treatment plan. These theories provide the framework for the seeking of knowledge relevant to the adolescent's transition from pediatric to adult health care.

Transition

Transition is a time during which major changes take place as well as development toward the next phase in life, bringing about instability. Transition occurs secondary to changes in life, health, relationships or environments, bringing about a sense of vulnerability exposing individuals to delayed or unhealthy coping and shifts in self management practices (Chick & Meleis, 1986). Transition is considered a process in addition to an outcome; the process of transition occurs from the point of anticipation of the transition from pediatric health care until stability in the new stage, adult health care has been met (Chick & Meleis; Lenz, 2001).

Transition may involve one or more persons and, in the case of diabetes, involves the adolescent, his or her parent(s), and the healthcare provider, both pediatric and adult. The transition is perceived relative to the context in which it occurs; and for diabetes, it is developmental, situational, organizational, and related to changes in health and illness (Chick & Meleis).

Defining characteristics of transition include: process, disconnectedness, perception, awareness, and patterns of response. Whether the duration of the transition process is short or long, it is always a process that ebbs and flows according to other events simultaneously occurring in the adolescent's life. During the process of gaining independence from the parent(s) in managing type 1 diabetes, there may be a feeling of loss of security, or disconnectedness, that was previously depended upon by the adolescent from the parent. These feelings may arise as result of the loss of immediate feedback or assistance from the parent(s) when questions crop up regarding treatment. Likewise, the parent may feel a loss of security from not knowing the day to day blood glucose readings and insulin dosages. The degree of disconnectedness is individually perceived based on transition events and the meaning ascribed to it and can occur in the adolescent as well as the parent(s). The parent may not feel their adolescent is mature enough to handle the responsibility and, yet, the adolescent may feel the parent is hovering and does not trust that he or she is capable of managing the disease (Dashiff, Riley, Abdullatif, & Moreland, 2011). Therefore, transition is a personal encounter and lacks a defined structure; it is related to the definitions of self and of the situation, and the adolescent in transition must have an awareness of the changes occurring to develop these new definitions. Patterns of response to changes and, what is happening at this time of their life, may be observed or unobserved and personify behaviors based upon cultural background and developmental stage (Chick & Meleis, 1986).

The adolescent is transitioning situationally by moving away to college or moving away from being under their parent's watchful eye and by progressing in psychosocial development. The adolescent with type 1 diabetes is also making the transition from pediatric to adult health

care and is experiencing a change organizationally, that may result in a change in the level of their perceived illness, resulting in poor glucose control.

Healthcare professionals are concerned with human beings, their environment, and health. Because of this, healthcare providers must address issues pertaining to transition due to disruption of the status quo and the effects on health, illness, or health-related behaviors that the transitioning process may produce, or issues occurring once the adolescent has reached the new stage (Chick & Meleis, 1986). This is especially important in the adolescent with type 1 diabetes given that unsuccessful transition can lead to dire consequences. Therefore transition readiness for the adolescent transitioning from pediatric to adult health care is imperative to maintain health. Transition readiness is defined as the acquisition of knowledge and skills in self management, decision making regarding healthcare and lifestyle, and taking responsibility for one's health. A goal is to provide interventions to achieve desired health outcomes, and because transition generally involves a shift in self management practices, both the healthcare provider and parent are needed to facilitate this process while maintaining the health and well-being of the adolescent.

Developmental

Erikson's Psychosocial Stages of Development. This theory posits that health is attained through successful completion of eight psychosocial stages: Trust vs. Mistrust, Autonomy vs. Shame and Doubt, Initiative vs. Guilt, Industry vs. Inferiority, Identity vs. Role Confusion, Intimacy vs. Isolation, Generativity vs. Stagnation, and Ego Integrity vs. Despair. Each stage is marked by a conflict or crisis that provides vulnerability and/or enhanced possibility. This conflict must be resolved to successfully develop the character quality of each stage, allowing progression to the next stage. If a stage is not resolved successfully, the

individual will have difficulties within each successive stage as well as a reduction in potential character quality (Elkind, 1970; Erikson, 1956; Graves & Larkin, 2006; Jenkins, Buboltz, Schwartz, & Johnson, 2005). The adolescent transitioning from pediatric to adult health care is considered a legal adult by age standards at age 18, and is no longer considered a pediatric patient.

In Erikson's Psychosocial Stages of Development, this adolescent is either in stage five-Identity vs. Role Confusion or stage six-Intimacy vs. Isolation (Elkind, 1970; Erikson, 1956; Jenkins et al., 2005). Identity vs. Role Confusion involves the development of a personal identity, allowing one to stay true to one's self, values, beliefs, and ideals. Failure to do this results in role confusion and a weak sense of self or a sense of not knowing who the self is, what group to belong to, or where to belong. The adolescent with diabetes may not have been given the chance to develop a sense of personal identity due to overprotective parents or responsibilities related to type 1 diabetes management (Fleming et al., 2002; Keough et al., 2011; LoCasale-Crouch & Johnson, 2005; Lotstein et al., 2005). A strong sense of personal identity is needed to forestall temptations that may arise and deter proper diabetes management.

Intimacy vs. Isolation entails the ability to form relationships without the fear of losing oneself in the process, whereas failure in this stage results in a feeling of isolation from others. The adolescent does not want to be "babied," yet is often kept under close observation of parents who fear their child may experience a hypoglycemic episode and not be able to treat the hypoglycemia independently, or the fear that those around the adolescent do not have enough knowledge to assist with this type of situation. This feeling can result in isolation from their peers. Also, the adolescent may prefer the comfortable atmosphere of the pediatric endocrinology office where they have an established relationship with the doctor and staff over

the “cold”, “alienating” atmosphere of the adult endocrinology office (Bowen et al., 2010; LoCasale-Crouch & Johnson, 2005; Rapley & Davidson, 2010; Visentin et al., 2006).

In summary, Identity vs. Role Confusion and Intimacy vs. Isolation, however, may not adequately describe adolescents embarking upon adulthood. A prolonged adolescence is typical of industrialized countries and is a period of free role experimentation, which was noted by Erikson but never defined (Arnett, 2000; Erikson, 1956).

Emerging Adulthood. Prolonged adolescence is typically considered to range from 18-25 years of age and Arnett (2007) describes this stage of development as Emerging Adulthood. This period is described as a time of exploration and experimentation, and is characterized by its instability, possibility, a feeling of being “in-between,” focusing on the self, and identity development. The emerging adult in this stage is, in general, not married, has transient residential status, and is less likely to be constrained by role requirements, i.e., is not a spouse or parent (Arnett, 2000). Experimentation and exploration is accelerated due to the freedom from role expectations and parental oversight (Arnett, 2000). As such, the instability associated with this life stage may be detrimental to prescribed type 1 diabetes management.

Self-Efficacy

Bandura’s self-efficacy is the belief in one’s capabilities to perform or achieve. Likewise, the adolescent’s judgment and beliefs of their ability affect their motivation and behavior with beliefs playing a role in the way they organize, create and manage the circumstances affecting their future (Bandura, 2005; Linn, Skyler, Linn, Edelstein, & Sandifer, 1985). Self-efficacy, which also may be regarded as personal or efficacy expectations, is based on four sources of information:

1. Vicarious experience, watching others perform successfully or unsuccessfully, and modeling the behavior resulting in increased or decreased efficacy. The person persuades himself that if others can do it, they should be able to perform the skill also, providing a basis for increased self-efficacy (Bandura, 2005; Bandura, 1977; Linn et al., 1985). The adolescent may model self management skills by watching another adolescent perform insulin injections or insert a pump site independently with ease and confidence and become motivated to do this on their own with parental assistance if needed.
2. Verbal persuasion, leading others through verbal suggestion that they can perform the skill, i.e., “you can do this, you are able to do this” (Bandura, 2005; Bandura, 1977; Linn et al., 1985). This source of information is weaker than those evolving from one’s successes. For this source of information to be helpful, the person must have reasonable goals (Linn et al.). This may be most effective in persuading the adolescent to self-administer insulin injections or placing a pump site.
3. Emotional arousal, the amount of physical or visceral arousal the person is experiencing in the situation, affects the degree of self-efficacy. High arousal hinders performance; therefore, the person must be calm and relaxed. The accurate assessment of physical symptoms is helpful to decreasing emotional arousal to controllable levels (Bandura, 2005; Bandura, 1977; Linn et al., 1985). In the adolescent with type 1 diabetes and fear of hypoglycemia, symptoms of hypoglycemia may be present, arousing emotions. However, an accurate assessment of these symptoms includes testing blood glucose to match a number with the physical symptoms. At times, the blood glucose reading may reflect a within-range or above-range number and may not coincide with the symptoms the adolescent is experiencing. Ensuring the adolescent tests his/her

blood glucose each time symptoms are felt, enables them to more accurately assess symptoms and bring emotions to a controllable level.

4. Enactive mastery, the actual performance of a skill and subsequent mastery. Each success raises efficacy expectations for future endeavors. Enactive mastery produces the strongest increase in coping and managing behaviors by learning through action (Bandura, 2005; Bandura, 1977; Linn et al., 1985). Each time the adolescent with diabetes adjusts an insulin dose based on glucose readings and the amount of carbohydrate ingested followed by within range glucose readings, mastery and success builds.

Efficacy expectations differ in magnitude, generality, and strength according to the task at hand. Magnitude refers to the level of difficulty of a task and the order in which the adolescent places them. More difficult tasks will result in higher ratings of self-efficacy compared with easier tasks. Generality is associated with the degree of specificity of the expectation. Some are focused and others provide a sense of efficacy that extends beyond the particular task. Strength of efficacy expectation alludes to perseverance. The adolescent with high expectations will be more diligent in completing a task (Bandura, 1977).

Developing a high level of self-efficacy requires knowledge and skills, afforded in a step-wise fashion, providing mastery at each level (Bandura, 1977). This also assists in development of motivation. Motivation is bolstered by past successes, degree of self-efficacy, and expectations (Bandura, 2005; Bandura, 1977; Linn et al., 1985). Motivation consists of goal setting and self evaluation. Each successive goal met provides increasing fortitude to set and reach higher goals bringing about a sense of self control over behavior and future events. Therefore, previous stressful events become predictable and less anxiety producing resulting in increased self-efficacy (Bandura, 2005; Bandura, 1977; Linn et al.). Ineffective self-efficacy

results in inadequate coping with the environment and a tendency to dwell on deficiencies and imagining difficulties as worse than they really are (Bandura, 2005; Bandura, 1977; Linn et al.).

For the adolescent to be successful in diabetes self management, he or she needs to develop a high sense of self-efficacy. Possessing a high sense of self-efficacy relays a higher motivational state, which is necessary for carrying out the daily tasks and the monitoring that diabetes requires, and is associated with improved glucose control (Johnston-Brooks, Lewis, & Garg, 2002).

Mastery. Mastery is a sense of control over diabetes management encompassing cognitive, behavioral, social, and physiological activities associated with its management (Price, 1993). As self-efficacy increases, the ability to perform behaviors necessary to control diabetes increases, thus promoting healthful living and a decrease in chances for diabetes complications and, consequently, functional decline (Arnold et al., 2005; Kurtz, Kurtz, Given, & Given, 2008). Mastery occurs when competency and command have been gained over the stress of the new experience (Stamler, Cole, & Patrick, 2001; Younger, 1991). The process of taking on more responsibility for diabetes management can produce stress, but as success is attained, mastery increases and stress decreases (Stamler et al.; Younger).

Mastery involves four components: certainty, change, acceptance, and growth. These occur on a continuum and are achieved by developing new abilities and resourcefulness through combating the challenges of diabetes management at each stage (Stamler et al., 2001; Younger, 1991). As the adolescent learns bodily patterns of responses to treatment, accepts lifestyle changes, and manages the variable course of diabetes, personal growth results (Price, 1993; Younger, 1991). Going through the process of mastery, resilience develops as does empowerment, and the sense of being able to handle obstacles to diabetes management with

aplomb. As mastery increases, self-confidence increases too and the illness becomes more of a challenge rather than a burden, establishing a cycle of success (Bandura, 2005; Bandura, 1977; DeSocio, Kitzman, & Cole, 2003; Linn et al., 1985; Macq, Torfoss, & Getahun, 2007; Paterson, Thorne, Crawford, & Tarko, 1999; Zinken, Cradock, & Skinner, 2008). As the adolescent gains experience managing diabetes, he or she becomes empowered resulting in competence and mastery in diabetes management.

Self Management

Self management includes all tasks and decision making the patient with diabetes must manage to live a full and productive life and remain as healthy as possible. Three domains associated with self management include medical management - managing symptoms and disease activity; role management - carrying out normal activities of daily living; and emotional management - coping with emotions related to living and managing diabetes (Lorig, 1993; Shumaker, Ockene, & Riekert, 2009). For effective self management, the adolescent and healthcare provider must function as a team, taking into account the adolescent's beliefs and knowledge in addition to collaborative goal setting. To do this, the adolescent must be an active partner incorporating their self knowledge continuously along with the healthcare provider as a coach (Holman & Lorig, 2004). Skills and problem-solving techniques must also be addressed so the adolescent is able to manage their life with diabetes instead of diabetes managing their life (Lorig, 2003; Shumaker et al.).

Self management is a continuous process resembling a feedback loop system including priority management. The adolescent with diabetes must make corrective adjustments based on responses to actions from self management processes. The adolescent, with the assistance of the diabetes healthcare provider, sets goals and formulates a plan to meet those goals, placing

priority on those targets most critical to maintaining glucose control. Criteria are established to monitor progress and identify goal attainment. As the adolescent progresses, negatively or positively, he or she adjusts the plan accordingly to meet the specified goal; therefore, diabetes self management becomes a continuous process (Bandura, 2005; Shumaker et al., 2009; Vohs & Baumeister, 2011).

Self management requires a level of competence and mastery, which the adolescent develops over the course of the disease and is achieved by advancing through the stages of activation, reflecting the capacity for self management. These stages are: (a) not having awareness of the importance of taking an active role in disease management; (b) having the awareness of the necessity for appropriate management but with limited knowledge, skills and/or confidence; (c) knowledge and action are present, but limited confidence is displayed in disease management; and (d) self management skills are embraced and the adolescent continues to develop confidence (Shumaker et al., 2009). Those adolescents in the first two stages are less likely to have effective self management skills and more likely to have deficient self management behaviors and poor health outcomes. Those in the higher stages are more likely to self manage their disease effectively and take an active role in disease management (Shumaker et al.). Adaptation to type 1 diabetes encompasses three domains of self management in that the adolescent is: (a) learning how to medically manage the disease by monitoring trends and patterns of glucose levels in response to insulin administration, (b) carrying out activities of daily living, and (c) coping with the emotional toll that daily attention to diabetes management requires.

Health Belief Model

The Health Belief Model (HBM) was developed in an attempt to understand the lack of disease prevention efforts of healthy people or those with subclinical disease with the premise that health is highly valued. This model states that behaviors of people depend on the value imposed on a goal by the individual and that person's estimate of the likelihood of meeting that goal. These values influence expected outcomes, therefore, affecting initial motivation and the decision to change health practices (Strecher, DeVellis, Becker, & Rosenstock, 1986). The desire to avoid complications and to maintain wellness with the belief that a specific health behavior can work to prevent complications or improve blood glucose values are the basic components of HBM applied to diabetes (Shumaker et al., 2009; Strecher et al.). Modifying factors of HBM that must be taken into account include demographics, cultural background, and social and psychological issues (Shumaker et al.).

Dimensions of HBM include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action. Susceptibility is the adolescent's perception of developing diabetes complication while severity concerns the seriousness of diabetes complications. Perceived benefits refers to beliefs surrounding the effectiveness of a diabetes management plan, or actions that eliminate or lessen the degree of future diabetes complications. Perceived barriers concern the side effects or negative aspects of treatment, such as fingersticks to obtain glucose readings or injecting insulin that must occur with type 1 diabetes disease management, and may impede follow-through with the treatment plan. In addition, being able to identify cues to action, such as several above-range blood glucose readings, requires taking steps to determine the cause of the hyperglycemia, and proceeding with a subsequent change in therapy (Shumaker et al., 2009).

Parent Development Theory

The Parent Development Theory (PDT), originally named the Parent Role Development Theory, concerns the social role of the parent by defining the parent as who they are and their role, explains how parents and parenting grows and transforms as the child matures, and describes how the role of the parent relates to parenting. In addition, this theory explains parents' perceptions of their role that is affected by their individual experiences with parenting, but is also affected by the growing and developing child. Central to this theory are the components of how the parental role is affected by individual parental perceptions and the developing child, besides how parents adjust and respond to the changes in themselves, their child, the parent-child relationship, family dynamics, and the cultural environment (Mowder & Sanders, 2007; Mowder, 2005; Sperling & Mowder, 2006).

In PDT, the six characteristics pertaining to the parent role are as follows: (a) bonding, which refers to the affection and love a parent feels and displays toward their child, (b) discipline, which refers to limit setting and assurance that the limits are regarded and followed by the child, (c) education, which refers to ensuring information and learning is passed to the child from the parent, (d) general welfare and protection, which refers to the parent providing for the child's general needs and protecting the child from harm, (e) responsivity, which refers to the degree that the parent takes action for their child, and (f) sensitivity, which refers to the ability of the parent to understand what the child is communicating and giving an appropriate response (Mowder & Sanders, 2007; Mowder, 2005; Sperling & Mowder, 2006).

In the adolescent with type 1 diabetes, these six characteristics may be intensified due to the close monitoring and daily management of the disease. In the bonding characteristic, the parent has already established this by parenting their adolescent. In the adolescent with type 1

diabetes, bonding may intensify due to the increased attention the parent must provide because of the disease. As the adolescent enters the transition process from pediatric to adult health care, the bond should remain intact in the midst of transition and after the transition. Discipline (providing, discussing, and following through with rules) surrounding diabetes management should already be in place prior to, during, and after transition. The adolescent should have behavioral expectations from the parent to follow regarding diabetes management that will not change during transition or after. The adolescent must continue with diabetes management in the same manner while assuming more responsibility for the daily tasks of self management.

The parent is provided diabetes management education at diagnosis and is responsible for the bulk of the transfer of this knowledge to their adolescent when he or she enters the transition period in addition to obtaining outside sources of knowledge when able to remain up to date with current diabetes management guidelines. All of the characteristics listed thus far are encompassed in the characteristic of general welfare and protection of the child by providing necessary diabetes supplies and appropriate food to follow a healthy diet. The parent protects the adolescent with diabetes from harm by closely monitoring blood glucose values, insulin administration, diet, exercise, and keeping doctor appointments. During transition, the parent continues to be responsible for these matters, but allows the adolescent to gradually perform these skills independently until after transition is completed, at which the adolescent is entirely independent in diabetes management.

Though the parent is relinquishing diabetes self management to the adolescent during the transition process, they should be available to assist with problem solving hypoglycemia and hyperglycemia episodes, and insulin administration. In addition, the parent should still be available emotionally as a sounding board for the adolescent when feelings of frustration arise

from not meeting personal goals of diabetes management. Providing encouragement of adolescent diabetes self management decision making is granting autonomy and promoting independence to the adolescent with the mutual goal of maintaining optimal glucose control (Hanna et al., 2012; Silk, Morris, Kanaya, & Steinberg, 2003). From the adolescent's point of view, the perception of autonomy granting is dependent on developmental stage but encompasses adolescents' perceptions that their parent is allowing them to participate in social activities, having the choice to make decisions regarding diabetes self management thus, allowing the adolescent to feel more in control of their diabetes self management without their parent meddling in the day-to-day tasks (Hanna et al., 2012; Silk et al., 2003).

Responsivity of the parent prior to transition requires the parent to react to cues of hypoglycemia or hyperglycemia, or closely monitor blood glucose values during illness. This should continue during and after transition however, the parent gradually relinquishes their responsibility in monitoring during these times, but is still available for problem solving. Finally, sensitivity refers to the parent's ability to understand and respond to the adolescent's emotional needs related to diabetes management. During transition and after, the parent is still available emotionally and acts as a sounding board for the adolescent when feelings of frustration arise from not meeting personal goals of diabetes management.

Review of Instruments Related to Transition Readiness, Self Management, and Parental Support for Autonomy

An assessment of adolescents' level of (a) transition readiness, (b) self management practices, and (c) parental support for adolescents autonomy in the transfer of diabetes management responsibilities must be completed to determine educational needs in the preparation for a successful transition of care from pediatric to adult health care.

Psychometrically sound measures to perform an educational needs assessment pre and post implementation of an education intervention is needed. There are numerous instruments available to test diabetes knowledge and self management practices however, most are fact-based and do not test problem-solving abilities related to daily diabetes management activities of the adolescent. Consequently, an evaluation of instruments that measure adolescents' with type 1 diabetes transition readiness, self management practices and problem-solving ability, and parental support for transfer of diabetes management responsibilities was completed. These instruments can be used to evaluate the educational needs of the adolescent and their parent so that an individualized education and transition planning intervention can be developed.

Method

The literature related to transition, diabetes self management, and parental support was reviewed through a computerized search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Health and Psychosocial Instruments (HAPI), PsychInfo, Medline, Academic Search Premier, Academic Search Elite, PsycArticles, and reference lists of research articles. Search terms included adolescent, diabetes mellitus type 1, parental support, transition, self management, psychometrics, and instruments. Thirty-seven articles were obtained from the databases and reference lists. Seventeen of those were eliminated because the subject matter was related to adherence, quality of life, type 2 diabetes only, or were used only in adults with diabetes. This sorting of articles produced twenty articles to evaluate for appropriateness to this intervention.

Results

Instruments identified from the literature were evaluated, divided into subject matter of the outcome tested: transition, self management, and parental support for adolescent's autonomy.

The instruments were then further categorized according to the sample tested i.e., adolescent only or both the adolescent and parent.

The following instruments are summarized in Tables 1 through 7: Transition Readiness Assessment Questionnaire (TRAQ; Sawicki et al., 2011); California Healthy and Ready to Work Transition Health Care Assessment Tool (CA HRTW THCA; Betz, Redcay, & Tan, 2003); Self Management of Type 1 Diabetes in Adolescents (SMOD-A; Schilling et al., 2009); Diabetes Knowledge Questionnaire (DKQ; Eigenmann, Skinner, & Colagiuri, 2011); Collaborative Parent Involvement Scale for Youth with Type 1 Diabetes (CPI; Nansel et al., 2009); Diabetes Specific Family Behavior Scale (DFBS; McKelvey et al., 1989); Readiness for Transition Questionnaire (RTQ-Teen, RTQ-Parent; Gilleland, Amaral, Mee, & Blount, 2011); Diabetes Self Management Self Report (DSMP-SR; Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2012); Diabetes Self Management Profile (DSMP; Harris et al., 2000); Assessment of Diabetes Adherence (ADA-C, ADA-P; Lehmkuhl et al., 2009); Diabetes Self Management Profile-Revised for Conventional and Flexible Insulin Regimens (DSMP-R; Wysocki et al., 2004); Diabetes Self Management Profile-Flex (DSMP-Flex; The Diabetes Research in Children Network [DirecNet] Study Group, 2005); Diabetes Self Management Questionnaire (DSMQ; Markowitz et al., 2011); Diabetes Awareness and Reasoning Test for children and parents (DART and DART-P; Heidgerken et al., 2007); Diabetes Problem Solving Measure for Adolescents (DPSMA; Cook, Aikens, Berry, & McNabb, 2011); Diabetes Problem-Solving Interview (DPSI; Wysocki et al., 2008); Self Care Inventory (SCI; Lewin et al., 2009); Diabetes Specific Parental Support for Adolescents' Autonomy Scale (DPSAAS; Hanna et. al, 2012; Hanna, DiMeglia, & Fortenberry, 2005); and Diabetes Family Behavior Checklist (DFBC; Schafer, McCaul, & Glasgow, 1986).

Adolescent

Transition Readiness. Two instruments were found that assessed adolescents' transition from pediatric to adult health care, the Transition Readiness Assessment Questionnaire (TRAQ; Sawicki, et al., 2011) and the California Healthy and Ready to Work Transition Health Care Assessment (CA HRTW THCA; Betz et al., 2003). The TRAQ was developed for youth with special healthcare needs such as those with cystic fibrosis, cerebral palsy, type 1 and type 2 diabetes, spina bifida, sickle cell disease, seizure disorders, autism, and other developmental disabilities. The CA HRTW THCA was also developed for youth with special healthcare needs but the diagnoses included adolescents with developmental disabilities, cancer, acquired neurologic conditions, sickle cell disease, and gastrointestinal disorders, not diabetes. The TRAQ was chosen for this transition intervention because it has been tested with adolescents with type 1 diabetes, has a content validity index of 0.93, it is a 20 item Likert type scale, does not require additional training to administer, and can be completed in less than 10 minutes (Appendix A). Additionally, completion of the TRAQ by the adolescent provides more information on the understanding of the level of knowledge related to transition readiness because of the Likert type continuous scale answering whereas the CA HRTW THCA has yes/no categories in its answering system and does not provide a true picture of the learning needs of the adolescent for transition readiness.

Self Management. One instrument was found to test self management behaviors in the adolescent. The Self Management of Type 1 Diabetes in Adolescents (SMOD-A; Schilling et al., 2009) consists of 5 subscales measuring collaboration with parents, diabetes care activities, problem solving, diabetes communication, and goals of self management. This instrument was chosen to evaluate self management of type 1 diabetes in the adolescent for this transition

intervention because of the high content validity, subscale reliability, established test re-test reliability, and assesses the target age range (Appendix B).

Support for Autonomy. Two instruments testing the support of parents and family from the adolescent perspective are the Collaborative Parent Involvement Scale for Youths with Type 1 diabetes (CPI; Nansel et al., 2009) and the Diabetes Specific Family Behavior Scale (DFBS; McKelvey et al., 1989). Neither one of these instruments fit the criteria for use in this transition intervention. The CPI measures quality of life, adherence to regimen, collaboration with parents, and the age cut-off is 16. The DFBS is outdated, no factor analysis was completed, and only one outcome was measured-metabolic control by HbA1c level.

Adolescent and Parent

Transition Readiness. One instrument testing both the adolescent and parent for transition readiness is Readiness for Transition Questionnaire. This instrument fits the criteria for internal consistency, age range, and is multiple choice but has been used specifically for adolescents post kidney transplant (RTQ-Teen, RTQ-Parent; Gilleland et al., 2012).

Self Management. Six instruments were found testing self management of the adolescent and their parent. Of these six, four are all variations on the Diabetes Self Management Profile (DSMP, DSMP-SR, DSMP-Flex, DSMP-R; Harris et al., 2000; Wysocki et al., 2012; DCCT, 2005; Wysocki et al., 2004). None of the DSMP variations met the criteria for this transition intervention since they are interview based; take too long to administer; require training of the interviewer; and determine adherence to diabetes regimen, and not problem-solving or critical thinking. The Assessment of Diabetes Adherence child and parent versions (ADA-C, ADA-P) meet the criteria for internal consistency, test retest reliability, age range, and are multiple choice, but they assess regimen adherence, not problem-solving or critical thinking (Lehmkuhl et

al., 2009). The Diabetes Self Management Questionnaire (DSMQ) and is adapted from the DSMP. It is not suitable for this transition intervention because it does not meet criteria for internal consistency, age cut-off is 15, and measures adherence to the diabetes regimen and not problem-solving or critical thinking.

Four instruments were found that addressed diabetes self management but were specifically related to problem-solving and factual knowledge. Three of these are problem-solving instruments: Diabetes Awareness and Reasoning Test (DART, DART-P), Diabetes Problem Solving Measure Adolescents (DPSMA), and the Diabetes Problem-Solving Interview (DPSI). All are interview based, take too much time to administer, and require training of the interviewer so are not suitable for this transition intervention (Heidgerken et al., 2007; Cook et al., 2001; Wysocki et al., 2008). The remaining instrument, Self Care Inventory (SCI), fits the criteria for internal consistency, age range, and is multiple choice but only measures factual knowledge and adherence, not problem-solving or critical thinking (Lewin et al., 2009).

Support for Autonomy. Three instruments testing the support of parents and family from the adolescent and parent perspectives are the Diabetes Specific Support for Adolescent's Autonomy Scale (DPSAAS; Hanna et al., 2012; Hanna et al., 2005), Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al, 1990), and the Diabetes Family Behavior Checklist (DFBC; Schafer et al., 1986). The Diabetes Specific Support for Adolescents' Autonomy Scale (Appendix C) was chosen for this transition intervention because it meets the criteria for internal validity, does not require additional training to administer, can be completed in less than 5 minutes, assesses the target age range, assesses enacted and perceived support, and has acceptable construct validity supported by the DFBC and the DFBS (McKelvey et al., 1989). The DFBC, like the DFBS, is outdated and does not meet criteria for internal consistency or test

retest reliability. Furthermore, they are interview based and would require training of the interviewer. While the DFRQ has higher internal consistency ratings, it is also outdated as some items no longer apply to current diabetes standards of care, is interview based, and would require training of the interviewer.

Criteria for Instrument Inclusion

This transition intervention has been developed for the adolescent with type 1 diabetes transitioning from pediatric to adult health care, therefore instruments measuring transition readiness, self management, and support in this group are necessary. Instruments developed specifically for use in the adolescent with type 1 diabetes must have construct validity, i.e., they have been tested on adolescents with type 1 diabetes and documented by significant relationships to other existing validated instruments (Field, 2009). The age range of 15-19 is important because this is the time in an adolescents life when they start to move toward independence from their parents thus, independence in diabetes self management. Also, by the age of 19, most have graduated from high school and may be leaving pediatric healthcare and entering the adult health care arena. In addition, adolescents younger than 15 may not be developmentally ready to assume increased responsibility for diabetes self management.

Internal consistency is important when choosing instruments since the desire to measure a specific outcome is improved when the items of an instrument measure the same underlying variable or characteristic. Some variation in a participant's answers to items in an instrument are to be expected, however, the smaller the variability among items in an instrument, the greater the internal consistency. An internal consistency value of $\alpha \geq 0.70$ is generally accepted (Field, 2009).

In summary, instruments were considered clinically useful if they were multiple choice or Likert type, could be administered by anyone in the clinic without special training, and could be completed quickly. In addition, scoring multiple choice or Likert type instruments is easy to process and interpret for the researcher. The instruments chosen for this study were the Transition Assessment Readiness Questionnaire (TRAQ), Self Management of Diabetes-Adolescent Version (SMOD-A), and Diabetes Specific Support for Adolescent's Autonomy Scale (DSPAAS). Criteria for inclusion in the instrument review are listed in Table 8.

There are some limitations to this review. Instruments that assess transition readiness are relatively new and therefore have not been used extensively in research. Assessing self management skills and problem-solving is difficult without actually observing the adolescent perform these skills so obtaining an accurate account of proficiency is problematic. Interviewing using vignettes would appear to be most advantageous at obtaining this information but is time consuming, requires in-depth training of the interviewer, and answers supplied by adolescents may not fit the scoring grid perfectly compromising the results. Therefore, instruments that use multiple choice or Likert scale answering systems work well, but the questions must be developed and presented in a way to ascertain critical thinking abilities regarding diabetes self management and problem-solving abilities of the adolescent.

The Diabetes Specific Parental Support for Adolescents' Autonomy Scale assesses parents ability to promote autonomy and encourage their adolescent's decision making and independence in the process of insulin administration, not necessarily all diabetes management responsibilities. Although this is the case, other aspects pertaining to diabetes management come together under insulin administration such as glucose monitoring, carbohydrate intake, and

exercise. Insulin administration can be regarded as a culmination of decisions regarding glucose monitoring, carbohydrate intake, and exercise.

Summary

Transition is inevitable; consequently it must be a coordinated process between the adolescent, their parent, and the healthcare team to succeed. Those with diabetes must transition and become their own principal caregivers, with parents and healthcare providers becoming consultants and or coaches supporting them in this role (Bodenheimer et al., 2002). A comprehensive literature review was completed that resulted in the development of a structured, timely transition planning intervention that addresses the adolescent's physical, emotional, financial, and reproductive health needs not found in transition literature. In addition, validated instruments were chosen to evaluate the effectiveness of the transition planning intervention. These were the Transition Readiness Assessment Questionnaire, the Self Management of Adolescents with Type 1 Diabetes, and the Diabetes Specific Parental Support for Adolescent's Autonomy Scale.

CHAPTER III

Introduction

Chapter III contains specific detail regarding the research design used to answer the research questions. This chapter describes the methods, recruitment, setting, sample, intervention, data collection procedures, and data analysis. It also includes a discussion of the instrumentation used and the limitations of the study. Last, a discussion of the protection of human subjects is presented.

Research Questions

The research questions for this study were:

Research Question 1: Will transition readiness in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 2: Will self management practices (collaboration with parents, diabetes care activities, diabetes problem-solving, diabetes communication, and goal setting) in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 3: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 4: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from the parent of adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 5: Is this intervention useful to help with getting ready to transition the child's care to adult medical health care providers?

Research Question 6: Does this intervention provide important information about how to take care of the child's diabetes as a young adult?

Research Question 7: Would adolescents and parents recommend this intervention to other families with teenagers and young adults with diabetes?

Research Question 8: What parts of the intervention were most useful?

Research Question 9: What parts of the intervention were least useful?

Research Question 10: Are there ways the intervention can be improved?

Related Question

The related question for this study was:

Related Question: Does the Diabetes Specific Parental Support for Autonomy in Adolescents Scale (DSPAAS) function in determining parental support for autonomy in adolescents age 15-19 after participation in a transition planning intervention?

Method

Design

This was a non-experimental pre-post feasibility study to assess transition readiness of adolescents with type 1 diabetes, self management practices of the adolescent with type 1 diabetes, and parents' ability to promote autonomy in their adolescents' transition to diabetes self management, from the adolescents' and separately from the parents' point of view. In addition, this study sought to gain information from the participants on the usefulness of a transition planning intervention.

In determining whether an intervention is appropriate for future large-scale testing, a feasibility study using an "implementation and does it work?" framework was used. This framework allows for an intervention to be carried out in a clinical setting using surveys and

observations to compare practices pre and post intervention. The goal of this feasibility study was to determine whether the intervention worked and was useful to the participants (Bowen et al., 2009).

Recruitment

Adolescent/parent dyads were recruited from the pediatric diabetes outpatient clinic at a major Midwestern university hospital where 95% of the adolescents with type 1 diabetes attend. Other recruitment venues were utilized (Table 9). Flyers were distributed to public places where adolescents frequent and letters of invitation were sent to the Children's patient registry (Appendices E & F). Potential participants that did not respond to the letters of invitation were phoned and messages left on voice mail inviting them to participate. IRB approval was obtained to use the Research Participant Registry (RPR-Registry) to increase recruitment. The Registry is a pool of potential study subjects that have completed surveys of their overall health and particular study interests. The Registry then matches study criteria to their pool of potential participants. In addition, the Registry publicized this study on Facebook, Centerwatch, at local health fairs, and in the Barnes-Jewish Hospital employee newsletter (Appendices I-L). No Registry registrants matched this study's eligibility criteria nor did any participants arise from the marketing of this study through the Registry.

Setting

The study site was a major Midwestern university hospital pediatric diabetes endocrinology outpatient clinic.

Sample

Inclusion criteria for the adolescent were: 1) age 15-19 with type 1 diabetes, 2) duration of type 1 diabetes \geq 1 year, 3) male or female, 4) willingness to attend all visits, provide all

outcome measures, and complete the study in a timely manner, and 5) voluntary parental consent and participant consent. Adolescents were excluded if they had type 2 diabetes. Inclusion criteria for parents were 1) willingness to accompany the adolescent to the visit or meet the adolescent at the visit and 2) willing to consent to the study and willing to consent for their participating child under 18 years of age.

Intervention

The intervention consisted of four, 1-1.5 hour coaching and strategy learning sessions held weekly. The coaching and strategy learning sessions for the adolescents were delivered by a physician and graduate nurse researcher while two registered nurses who are Certified Diabetes Educators (CDE), managed the parent support sessions. As part of the intervention, adolescents were asked to complete a log noting daily blood glucose levels, carbohydrate intake, insulin administered, physical activity, and whether prompts from the parent were necessary to complete self management activities. The completed log, which the healthcare provider asks those with type 1 diabetes to complete as usual practice, was used as a coaching learning tool and referred to at each session for problem-solving, related to self management activities as well as hypoglycemia and hyperglycemia episodes. The log was reviewed taking note of glucose values, carbohydrate intake, insulin administered, and physical activity looking for patterns surrounding episodes of hypoglycemia or hyperglycemia in order to problem solve which aspect of therapy needed adjusting, be it amount of insulin, carbohydrate intake, or physical activity. Adolescents and parents attended session 1 together so they received the same accurate information on type 1 diabetes pathophysiology and nutrition. For sessions 2-4, the adolescent and parent were separated to allow both parties to freely discuss, without inhibition from each other's presence, type 1 diabetes management issues and concerns. Methods of delivery of educational content for

the coaching and strategy learning sessions consisted of powerpoint presentations, problem-solving with case studies using their logs, discussion, and handouts for reference at home. Brief descriptions of the four sessions are as follows:

Session 1. This session focused on the introduction of the study and the team. A review of the pathophysiology of type 1 diabetes including nutrition was presented. Parents and adolescents both attended this session.

Session 2. This session focused on the day-to-day management of type 1 diabetes. This includes problem-solving surrounding episodes of hypoglycemia and hyperglycemia, and insulin administration. Parents had a separate concurrent support session.

Session 3. This session focused on preparation in managing type 1 diabetes independently for the adolescent who may be beginning employment, moving out of the parental home to live independently or leaving for college. Parents had a separate concurrent support session.

Session 4. This session focused on reproductive health. This session was presented using the READY-Girls (Charron-Prochownik et al., 2008) curriculum and The WISE GUYS (Gruchow, 2009) curriculum. Females and the males were in separate rooms. Parents had a separate concurrent support session.

Data Collection Measures

Transition readiness is defined as the total score the *Transition Readiness Assessment Questionnaire* (TRAQ; Appendix A). The TRAQ, based on the Stages of Change Model, is a 20-item Likert questionnaire for adolescents and young adults aged 16-26 with a wide variety of chronic complex health conditions including type 1 diabetes. This instrument takes about 15 minutes to complete. A sample item is “Do you take medications correctly and on your own?”

Higher scores indicate higher self management ability and self-advocacy. Internal consistency (self management $\alpha = 0.92$; self advocacy $\alpha = 0.82$) overall $\alpha = 0.93$; domains moderately correlated $r = 0.46$, $p < 0.0001$ (Sawicki et al., 2011).

Self management practices are defined as the scores obtained from the 5 subscales of the *Self-Management of Type 1 Diabetes in Adolescents* (SMOD-A; Appendix B). The SMOD-A is a 52-item self-report Likert questionnaire for persons with type 1 diabetes. The subscales measure collaboration with parents, diabetes care activities, diabetes problem solving, diabetes communication, and goal setting for self management in adolescents aged 13-21; the five subscales are scored, but there is no total score. It takes about 15 minutes to complete the SMOD-A. A sample item is: Is the adolescent “checking my blood sugar before eating.” Higher scores indicate more diabetes care activities and problem solving, and a committed and consistent approach to self management. Overall, content validity was CVI = 0.93 with subscale reliability ($\alpha = 0.71$ to 0.85), 2 week test-retest reliability ($r = 0.60$ to 0.88), and at 3 months ($r = 0.59$ to 0.85). Goal subscale test-retest reliability for both 2 week and 3 month was < 0.60 (Schilling et al., 2009).

Parents’ ability to promote autonomy in their adolescents’ transition to diabetes self-management, from the adolescents’ and separately from the parents’ point of view, is defined as the total score from the *Diabetes-Specific Parental Support for Adolescents’ Autonomy Scale* (DSPAAS; Appendix C). The 4-item questionnaire is designed to measure (from the adolescent’s or the parent’s viewpoint) parents ability to promote autonomy and encourage their adolescent’s decision making and independence with the process of insulin administration with the adolescent, age 12-19. A sample item is “the suggestion by the parents to give insulin before telling to do it”. Higher scores indicate higher parental support. Construct validity is supported

by its moderate relationship with other measures of parental support: the Supportive Subscale of the Diabetes Family Behaviors Checklist and the Guidance/Control and Total Scale of the Diabetes Family Behavior Scale. Internal validity between parent and adolescent versions is acceptable to good ($\alpha = 0.67$ to 0.80 ; Hanna et al., 2012; Hanna et al., 2005).

A post evaluation to determine usefulness to help with getting ready to transition to adult health care, importance of the information provided on how to take care of diabetes as young adult, and whether adolescents and parents would recommend this intervention to other families with adolescents with type 1 diabetes. In addition, the participants were queried on what portions were least useful and suggestions for improvement of the intervention.

Data Collection Procedures

After receiving Institutional Review Board (IRB) approval, participants who met the eligibility criteria were recruited from the pediatric diabetes outpatient clinic at a major Midwestern university hospital by the graduate nurse researcher. Flyers advertising the study were posted at the clinic and letters describing the study were mailed to potentially eligible participants. At the next clinic visit after receipt of the letter, the physician or clinic nurse described the study to potential participants and consent was obtained. Next, all adolescent participants completed a demographic form (Appendix G) and adolescents completed the readiness, self management practices, and autonomy measures. Parents completed the autonomy measure. At baseline visit, all adolescents were given a \$15 gift card; parents were not paid.

The dyads were given information sheets listing session topics, dates, times, locations, and researcher contact information. All adolescent/parent dyads were expected to complete the 4-session intervention. The parent attended the first session of the series together with the adolescent. Concurrent support sessions were held separately for the parent, at sessions 2-4, to

discuss enabling independent self management of type 1 diabetes in their adolescent. The adolescent/parent dyads were encouraged to discuss session content outside of the study.

At the end of session four, adolescents completed the readiness, practices, and autonomy measures again and received a \$25 gift card. The parents completed the autonomy measure again at the session site and were not paid. Two sets of sessions were held, one in September and the other in November 2014. The data collection schedule is outlined for both groups (Table 10).

Data Management and Analysis

Descriptive statistics were used and data were managed using SPSS version 18.

Protection of Human Subjects

Institutional Review Board (IRB) approval was obtained (Appendix D) and participants who met the eligibility criteria were recruited from the pediatric diabetes outpatient clinic at a major Midwestern university hospital. All participants received study consent forms including those under age 18. Adolescents and parents signed the same consent form. No adolescent turned 18 during the study so second consent by the adolescent was not required.

Participation in this study was voluntary and participants could withdraw at any time. The data that was collected was used for research purposes only. Confidentiality was maintained in a variety of ways: 1) data collection and management were conducted in a sensitive and confidential manner; 2) participant's names did not appear on any surveys; 3) all participants were assigned a code number; 4) the list with names and code numbers are kept in a locked file and a password protected computer program to which only the graduate nurse researcher has access; 5) only aggregate data will be used in any presentation or publications; 6) all data is stored in a locked cabinet; and 7) only the investigators and research team members have access to the data.

Study Subjects. Participants were recruited from the a pediatric diabetes clinic at a major Midwestern university hospital. Overall inclusion criteria for the adolescent participants were: 1) age 15-19 with T1D, 2) duration of T1D ≥ 1 year, 3) male or female, 4) willingness to attend all visits, complete all study measures, and complete the study in a timely manner, and 5) voluntary parental consent and participant consent. Adolescents were excluded if they had type 2 diabetes. Inclusion criteria for parents were 1) willingness to accompany the adolescent to the visit or meet the adolescent at the visit and 2) willingness to consent to the study and willing to consent for their participating child under 18 years of age.

The study utilized adolescents, a vulnerable population. Biological specimens were not collected in this study. Assessments were self-report and participants were free to decline answering any questions.

Inclusion by Sex/Gender. Both males and females were offered participation in this project in approximately equal numbers.

Inclusion by Race/Ethnicity. Subjects of all races and ethnic backgrounds were offered the opportunity to participate in this project. However, it should be noted that T1D in children and adolescents in the USA is more common among Caucasian/White persons than among African Americans/Blacks. In addition, it is less common among Hispanics; and the Hispanic population in the St. Louis area is relatively small. Therefore, it is likely that, even though we recruited from all race/ethnic backgrounds, the majority of the enrolled subjects were Caucasian/White.

Minimization of Risk. Confidentiality will be maintained by keeping all data in locked file drawers. Participants were provided with a copy of the informed consent and the study contact information, in addition to contact information for the Human Subjects Committee.

Guidelines from the Code of Federal Regulations Concerning Informed Consent (HHS, 1991) were followed. National Institute of Health (NIH) and University guidelines for reporting adverse events to the Human Research Protection Office were followed but not necessary. The protection of human subjects follows UMSL IRB, the UMSL Office of Compliance, Washington University IRB and Office of Compliance, and the Health Insurance Portability and Accountability (HIPPA) guidelines. The HIPPA compliance will be guided by the Department of Health and Human Services (HHS) final Privacy Rule dated April 14, 2002 (American Council on Education, 2002).

CHAPTER IV

Introduction

In chapter IV, the research questions, related question, results including sample characteristics, missing data, and findings related to the research questions and the related question are provided. Finally, a summary of the results are presented.

Research Questions

The research questions for this study were:

Research Question 1: Will transition readiness in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 2: Will self management practices (collaboration with parents, diabetes care activities, diabetes problem-solving, diabetes communication, and goal setting) in adolescents age 15-19 improve after participation in a transition planning intervention?

Research Question 3: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 4: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from the parent of adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Research Question 5: Is this intervention useful to help with getting ready to transition the child's care to adult medical health care providers?

Research Question 6: Does this intervention provide important information about how to take care of the child's diabetes as a young adult?

Research Question 7: Would adolescents and parents recommend this intervention to other families with teenagers and young adults with diabetes?

Research Question 8: What parts of the intervention were most useful?

Research Question 9: What parts of the intervention were least useful?

Research Question 10: Are there ways the intervention can be improved?

Related Question

Related Question: Does the Diabetes Specific Parental Support for Autonomy in Adolescents Scale (DSPAAS) function in determining parental support for autonomy in adolescents age 15-19 after participation in a transition planning intervention?

Results

Sample Characteristics

A total of 11 adolescent/parent dyads consented and completed the first round of surveys. The majority of the participants were white (73%), male (55%), age 15 (45%), and the duration of type 1 diabetes was less than 10 years (72%). About half of the participants used a pump (55%) and tested their blood glucose 5-6 times per day (55%). Sixty four percent of the participants had been hospitalized once since diagnosis for diabetes-related issues and most had not required the use of glucagon (73%). The participants' most recent HbA1c levels were between 7.5% and 13.1% and most did not need help with hypoglycemic episodes (64%). Most went to the diabetes doctor 4 times a year (73%) and were planning on leaving the home for college (73%; Tables 11 and 12).

Of the 11 adolescent/parent dyads that consented for the study, 3 did not attend any session or complete the post surveys. Of the 8 remaining dyads, one adolescent completed the pre and post surveys and attended all four sessions but the parent did not complete the pre

autonomy scale or attend any sessions. Therefore, 7 dyads underwent the complete intervention. There were 5 males (75%) and 2 females (25%), 4 of the males were age 15 and the other was 18, the females were both age 17. The participants completing the intervention were mostly Caucasian (88%) and some African-Americans (12%), which is consistent with the majority of those with type 1 diabetes being Caucasian, and is representative of national type 1 diabetes demographics. The parent who attended the sessions with the adolescent was the mother (63%), or the father (13%). Two adolescents had both mother and father attend the sessions with them (13%).

Missing Data

There was one missing data point on the SMOD-A, that is accounted for in the scoring. One adolescent did not complete the helpfulness section of the DSPSAAS pre intervention but did finish the post survey.

Findings Related to Research Questions and Related Question

Due to small sample size, statistical testing is not reported. Any statement of “improved” means the post intervention mean score increased and “not improved” means the post intervention score decreased. Therefore, even small changes between pre and post intervention mean scores are reported as improved or not improved.

Research Question 1: Will transition readiness in adolescents age 15-19 be improved after participation in a transition planning intervention?

Transition readiness improved in adolescents age 15-19 after participation in the intervention. Overall, the transition readiness mean score among the participants was higher post intervention ($M = 3.37$; Table 13) compared to pre intervention ($M = 2.82$; Table 13). Differences in mean scores in this group pertained to managing medications and appointment

keeping. Questions regarding managing meds included: Do you fill a prescription? Do you know what to do if you are having a bad reaction to your medications? Do you take medications correctly and on your own?, and Do you reorder medications before they run out?. Filling a prescription, reordering medications, and treating bad reactions increased while taking medications on your own remained stable (Appendix A).

Research Question 2: Will self management practices (collaboration with parents, diabetes care activities, diabetes problem-solving, diabetes communication, and goal setting) in adolescents age 15-19 be improved after participation in a transition planning intervention?

Self management improved in adolescents age 15-19 after participation in the intervention except for the collaboration subscale. Mean scores increased among the participants in the following SMOD-A subscales: Diabetes care activities post intervention ($M = 34.00$) compared to pre intervention ($M = 33.14$), problem solving post intervention ($M = 14.71$) compared to pre intervention ($M = 14.57$), communication post intervention ($M = 19.08$) compared to pre intervention ($M = 16.29$), and goals post intervention ($M = 18.29$) compared to pre intervention ($M = 16.86$; Table 14). The communication and goals subscales had the most increase in mean scores from pre to post intervention. Items in the communication subscale that increased post intervention included: I try to change my diabetes routine if my nurse or doctor asks me to, I review my blood glucose records with my nurse or doctor, I contact my nurse or doctor when I can't get my blood glucose back into range, and If my parents have a problem with how I manage my diabetes, we talk about it. Items in the goals subscale that increased include: I take care of my diabetes to try not to have problems in the future and I take care of my diabetes so I am able to do things with my friends (Appendix B).

The collaboration subscale mean decreased among participants post intervention ($M = 16.14$; Table 14) compared to pre intervention ($M = 17.43$; Table 14). The collaboration subscale assesses care activities such as adjusting insulin dose, handling high blood sugars independently, discussion on insulin dose and carbohydrate counts, working together to problem solve blood glucose numbers and insulin dosages, and parents checking whether diabetes care activities have been completed. Three of the participants' scores for the collaboration subscale decreased while the other 4 increased. Mean scores decreased post intervention with these questions: I consult my parents when unsure of what to do to manage my diabetes, I adjust insulin doses by myself (reverse scored), I handle high blood sugars by myself (reverse scored), My parents help me decide my insulin dose, My parents and I look together at blood glucose records to make adjustments, and My parents check to see if I took my insulin (Appendix B).

Research Question 3: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Parental support to promote autonomy from the adolescent's perspective did not improve in adolescents age 15-19 after participation in the intervention. Overall mean scores decreased post intervention ($M = 25.00$; Table 15) compared to pre intervention ($M = 25.67$; Table 15). Questions that decreased in scores were: What do you think needs to be done about your insulin? and Your parent answered your questions about figuring insulin dose. Both of these questions decreased in the frequency and helpfulness portions of the survey. The question, Suggested that you give insulin before telling you to do it, was decreased in the frequency portion but not in the helpfulness. There was less promotion, post intervention compared to pre intervention, of

autonomy and encouragement of adolescent decision making and independence with the process of insulin administration as perceived by the adolescent (Appendix C).

Research Question 4: Will parental support to promote autonomy in adolescents' transition to diabetes self management, from the parent of adolescents' age 15-19 point of view, improve after participation in a transition planning intervention?

Parental support to promote autonomy from the parent's perspective did not improve from the parent of adolescents age 15-19 after participation in the intervention. Overall mean scores decreased post intervention ($M = 22.29$; Table 15) compared to pre intervention ($M = 25.86$; Table 15). A question that showed a decrease in score was: Suggested that he/she give insulin before telling him/her to do it. This question showed a decrease in scores for both frequency and helpfulness portions of the survey. There was only one question for the parents that decreased in the frequency portion and that was: You answered your adolescent's questions about figuring insulin dose. There was less promotion, post intervention compared to pre intervention, of autonomy and encouragement of adolescent decision making and independence with the process of insulin administration as perceived by the parent (Appendix C).

Research Question 5: Is this intervention useful to help with getting ready to transition the child's care to adult medical health care providers?

The intervention was useful to help with getting ready to transition to adult medical healthcare providers. Five out of 6 respondents to this question on the post evaluation strongly agreed or agreed with this question. One respondent was neutral (Table 16).

Research Question 6: Does this intervention provide important information about how to take care of the child's diabetes as a young adult?

The intervention provided important information about how to take care of diabetes as a young adult. Six out of 6 respondents to this question on the post evaluation strongly agreed or agreed with this question (Table 16).

Research Question 7: Would adolescents and parents recommend this intervention to other families with teenagers and young adults with diabetes?

Adolescents and their parents would recommend this intervention to other families with teenagers and young adults with diabetes. Five out of 6 respondents strongly agreed and one respondent was neutral to this question on the post evaluation. One respondent commented, “There was a lot of good information in this that I didn’t know. I will talk to my brother about doing this” (Table 16).

Research Question 8: What parts of the intervention were most useful?

Comments pertaining to parts of the intervention that were most useful include:

“The affect of drugs on diabetes; sexual health with diabetes.”

“I feel certain examples of situations were helpful on what we should do and how they can affect us.”

“Being able to ask questions and just talk back and forth helps me learn more.”

“The material was very helpful, more like a refresher course.”

“I think all parts made a nice package of useful information that can be applied now.”

“The additional information provided via the handouts, presentation, etc. it gave us info to talk about after each session.”

Participants felt the intervention was useful in helping to get ready for transition to adult health care and provided relevant information in taking care of diabetes as a young adult.

Research Question 9: What parts of the intervention were least useful?

Comments pertaining to parts of the intervention that were least useful include:

“Nothing”

“I can't really think of anything we learned that was unnecessary. The first class was a nice overview of some things I already knew.”

“Most parts were very useful but less background knowledge because we were already aware of certain diabetic facts.”

“I felt all parts were important. I don't think there were any parts not useful.”

Participants did not feel any part of the intervention was not useful but would have liked less background knowledge on diabetes pathophysiology.

Research Question 10: Are there ways this intervention can be improved?

Comments pertaining to improvement of the intervention include:

“It would be better if the classes took place earlier in the evening.”

“Nothing really, sorry.”

“There could be more hands on opportunities.”

“Perhaps start meetings a bit earlier, maybe 6 p.m.”

“Could this be held in West County Location?”

“Would like more practice problem solving hypo and hyperglycemia and with insulin dosing.”

“I would pay for classes like this.”

“Great!”

“Time of day was o.k.”

“This was well worth the time.”

Participants' suggestions for improvement of the intervention included moving the start time of the sessions earlier in the evening and rotating session sites to different locations

throughout the metropolitan area. Participants suggested more hands-on activities and providing more time for problem solving.

Related Question 1: Does the Diabetes Specific Parental Support for Autonomy in Adolescents Scale (DSPAAS) function in determining parental support for autonomy in adolescents age 15-19 after participation in a transition planning intervention?

Questions emerged as to whether the DSPAAS was functional because the study findings were opposite of what was expected for Research Questions 3 and 4. The instrument's author, Dr. Kathleen Hanna (Personal communication, January 30, 2015), was contacted. It was interesting that Dr. Hanna, working with investigators on two other studies that used this instrument, discovered that the instrument appears to be better suited for use in the early adolescent (age 12-14) who is just beginning to strive for autonomy from their parent. Wu et al. (2014) found that autonomy support and blood glucose monitoring decreased over time as responsibility for diabetes management shifted from the parent to the adolescent. In the second study, the authors found a decrease in autonomy support as the adolescent aged but in the 3 month period immediately post high school graduation, autonomy support increased (Hanna, Weaver, Stump, Guthrie, & Oruche, 2014). Early adolescence is typically a time in which granting of parental autonomy is just beginning and may start with allowing the early adolescent more time away from parents, typically with friends and school activities. Parents allowing independence with diabetes care may come after the adolescent proves he or she is capable of making mature decisions in other aspects of their life in addition to appropriate diabetes decision making in collaboration with the parent (Silk et al., 2003). The time immediately post high school graduation is critical in the adolescent's life, especially if he or she is leaving the parental

home for college. Suddenly, the adolescent must become more autonomous and the parent needs to support their adolescent

Summary of Results

The current study was conducted with a majority of white males, aged 15, with diabetes duration of less than 10 years. Transition readiness improved in adolescents age 15-19 after participation in the intervention. Self management improved in adolescents age 15-19 after participation in the intervention except for the collaboration subscale. Parental support to promote autonomy from the adolescent's perspective did not appear to improve in adolescents age 15-19 after participation in the intervention. Parental support to promote autonomy from the parent's perspective did not appear to improve from the parent of adolescents age 15-19 after participation in the intervention. The intervention was useful to help with getting ready to transition to adult health care in the opinion of the participants. The intervention provides important information about how to take care of diabetes as a young adult. Adolescents and their parents would recommend this intervention to other families with teenagers and young adults with diabetes. Participants felt the intervention was useful in helping to get ready for transition to adult health care and provided relevant information in taking care of diabetes as a young adult. Participants did not feel any part of the intervention was not useful but would have liked less background knowledge on diabetes pathophysiology. Participants' suggestions for improvement of the intervention include moving the start time of the sessions earlier in the evening and rotating session sites to different locations throughout the metropolitan area. Participants suggested more hands-on activities and providing more time for problem solving. Future use of the DSPSAAS in determining parental support for autonomy in adolescents age 15-19 requires

further research, because it's author has indicated that this instrument may not be appropriate for this age group.

CHAPTER V

Introduction

In Chapter V, the summary of the problem, the significance, and the purpose as well as the findings are discussed. This chapter also presents study limitations, implications, and directions for future research. Finally, conclusions are presented.

Summary of the Problem

Type 1 diabetes is an autoimmune disorder that occurs when the body destroys its insulin-producing beta-cells leading to a lack of insulin production for proper carbohydrate metabolism. Medical expenditures among people diagnosed with type 1 diabetes in the United States are about nine times higher than for those without type 1 diabetes, and the total cost of type 1 diabetes per year is equal to \$14.9 billion (JDRF, 2011). It is estimated that one in every 400 to 500 youth has type 1 diabetes (CDC, 2010). Macrovascular and microvascular complications arising from poor glucose control in those with type 1 diabetes are a continual threat. Serious complications of diabetes are imminent unless daily blood glucose is controlled and maintained over time. Fewer than 1 in 20 young adults with diabetes achieve target HbA1c levels and up to 37% already have, at a young age, serious complications as a result of poor glucose control (Balfe, 2009b). Tight glucose control results in decreased rates of diabetes complications and premature mortality (CDC, 2011) therefore, preventing complications before they manifest, rather than attempting to reduce the effects of diabetes complications after they occur, is advantageous.

Research indicates that the adolescent to young adult period is a critical time for prevention of diabetes complications. Making poor choices in diabetes management can result in negative life-changing situations including poor metabolic control (an increase in HbA1c levels),

feeling unwell, premature cardiovascular disease, and failure to reach desired life goals as an adult. Other sequelae are loss to medical follow-up, hospitalizations, and possibly premature death (Anderson & Wolpert, 2004). As adolescents age, they must take on more responsibility for diabetes management, however, they may not have adequate background information to manage type 1 diabetes well (ADA & Barclay, 2011). At a young age at diagnosis, they were unable developmentally to comprehend the disease and the complexity of its management, and their parents received type 1 diabetes education in the hospital, typically an intensive two-day training session that focuses solely on survival with diabetes. As a result, adolescents receive information about diabetes management second hand from their parents (Jameson, 2011).

Understanding the pathophysiology of type 1 diabetes and the rationale behind self management practices is vital to remain healthy (Anderson & Wolpert, 2004). Clinically, adolescents do receive ongoing coaching, preventive, and self management strategies during doctor visits and during diabetes emergencies such as hospitalization for diabetic ketoacidosis, but instruction at these times tends to be reactive rather than proactive, and emergency visits are not ideal venues for learning and retention of knowledge (Visentin et al., 2006).

Transitioning from adolescent to adult diabetes endocrine services at age 18, most adolescents are not ready and by that time have not mastered daily self management of their type 1 diabetes (ADA & Barclay, 2011). This transition between services may be planned or abrupt depending upon the structures in place between these services (Lugasi et al., 2007). Once the adolescent enters adult health care, they are viewed differently, as independent, self-reliant, and able to make decisions about treatment without parental help which can be challenging for some 18-year olds (Bowen et al., 2010).

Much of the literature on adolescent transition between pediatric and adult diabetes health care uses focus groups, interviews, or non-validated surveys as a means to study transition in adolescents to adult health care, concentrating on discrepancies between the services. Observational and descriptive studies on non-structured transition planning interventions showed them to be less than effective, with poor outcomes related to clinic attendance and early onset of diabetes complications (Garvey et al., 2012). Studies with structured transition plans measured clinic attendance, hospitalizations, severe hypoglycemia, diabetes complications, and barriers to accessing care (Cadario et al., 2009; Nakhla et al., 2009; Orr et al., 1996), yet none focused on these important factors: transition readiness or self management practices before and after the implementation of a transition plan, smoking or alcohol consumption that may affect daily management of type 1 diabetes, reproductive health, or involvement of parents in the process. No published randomized controlled studies of type 1 diabetes transition planning interventions from pediatric to adult healthcare services were found.

Summary of the Significance

Transitioning from pediatric to adult health care is not an automatic process for the adolescent with type 1 diabetes or their parent. The adolescent needs time to transition to independent diabetes self management while at the same time the parent needs time to relinquish diabetes management responsibilities to the adolescent. Adolescents need a review of basic type 1 diabetes pathophysiology, insulin action, nutrition, exercise and glucose management in addition to the mechanisms of diabetes complications and problem solving related to hypoglycemia and hyperglycemia episodes. Other aspects of daily living with type 1 diabetes including determining and procuring needed supplies, phoning the doctor, gaining employment, moving out of the parental home, obtaining Individual Education Plans (IEP) in preparation for

college entrance exams, and disclosing to others that the adolescent has diabetes are skills that take time to learn. Additionally, the adolescent needs to know the effects of alcohol use, drug use, and smoking on glucose control as well as overall health. Lastly, information on pregnancy and how diabetes affects the mother, fetus, and infant post delivery are essential for the female adolescent to know for future family planning. While the effects of type 1 diabetes on male reproductive health are generally not apparent until adult years, adolescent males should receive information on normal reproductive health and preventative health measures.

Transitioning the adolescent with type 1 diabetes from pediatric to adult health care must be a planned, gradual process to ensure both the adolescent and the parent are adequately prepared for the change in diabetes management responsibilities. This process could take up to four years, or the entire period of time the adolescent is in high school. This study facilitates the education of adolescents on diabetes self management in preparation for the transition from pediatric to adult health care. This study also includes support for the parent in the relinquishing of diabetes management responsibilities to the adolescent.

Summary of the Purpose

Extensive work has been done on what transition planning interventions should provide to the adolescent getting ready to move to adult health care. These interventions should be comprehensive, interactive, collaborative, and proactive intervention that optimizes health and meets the complex developmental and psychosocial needs of the adolescent in a structured format, and should contain diabetes coaching, preventive, and self management strategies for adolescents with type 1 diabetes (Daneman & Nakhla, 2011). Though these interventions have been described, they have not been systematically studied. A feasibility study, based on a framework described by Bowen (2009), was used to investigate whether the intervention could

be implemented and to determine the usefulness of a transition planning intervention to adolescents and their parents. The purpose of this study was to determine the feasibility of a transition planning intervention, focused on educating adolescent/parent dyads about diabetes self management in preparation for the transition from pediatric to adult health care, using a newly developed transition plan and framework. Transition readiness, diabetes self management practices, and parental support for autonomy in adolescent decision making from the adolescents' and parents' point of view were examined.

Discussion of Results

Transition readiness showed improvement in adolescents age 15-19 after participation in the intervention. Overall, transition readiness among the participants was higher post intervention. The largest gains in mean scores resulted from an increased knowledge of how to manage medications i.e., when and how to refill medications and how to handle a difficult hypoglycemic event; and in appointment keeping i.e., scheduling and keeping a calendar of appointments, and phoning the doctor with concerns following up on labwork. The participants in this study already had a good rapport with their healthcare providers pre intervention and this was maintained post intervention, which will be necessary when they transition to adult health care providers. The findings of this study were in agreement with other studies in the literature that used the TRAQ. Mean scores of transition readiness increased post intervention compared to pre intervention (Sawicki, Kelemen, & Weitzman, 2014; Wood et al., 2014). These studies were completed in adolescents with childhood chronic diseases including type 1 diabetes.

Self management showed improvement in adolescents age 15-19 after participation in the intervention except for the collaboration subscale on the SMOD-A. The diabetes care activities subscale showed an increase in self-directed diabetes management activities such as testing

blood glucose without being reminded and keeping a log of blood glucose readings. The problem solving subscale showed an increase in managing insulin administration with exercise while the rest of the questions in this subscale were generally static. The communication subscale showed an increase in communication with the healthcare provider and talking with parents when there is a disagreement over how the adolescent is taking care of his/her diabetes rather than arguing. In the goals subscale, the adolescents increased their awareness of the need to take care of their diabetes to prevent complications in the future. In contrast, Keough et al. (2011), and Schilling et al. (2009) found that all subscales improved when using this instrument in the study of adolescents with type 1 diabetes.

Items in collaboration with parents subscale assess care activities such as adjusting insulin dose, handling high blood sugars independently, discussion on insulin dose and carbohydrate counts, working together to problem solve blood glucose numbers and insulin dosages, and parents checking whether diabetes care activities have been completed. Possibly, collaboration is not necessary once the skill has been mastered by the adolescent and the parent is comfortable with allowing independence in these diabetes care activities. Areas to address in the intervention pertaining to this subscale would include providing more time during the intervention to role play and discussion surrounding counting carbohydrates and insulin dosing. Also, presenting a specific section on collaboration techniques would be beneficial since this was not done in the current study.

The DSPSAAS did not reflect an increase as expected in parents' support to promote autonomy from the adolescents' and parents' perspective in adolescents age 15-19, or their parent, after participation in the intervention. There was a decrease in the perceived parental support for promotion of autonomy and encouragement of adolescent decision making and

independence with the process of insulin administration by both the adolescent and parent. During the sessions, the adolescents were very knowledgeable about insulin dosing when the logs were reviewed. This group may have already achieved autonomy and receive encouragement in diabetes self management and decision making from their parents. The findings of two recent studies (Hanna et al., 2014; Wu et al., 2014) agreed with the results of the current study; a decrease in parental support for autonomy when using this instrument in the study of older adolescents age 15-18. In contrast, other studies (Hanna et al., 2012; Hanna et al., 2005; Hanna & Guthrie, 2000; & Hanna & Woodward, 2013) found that parental support for autonomy improved when using this instrument in the study of adolescents age 12-19 with type 1 diabetes. Therefore, the validity of this instrument used in this age group is questioned.

The process of the parent granting autonomy in diabetes decision making requires more time for the parent to be comfortable with “letting go”. Possibly, the participants in the current study already showed their ability to adjust insulin dosages successfully that the need to grant autonomy was not necessary. The adolescent group in this study may have already been granted more autonomy by their parents. In addition, a longer duration of study may have yielded different results as 4 weeks is not long enough to allow for behavior changes. The range of HbA1c levels in this group was 8.1%-9.0% (Table 12), which shows some ability to administer insulin and monitor other aspects of diabetes self management adequately. While this level of HbA1c is not desirable, it is not unexpected for an adolescent.

The transition planning intervention was useful to help with getting ready to transition to adult health care providers. The intervention provided important information about how to take care of diabetes as a young adult. Adolescents and their parents would recommend this intervention to other families with adolescents and young adults with diabetes. Post intervention

evaluations completed by participants were favorable. Most agreed or strongly agreed that this transition planning intervention was helpful in getting adolescents ready for transition and taking care of diabetes as a young adult, type 1 diabetes. Because this intervention was a first of its kind, there are no other studies in which to compare findings.

Post intervention comments by participants were favorable. The review of type 1 diabetes was helpful as well as being able to ask questions and discuss the material were beneficial. In addition, the provision of handouts allowed for further discussion amongst the adolescents and parents at home. All of the information presented in the coaching and learning strategy sessions was found useful however one participant commented that the background type 1 diabetes review was not necessary since this person was already aware of certain diabetes facts. Some aspects that need addressing include time of day of the intervention and location of the sessions. Overall the content of this intervention is applicable to transitioning adolescents from pediatric to adult health care but more hands on activities could be added. Because this intervention was a first of its kind, there are no other studies in which to compare findings. The current study used an evidence-based intervention to determine pre transition readiness, self management practices, and parental support for adolescents autonomy in decision making, provided education on topics pertinent to daily living not covered in other transition programs, and performed a post evaluation of the effectiveness and usefulness of the intervention.

Study Strengths

A major strength of this study was that it provided valuable information on a method to prepare the adolescent for transition to adult health care and daily living skills. The interventions includes: (a) diabetes pathophysiology and nutrition with the adolescent and parent, (b) insulin action and problem solving hypoglycemia and hyperglycemia episodes, (c) the effects of

smoking, alcohol use and drug use and their effects on the person with type 1 diabetes, (d) how insurance works, (e) when to call the doctor and what to say, (f) being employed and having type 1 diabetes, (g) discussing diabetes with employers and professors at school, (h) reproductive health for male and females, and (i) supporting the parent in the transition process.

This feasibility study added to the body of knowledge about adolescents with type 1 diabetes transitioning from pediatric to adult health care by showing a need for a structured transition planning intervention for adolescents age 15-19 and their parents. This intervention was well received by the participants and was beneficial because it was relevant and the information could be immediately applied.

Furthermore, this transition planning intervention was structured. An instructor manual was developed for each session that included objectives, a presentation, discussion points on the current session in addition to the content previously presented, and handouts to be used for reference as well as more detailed information on session content. All instructors were trained on presenting content prior to the start of the intervention and met after each session to discuss the proceedings and areas needing improvement. Another plus for this study was separating the adolescents from the parents for sessions 2-4. This provided privacy and enabled the adolescents to discuss more freely their problems with diabetes self- management.

Study Limitations

The study lacked diversity since a majority of the participants were Caucasian. Another limitation was reliance on self-report in the completion of the survey instruments. Sample size was small therefore only changes in mean scores were reported instead of statistical significance. In addition, sample size limits generalization to the target population.

Recruitment of Adolescents

Recruiting adolescents to clinical studies is an inherent challenge for researchers. Some reasons in the literature for slow recruitment are perception of invulnerability, few clinical symptoms, lack of trust with the researcher, possible breach of confidentiality, and time restraints (Hendricks-Ferguson et al., 2012; Nguyen et al., 2014). Conducting a study out of a reputable pediatric diabetes clinic may diminish issues with lack of trust or worry over breach of confidentiality. Invulnerability is related to developmental stage where the adolescent does not believe anything terrible such as diabetes complications can happen or they do not have clinical symptoms right now so their management of diabetes is sufficient; therefore, they may think that further education on self management is not needed.

Based on the literature, methods of recruitment of adolescents in the literature include bright, eye-catching flyers posted throughout campus and clinics, email blasts to potential participants and school staff, word-of-mouth, school website, Facebook, support groups, diabetes related websites, monetary incentives, text messages, pre-paid mobile phones, radio and television ads, accommodating adolescents' and parents' schedules by offering study visits before or after working hours or on the weekends, or holding sessions in sites other than the hospital (Cantrell et al., 2012; Hendricks-Ferguson et al., 2012; Leonard, Hutchesson, Patterson, Chalmers, & Collins, 2014; Nguyen et al., 2014).

Successful recruitment of adolescents age 15-19 for the current study proved challenging. Strategies used to entice potential participants to join the study are found in Table 9. After consulting with a pediatric endocrinologist and completion of a literature review on recruiting adolescents for research, no other strategies for recruitment were found. This confirmed that recruitment avenues by the graduate nurse researcher had been exhausted. A possible reason for

recruitment difficulty for the current study includes time of day of the sessions. The time of day these sessions were held was 7 p.m. to allow for after school activities, dinner, and travel time to the session site. Anecdotal comments about the session time were that coming home later in the evening allowed less time to complete homework. This could be improved by moving the start time of sessions 30 minutes to 1 hour earlier.

Theoretical Considerations

The theories used in this study were Transition, development including Erikson's Stages of Psychosocial Development and Emerging Adulthood, Self-Efficacy including Mastery, Self Management, Health Belief Model, and Parent Development Theory. These theories were appropriate and highly applicable for this topic by providing explanations for behavior in addition to offering insight into a method or process to change behavior. These theories provided the framework for the development of the transition plan and subsequent transition planning intervention used in the current study.

Transition Theory

The constructs of Transition theory were vital to this study because health care providers must address issues relevant to the transition process due to disruption of the status quo and the effects on health, illness, or health-related behaviors that transitioning may produce, or issues occurring once the adolescent has reached the new stage in the transition process (Chick & Meleis, 1986). This is especially important in the adolescent with type 1 diabetes given that unsuccessful transition can lead to dire consequences. A goal is to provide interventions to achieve desired health outcomes and, because transition generally involves a shift in self management practices, it is the healthcare provider's role to facilitate this process to maintain the health and well-being of the adolescent.

Erikson's Stages of Psychosocial Development and Emerging Adulthood

The developmental theories, Erikson's Stages of Psychosocial Development and Emerging Adulthood were important in providing background on the behavioral and developmental status of the adolescent age 15-19. Both of Erikson's Role vs. Confusion stage and Intimacy vs. Isolation stages concern the development of personal identity that allows one to stay true to one's self, values, beliefs, and ideals while forming relationships. Emerging Adulthood is a time of exploration and experimentation, characterized by instability, possibility, a feeling of being "in-between," focusing on the self and identity development. The adolescent must successfully complete Erikson's two stages in order to be prepared for the instability of the Emerging Adulthood stage. If the adolescent has developed good habits in diabetes self management, he or she is more likely to continue those into the Emerging Adulthood stage and maintain optimal glucose control.

Self-Efficacy, Mastery, and Self Management Theories, and Health Belief Model

Self-Efficacy, Mastery, and Self Management theories, and the Health Belief Model were appropriate and useful for this study. Transition readiness and diabetes self management (collaboration with parents, diabetes care activities, diabetes problem-solving, diabetes communication, and goal setting) scores (except collaboration with parents) increased post intervention. These instruments were chosen for this study because they measured diabetes self management practices directly, and self-efficacy and mastery of diabetes self management practices indirectly. The Health Belief Model states that behaviors of people depend on the value imposed on a goal by the individual and that person's estimate of the likelihood of meeting that goal. These values influence expected outcomes, therefore, affecting initial motivation and the decision to change health practices (Strecher et al., 1986). This was reflected in the increase in

scores post intervention on the TRAQ that included a section on goal-setting to improve diabetes self management practices.

Parent Development Theory

Finally, the Parent Development theory concerns how the parental role is affected not only by individual perceptions and the developing child, but also by how parents adjust and respond to the changes in themselves, their child, the parent-child relationship (Mowder & Sanders, 2007; Mowder, 2005; Sperling & Mowder, 2006). The parents who attended the coaching and strategy sessions demonstrated responsiveness and concern for the safety of their adolescent by participating in this study. They sought further education through this intervention to ensure their adolescent had the knowledge to transition to adult health care.

Implications for Practice

Two major sets of guidelines recommend using a structured transition plan from pediatric to adult health care for adolescents with type 1 diabetes (ADA & Barclay, 2011; AAP, AAFP, and ACP, Transitions Clinical Report Authoring Group, 2011). Nursing practice will change as a result of instituting structured transition plans in pediatric diabetes clinics. Nurses will be assessing adolescents' diabetes transition readiness, self management capabilities, and parental support for autonomy in the relinquishing of self management responsibilities to their adolescent. Not only will the nurse instruct the adolescent and parent on diabetes self management, he or she will be tailoring a care plan specific to the needs of the dyad in preparation for transition readiness. This may include garnering referrals for consults from social work, psychologists, dietitians, and other ancillary healthcare teams to ensure the adolescent transitions smoothly from pediatric to adult health care without becoming lost to follow-up and without experiencing rapid increases in diabetes complications.

The transition to independent management of type 1 diabetes must be a gradual process of the parent releasing responsibility while the adolescent gradually increases his or her responsibility in diabetes management. This is an active process but must be planned and gradual to ensure both the adolescent and the parent are adequately prepared for the exchange of diabetes management responsibilities while maintaining open lines of communication. The parent needs time to relinquish these responsibilities and should be provided information on how to support their adolescent in this process. With each year of the transition plan, the adolescent should become more responsible for their diabetes care while the parent responsibility decreases. Also, the diabetes healthcare provider and clinic staff gradually become, with each passing year, resources and coaches for the adolescent in diabetes self management, and will also need to “let go” of the adolescent. Because structured transition plan will be implemented over 3-4 years, the diabetes healthcare provider will have more time to devote to educating the adolescent on psychosocial topics and healthy lifestyle habits in addition to therapy adherence.

This transition planning intervention will be used in the pediatric diabetes outpatient clinic at a major Midwestern university hospital. Initiating this intervention into the clinic requires a structured roll-out. The intervention, as executed in this study, consisted of once weekly sessions over 4 weeks with adolescent/parent dyads in attendance. Now, the transition plan will be used in the clinic. Although an instructor manual was developed for the current study, the format of the curriculum was developed to use once weekly over 4 weeks. A new, expanded instructor manual for use over 2-4 years is needed. A standardized list of goals pertaining to each aspect of diabetes self management is necessary for mutual understanding among the disciplines when developing the transition care plan for the adolescent/parent dyad. In addition, pre-transition plan implementation and post-transition implementation data using the

TRAQ and SMOD-A instruments to assess intervention effectiveness is necessary. The DSPSAAS will require further evaluation to determine applicability to the target population if used in the clinic.

Implications for Further Research

This study only required one parent to attend, but for future research, it may be beneficial to include both parents. Further research using the DSPSAAS scale is needed for this age group within adolescence to determine whether the decreased post intervention mean scores from the DSPSAAS are due to the need to revise the transition planning intervention in this particular area or whether the instrument was not appropriate for this age group. Additional research concerning transition readiness includes determining the transition readiness of the healthcare provider and clinic staff in “letting go” of the adolescent to adult health care. Further research on diabetes self management in the adolescent would be determining improvement of hypoglycemia and hyperglycemia problem solving and level of adolescent autonomy after being involved in a transition plan.

Although this study did not measure clinic attendance, (Cadario et al., 2009; Masding et al., 2010), number of hospitalizations (Nakhla et al., 2009), severe hypoglycemic reactions (VanWalleghem et al., 2008), diabetes complications (Logan et al., 2008), barriers to accessing care (VanWalleghem et al., 2008; Van Walleghem et al., 2006), changes in HbA1c levels (Orr et al., 1996), or hold focus groups, support groups, or patient interviews, or surveys to determine likability of the experienced transition process post transition (Markowitz & Laffel, 2012; Peters et al., 2011), these variables could be examined in a larger study. Finally, financial considerations on implementing a transition plan in a clinic setting must be taken into account to determine the return on investment.

Conclusions

1. The theoretical framework was useful and applicable to preparing the adolescent age 15-19 for the transition to adult health care.
2. The Transition Plan and transition planning intervention with its instructor training manual provide a resource to guide clinicians in facilitating transition to adult health care.
3. The transition planning intervention shows promise. Both transition readiness and self management practices (except for collaboration) improved in adolescents age 15-19 after participation in the intervention.
4. The transition planning intervention was useful based on responses from the adolescents and parents.
5. Before the DSPSAAS instrument is used in future research with the transition planning intervention, survey items need further review and the instrument needs to be discussed further with the author in regard to applicability to adolescents 15-19 years old.
6. Based on the data and findings of this study and related evidence found in the literature, the diabetes endocrinologist and the graduate nurse researcher have decided to roll out the intervention in the pediatric diabetes clinic used as the study site. The intervention will be expanded, converting the 4 weekly sessions to 4 quarterly sessions each year held during the clinic visit for adolescents age 15-19.

Table 1 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes-Transition*

Instruments Measuring Transition		
Characteristics	TRAQ	CA HRTW THCA
Descriptor	Transition readiness in 2 domains: self management and self-advocacy	Self-sufficiency-health care self-care needs- knowledge, skills, preventative care, community resources, long term disability, communication, insurance, sexual activity, legal issues, transportation
Type, subscales, and number of items	Likert type self-report, total score with two domains: self management and self-advocacy, 20 items	Yes/no ordinal self-report, total score with 14 domains, 72 items
Reliability and validity	Internal consistency (self management $\alpha = 0.92$,; self advocacy $\alpha = 0.82$) overall $\alpha = 0.93$; domains moderately correlated $r = 0.46$, $p < 0.0001$	Kuder-Richardson Level range from 0.0-1.00 (>0.66) for 7/14 domains
Age range of sample with Type 1 Diabetes	Young adults with various chronic health conditions age 16-26	Adolescents with various chronic conditions age 14-21
Disadvantages	New, not widely utilized, Total score only, No subscale totals, Starts at age 16	Internal validity >0.66 -provided only for 7/14 domains, Pilot study-small sample size (25), 72 items yes/no answers, Not tested on adolescents with type 1 diabetes
Clinically usable with high ease of use	Yes	Yes

Note. TRAQ = Transition Readiness Assessment Questionnaire; CA HRTW THCA = California Healthy and Ready to Work Transition Health Care Assessment Tool.

Table 2 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes-Self Management*

Instruments Measuring Self Management		
Characteristics	SMOD-A	DKQ
Descriptor	Collaboration with parents, diabetes care activities, problem solving, diabetes communication, and goals of self management	Outcomes of diabetes education
Type, subscales, and number of items	Likert type self-report, five independent subscales, no total score: collaboration with parents, diabetes care activities, problem solving, diabetes communication, and goals of self management; 52 items	Multiple choice self-report, total score, 13 items
Reliability and validity	Content validity index 0.93 Subscale internal consistency (α = 0.71 to 0.85) Test re-test 2 weeks 0.60 to 0.88, and 3 months 0.59 to 0.85	12 items α = 0.73, with the addition of a specific type 1 diabetes question, α = 0.79; test/retest reliability r = 0.62
Age range of sample with Type 1 Diabetes	Adolescents age 13-21	No age range given, also type 2 diabetes
Disadvantages	No overall score, Validation completed on a small homogeneous sample, Length of instrument-52 items	Tests knowledge only, Not reasoning or problem solving, No age range specified
Clinically usable with high ease of use	Yes	Yes

Note. SMOD-A = Self-Management of Type 1 Diabetes in Adolescents; DKQ = Diabetes Knowledge Questionnaire.

Table 3 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes-Support*

Instruments Measuring Support		
Characteristics	CPI	DFBS
Descriptor	Quality of life, adherence, and glycemic control, and collaborative parental involvement	Family behaviors specific to diabetes care related to metabolic control
Type, subscales, and number of items	Likert type youth-report, total score, 12 items	Likert type self-report, total score, 60 items
Reliability and validity	$\alpha = 0.91$; item-to-total correlations $r = 0.52$ to 0.78	Test re-test warmth and caring 0.79 $p < 0.0001$, guidance control 0.83 $p < 0.0001$, problem solving 0.52 $p < 0.0006$
Age range of sample with Type 1 Diabetes	Children age 11-16	Children and adolescents age 7-17
Disadvantages	Measures quality of life, adherence, and collaboration-not releasing responsibility to adolescent and providing autonomy, Age cut-off is 16	No factor analysis completed, No normative data, Only outcome measure was HbA1c levels, Some wording outdated
Clinically usable with high ease of use	Yes	Yes

Note. CPI = Collaborative Parent Involvement Scale for Youth with Type 1 Diabetes; DFBS = Diabetes Specific Family Behavior Scale.

Table 4 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes and their parent-Transition*

Instruments Measuring Transition	
Characteristics	Transition
Descriptor	RTQ-Teen, RTQ-Parent
Type, subscales, and number of items	Transition readiness, adolescent responsibility or the frequency of responsible adolescent healthcare behaviors, parental involvement, and frequency of familial involvement
Reliability and validity	Likert type self-report, total score, 22 items
Age range of sample with Type 1 Diabetes	RTQ teen $\alpha = 0.79$; parent $\alpha = 0.88$; Reliability overall ($r = 0.68$, $p \leq 0.01$)
Disadvantages	Age 15-21 post kidney transplant
Clinically usable with high ease of use	Specifically for post-kidney transplant patients

Note. RTQ-Teen/RTQ-Parent = Readiness for Transition Questionnaire.

Table 5 Instruments useful for creating a transition plan in adolescents with type 1 diabetes and their parent-Self Management

Characteristics	Instruments Measuring Self Management				
	DSMP-SR	DSMP	ADA-C, ADA-P	DSMP-R	DSMP-Flex
Descriptor	Self-manage-ment behaviors of those with type 1 diabetes	Self-manage-ment behaviors of those with type 1 diabetes over the preceding 3 months	Adherence in insulin administra-tion, diet, exercise, blood glucose monitoring, and hypoglycemia management-adapted from the DSMP	Self-manage-ment behaviors of those with type 1 diabetes over the preceding 3 months	Self management behaviors and adherence to treatment of those with type 1 diabetes on flexible insulin regimens-modified version of DSMP for flexible insulin regimens
Type, subscales, and number of items	Type not stated self-report, total score, 24 items	Interview, Total and subscales, 25 items	Likert type self-report, total score, 20 items	Telephone interview, total score, 25 items	Interview, total score, 25 items
Reliability and validity	Youth $\alpha = 0.82$, parent $\alpha = 0.80$; youth/parent correlation $r = 0.60$ $p < 0.001$;	$\alpha = 0.76$ overall and < 0.50 for the subscales; test/retest reliability overall $r = 0.67$ and a range of 0.34-0.47 for the subscales; inter-interviewer reliability $r = 0.94$; parent-child reliability $r = 0.61$	ADA-C $\alpha = 0.75$, ADA-P $\alpha = 0.82$; correlation between child and parent versions 0.61 (CI 0.5-0.7); test retest (1 week apart) $r = 0.96$ $p < 0.001$ for both versions	Conventional $\alpha = 0.62$, Flexible $\alpha = 0.69$; parent-child reliability $r = 0.42$ -0.72	Child/adolescent $\alpha = 0.47$ -0.65, parent $\alpha = 0.69$ -0.70; test re-test (6 months) child/adolescent $r = 0.73$, $p < 0.001$, parent $r = 0.42$, $p = 0.002$; child/adolescent/parent correlation 0.59, $p < 0.001$
Age range of sample with Type 1 Diabetes	Age ≥ 11 and their parent(tested on age 8-18)	Age 6-15 and their parent	Age 6-18 and their parent	Age 7-17 and their parent	Age ≥ 11 and their parent
Disadvantages	Cross-sectional study-no test re-test data, treatment adherence	Semi-structured interview, requires training for those administering, open-ended questions-responses may not fit scoring system, difficult to score, age cut-off at 15	Test-retest 0.96 but was completed 1 week apart, a tally of behaviors and adherence	Interview based; requires training the interviewer, age cut-off at 17, inter-interview reliability not stated	Interview based telephone survey
Clinically usable with high ease of use	Yes	No	Yes	No	No

Note. DSMP-SR = Diabetes Self Management Self Report; DSMP = Diabetes Self Management Profile; ADA-C/ADA-P = Assessment of Diabetes Adherence; DSMP-R = Diabetes Self Management Profile-Revised for Conventional and Flexible Insulin Regimens; DSMP-Flex = Diabetes Self Management Profile-Flex.

Table 6 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes and their parent-Self Management*

Instruments Measuring Self Management					
Characteristics	DSMQ	DART , DART-P	DPSMA	DPSI	SCI
Descriptor	Adherence to diabetes self management tasks over preceding month - adapted from DSMP	Knowledge, insulin, nutrition, hyper-hypoglycemia, pump, problem-solving, and school factors	Diabetes-related self-management problem-solving	Reason-ing and critical thinking	Know-ledge and adherence to diabetes regimen over four domains: monitoring, insulin, diet, and exercise
Type, subscales, and number of items	Type not stated self-report, total score, 9 items	Type not stated; Seven subscales and total score: general knowledge, insulin, nutrition, hyperglycemia/hypoglycemia, pump, problem-solving, and school factors; 84 items	Interview, total score, 17 items	Interview, total score, 12 items	Likert type, self-report, total score, 14 items
Reliability and validity	Adolescent $\alpha = 0.59$, parent $\alpha = 0.57$; correlation between adolescent and parent $r = 0.56$, $p < 0.0001$	DART $\alpha = 0.94$ total, Child subscales: general knowledge $\alpha = 0.73$, insulin $\alpha = 0.85$, nutrition $\alpha = 0.70$, school $\alpha = 0.43$, hyper-hypoglycemia $\alpha = 0.79$, problem-solving $\alpha = 0.78$, pump $\alpha = 0.84$; correlation between subscales and total $r = 0.49-0.93$; DART-P $\alpha = 0.92$ total, Parent subscales: general knowledge $\alpha = 0.80$, insulin $\alpha = 0.79$, hyper-hypoglycemia $\alpha = 0.69$, problem-solving $\alpha = 0.83$, pump $\alpha = 0.89$; correlation between subscales and total $r = 0.47-0.93$; correlation between child age 8-11 with parent $r = 0.19$, child age 12-18 with parent $r = 0.37$	$\alpha = 0.71$; inter-rater reliability 0.8-0.9	Child $\alpha = 0.51-0.67$; Parent $\alpha = 0.53-0.59$; between child and parent $\alpha = 0.36-0.44$	Adolescent $\alpha = 0.8$; parent $\alpha = 0.72$; test-retest adolescent $r = 0.91$; parent = 0.86
Age range of sample with Type 1 Diabetes	Age 9-15 and their parent	DART for age 8-18; DART-P for parent	Age 13-17 and their parent	Age 9-14.5 and their parent	Age 11-18 and their parent

Disadvantages	Measures adherence, age cut-off 15	Interview based, 84 items, age cut-off is 18	Interview based with vignettes, Requires training of interviewer, Age cut-off at 17	Interview based, Requires training the interviewerAge cut-off 14.5	Knowledge only, not critical thinking or reasoning; Adherence behaviors only
Clinically usable with high ease of use	Yes	Yes	No	No	Yes

Note. DSMQ = Diabetes Self Management Questionnaire; DART/DART-P = Diabetes Awareness and Reasoning Test for Children and Parents; DPSMA = Diabetes Problem Solving Measure for Adolescents; DPSI = Diabetes Problem Solving Interview; SCI = Self Care Inventory.

Table 7 *Instruments useful for creating a transition plan in adolescents with type 1 diabetes and their parent-Support*

Instruments Measuring Support		
Characteristics	DSPSAAS	DFBC
Descriptor	Parental behaviors of reasoning and discussing diabetes management	Supportive and non-supportive behaviors of family members for self management of type 1 diabetes
Type, subscales, and number of items	Likert type, self-report, 4 items	In home interview
Reliability and validity	Internal validity between adolescent and parent versions $\alpha = 0.67-0.80$	Adolescents supportive $\alpha = 0.63$, non-supportive $\alpha = 0.60$; adults supportive $\alpha = 0.73$, non-supportive $\alpha = 0.43$; test re-test adolescent supportive $r = 0.60$ and 0.75 , non-supportive $r = 0.60$ and 0.28 ; adult range $r = 0.58-0.72$
Age range of sample with Type 1 Diabetes	Age 12-19 and their parent	Age 12-64
Disadvantages	Only covers insulin administration	Interview based, Requires training of interviewer
Clinically usable with high ease of use	Yes	No

Note. DSPSAAS = Diabetes Specific Parental Support for Adolescents Autonomy Scale; DFBC = Diabetes Family Behavior Checklist.

Table 8 *Criteria for intervention inclusion*

Type 1 diabetes
Population for instrument-adolescents age 15-19
Subject <ul style="list-style-type: none"> ○ Transition <ul style="list-style-type: none"> ▪ Adolescent preparation for self management ▪ Adolescent autonomy in diabetes care ▪ Communication to the healthcare team ▪ Parental assistance in adolescent reaching autonomy ○ Self management <ul style="list-style-type: none"> ▪ Problem solving, not factual knowledge <ul style="list-style-type: none"> • Insulin administration • Hypoglycemia and hyperglycemia management • Diet • Exercise ○ Support <ul style="list-style-type: none"> ▪ Adolescent view ▪ Parent view
Written in English and for English speaking subjects
Evidence of psychometric testing
High internal consistency and reliability 0.7 or higher
Non-interview type
Ability to administer quickly, without administrator training necessary

Table 9 *Recruitment venues*

Diabetes camp 7-14-2014
Children's patient registry-letters and flyers mailed 6-18-2014
Children's support group (Children's patients only) 7-3-2014
Diabetes Corner Support Group 7-7-2014
JDRF support group 7-7-2014
Phoned non-responders, emailed information/consent to those that were interested, left messages for others 7-9-2014
ADA support group 7-16-2014
Extended Children's support group to all members 7-17-2014
Cardinal Glennon educators 7-17-2014
Dr. Galgani at St. John's 7-17-2014
Posted study information to an online diabetes support group 7-20-2014
Type 1 Diabetes and Athletes Support Group 7-20-2014
Posted Flyers at United Church of Christ 7-21-2014
Lutheran Church parish nurses 7-21-2014
SLSSNA-St. Louis Suburban School Nurses' Association 7-21-2014
Parish Nurse at St. Gabriel the Archangel Parish 7-21-2014
Children's patient registry-letters and flyers mailed 7-25-2014
Flyer at South City YMCA community bulletin board
Flyer at Kirkwood and Webster Groves YMCA community bulletin board
Flyer at Carondolet YMCA community bulletin board
Flyer at Mid County YMCA community bulletin board
Flyer at St Charles County YMCA
West County YMCA has no community bulletin board - teen director disseminated the information
Phoned non-responders, emailed information/consent to those that were interested, left messages for others 7-28-2014
Children's patient registry-letters and flyers mailed 8-10-2014
Children's patient registry-letters and flyers mailed 8-23-2014
Lutheran School Systems lead nurse and lead school nurses 9-2-14
Children's patient registry-letters and flyers mailed 9-14-2014
Children's patient registry-letters and flyers mailed 11-10-14
ICTS Recruitment Enhancement Center , Registry 11-2-14
Phoned non-responders, emailed information/consent to those that were interested, left messages for others 11-16-2014

Table 10 *Data collection schedule*

	Began September 2014	Began November 2014
Time	Intervention	Intervention
Before Session 1	Complete pre measures at clinic	Complete pre measures at clinic
Session 1	Attend	Attend
Session 2	Attend	Attend
Session 3	Attend	Attend
Session 4	Attend and complete post measures	Attend and complete post measures

Table 11 *Diabetes transition demographics table pre intervention (n = 11)*

Demographic	Percent	Demographic	Percent
Gender		Insulin Delivery	
Male	55%	Injection	36%
		Pump	55%
		Both	9%
Age		Glucose Testing/Day	
15	45%	3-4	45%
16	9%	5-6	55%
17	9%		
18	18%		
19	18%		
Race		Glucagon Use	
Caucasian	73%	Yes	27%
African- American	18%	No	73%
Indian	9%		
Diabetes Duration (years)		Hospitalized Since Diagnosis	
<5	36%	1x	64%
5-10	36%	2x	27%
10-15	27%	3x	9%
Time/Year see Diabetes Doctor		Needed Help with a Low	
1	9%	Yes	36%
2	0%	No	64%
3	18%		
4	73%		
Leaving Home for College			
Yes		73%	
No		9%	
In college		18%	

Percentages may not add up to 100 due to rounding.

Table 12 *Diabetes transition HbA1c table pre intervention (n = 11)*

Last HbA1c*/Frequency	
	7.5
	7.6**
	8.2
	8.3**
	8.5
	9.0
	9.4
	9.9
	13.1**

*Missing data from 2 participants. **Did not attend sessions.

Table 13 *Transition Readiness Assessment Questionnaire Results (TRAQ), n=7*

TRAQ	Mean/Pre (n=7)	Mean/Post (n=7)	Mean Difference
Manage Medications	2.93	3.50	+0.57
Appointment Keeping	2.00	2.71	+0.71
Health Issues	2.50	2.82	+0.32
Talking with Providers	4.64	4.86	+0.22
Managing Daily Activities	4.33	4.33	NC
Overall	2.82	3.37	+0.55

*Overall score only and an increase in overall score indicates an increase in transition readiness; NS = not statistically significant; NC = No change

Table 14 *Self Management of Type 1 Diabetes-Adolescent Results (SMOD-A), n=7*

SMOD-A	Mean/Pre (n=7)	Mean/Post (n=7)	Mean Difference
Collaboration	17.43	16.14	-1.29
Diabetes Care Activities	33.14	34.00	+0.86
Problem Solving	14.57	14.71	+0.14
Communication	16.29	19.08	+2.79
Goals	16.86	18.29	+1.43

*Subscale measurement only and an increase in subscale score indicates an increase in self management in the particular subscale; NS = not statistically significant

Table 15 *Diabetes Specific Parental Support for Autonomy Scale Results (DSPAAS), n=7*

DSPAAS	Mean/Pre (n=7)	Mean/Post (n=7)	Mean Difference
Adolescent: Overall	25.67	25.00	-0.67
Parent: Overall	25.86	22.29	-3.57

*Overall score only and an increase in overall score indicates an increase in parental support for adolescent's autonomy; NS = not statistically significant

Table 16 *Post intervention evaluations*

Question	Strongly Agree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
1. This program was useful to help with getting ready to transition my/my child's care to adult medical health care providers.			<i>1</i>	<i>4</i>	<i>1</i>
2. This program provided important information about how to take care of my/my child's diabetes as a young adult.				<i>4</i>	<i>2</i>
3. I would recommend this program to other families with teenagers and young adults with diabetes.			<i>1</i>		<i>5</i>

Figure 1. Transition Plan from Pediatric to Adult Endocrinology Services for the Patient with Type 1 Diabetes

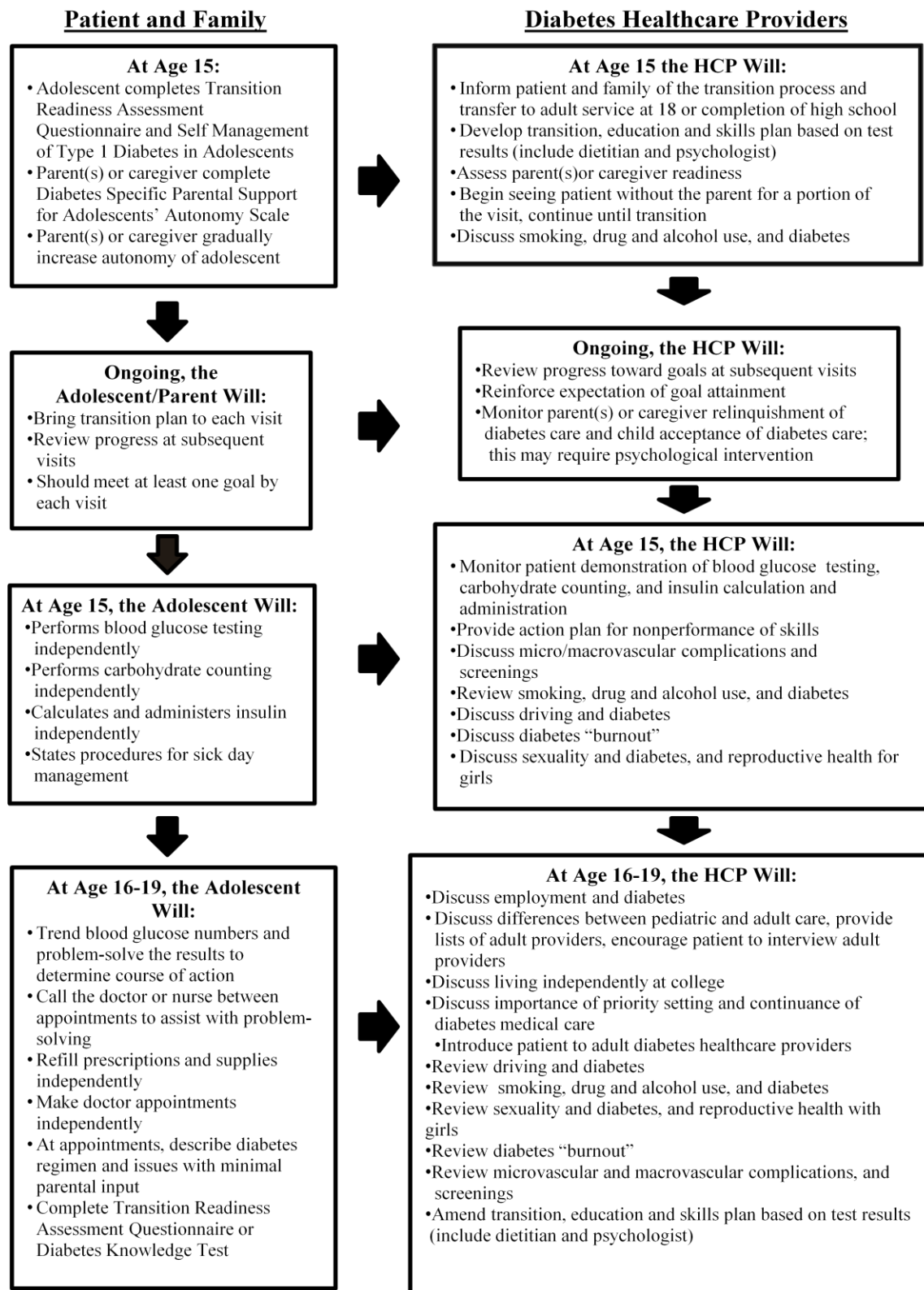
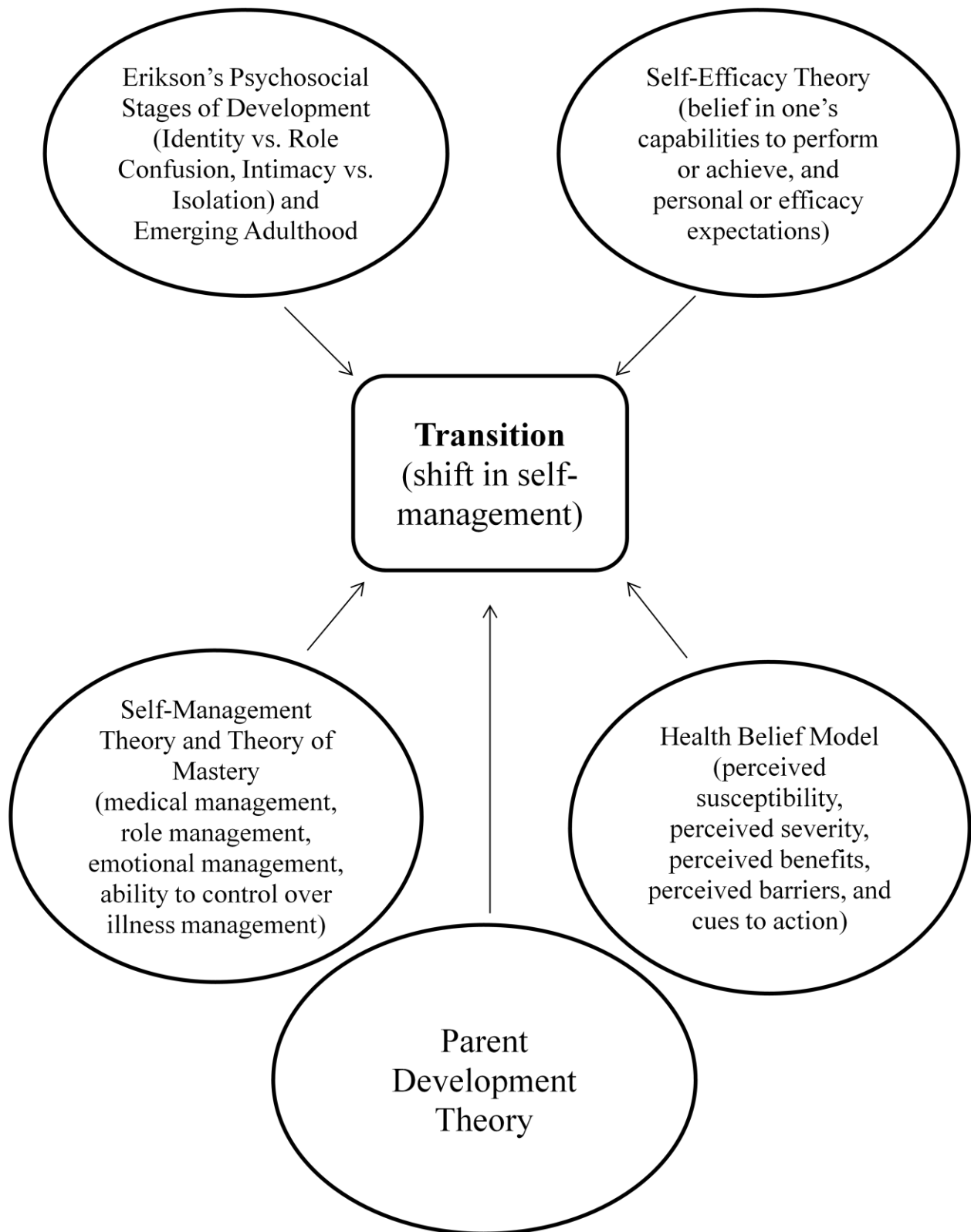


Figure 2. Theoretical Model of Transition from Pediatric Endocrinology Health Services to Adult Endocrinology Health Services



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Appendix A

Transition Readiness Assessment Questionnaire (TRAQ)

Subject Name: _____ Date of Birth: __/__/__ Today's Date __/__/__ (MRN# _____)

Transition Readiness Assessment Questionnaire 5.0

Directions: Please check the box that best describes your ability level in each of the following skill areas related to your health and health care. There are no right or wrong answers.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests or check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you fill out the medical history form, including a list of your allergies?					
10. Do you keep a calendar or list of medical and other appointments?					
11. Do you tell the doctor or nurse what you are feeling?					
12. Do you answer questions that are asked by the doctor, nurse or clinic staff?					
13. Do you make a list of questions before the doctor's visit?					
14. Do you apply for health insurance if you lose your current coverage?					
15. Do you know what your health insurance covers?					
16. Do you get financial help with school or work?					
17. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Appendix B

Self-Management of Type 1 Diabetes in Adolescents (SMOD-A)

Part I

<p><u>Instructions:</u></p> <p>The statements below describe different things adolescents may do in taking care of their diabetes. Circle the number that indicates how frequently you do each thing.</p> <p>Statements</p>	Never	Sometimes	Most of the time	Always
1. I consult my parents when I'm not sure what to do to manage my diabetes.	0	1	2	3
2. I adjust my insulin dose by myself.	0	1	2	3
3. I handle my high blood sugars myself.	0	1	2	3
4. My parents talk to me about what to eat or not to eat.	0	1	2	3
5. My parents help me decide my insulin dose.	0	1	2	3
6. My parents count carbohydrates with me.	0	1	2	3
7. I ask my parents what to do when my blood sugar is out of range.	0	1	2	3
8. My parents and I look together at the record of my blood sugar readings to make adjustments.	0	1	2	3
9. My parents check to see if I've taken my insulin.	0	1	2	3
10. My parents check my meter to see if I've tested my blood sugar.	0	1	2	3
11. I ask my parents how many carbohydrates are in some foods.	0	1	2	3
12. My parents tell me how much insulin to take.	0	1	2	3
13. I tell my parents when my blood sugar is out of range.	0	1	2	3
14. I follow my meal plan or count carbohydrates.	0	1	2	3
15. I check my blood sugar before eating.	0	1	2	3

16. I eat without first checking my blood sugar.	0	1	2	3
17. If my blood sugar is high, I check it again in 1 to 2 hours.	0	1	2	3
18. I carry glucose tabs or some quick-acting sugars.	0	1	2	3
19. I test for ketones if my blood sugar is high.	0	1	2	3
20. If my blood sugar is too low, I treat and then check later if I still feel low.	0	1	2	3
21. I need to be reminded to take my insulin.	0	1	2	3
22. I skip insulin injections or boluses.	0	1	2	3
23. My parents and I argue about when I should test my blood sugar.	0	1	2	3
24. I carry something with me that says I have diabetes.	0	1	2	3
25. I go out without my diabetes supplies.	0	1	2	3
26. I don't like it when someone reminds me to check my blood sugar.	0	1	2	3
27. I check my blood sugar without being reminded.	0	1	2	3
28. I keep my own record of blood sugar numbers.	0	1	2	3
29. When I exercise I change how I eat or how much insulin I take.	0	1	2	3
30. I decide how much insulin to take.	0	1	2	3
31. I adjust my dose of insulin based on my blood sugar numbers.	0	1	2	3
32. If my blood sugar is high, and it's not mealtime, I give myself insulin.	0	1	2	3

Part I (Cont'd)

<u>Instructions:</u> The statements below describe different things adolescents may do in taking care of their diabetes. Circle the number that indicates how frequently you do each thing. Statements	Never	Sometimes	Most of the time	Always
33. I remember what my HbA1c (A1c) number is from my last clinic visit.	0	1	2	3
34. I know what my HbA1c (A1c) number should be.	0	1	2	3
35. To figure my insulin dose, I consider my blood sugar and what I will eat.	0	1	2	3
36. When my diabetes bothers me, I talk to my nurse or doctor about it.	0	1	2	3
37. I try to change my diabetes routine if my nurse or doctor asks me to.	0	1	2	3
38. If my parents have a problem with how I manage my diabetes, we talk about it.	0	1	2	3
39. Before clinic visits I think about what I want to say to my nurse or doctor.	0	1	2	3
40. I stay informed about what's new in diabetes.	0	1	2	3
41. I review my blood sugar records with my nurse or doctor.	0	1	2	3
42. During clinic visits, I spend some time alone with my nurse or doctor.	0	1	2	3
43. I tell my friends that I have diabetes.	0	1	2	3
44. If something is bothering me about the way things are going with my diabetes, I talk to my parents about it.	0	1	2	3
45. I contact my nurse or doctor when I can't get my blood sugars back into range.	0	1	2	3

Part II

<p>Instructions:</p> <p>The statements below describe different goals adolescents may have in taking care of their diabetes. Circle the number that indicates if – and how frequently – each is a goal for you,</p> <p>or whether it is a goal that you have already met.</p>	Never a goal for me	Sometimes a goal for me	Definitely a goal for me	I've met this goal.
Statements				
1. One of my goals is to take care of my diabetes more on my own.	0	1	2	3
2. I take care of my diabetes to try to not have problems in the future.	0	1	2	3
3. I take care of my diabetes to feel good.	0	1	2	3
4. I take care of my diabetes so I'm able to do things with my friends.	0	1	2	3
5. One of my goals is to be able to stay away from home overnight.	0	1	2	3
6. One of my goals is to be in charge of taking care of my diabetes.	0	1	2	3
7. I want to understand why sometimes my blood sugar numbers are too high or too low.	0	1	2	3

Appendix C

Diabetes Specific Parental Support for Adolescents' Autonomy Scale (Parent and Teen Versions)

Parents' Help with Diabetes Care: Think about the things that you do to help your son or daughter be responsible for diabetes care in the past 3 months. First, circle the number that best describes how often you did the following things. Then for the things you have done, circle the number that describes how helpful these things were. Give insulin means pump or injection. 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 the time				
						Not at All Helpful				
						Very Helpful				
Asked him/her "what do you think needs to be 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

Teens' Perceptions of Parents' Help with Diabetes Care: Think about the things that your parents do to help you be responsible for your diabetes care in the past 3 months. First, circle the number that describes how often your parents did the following things. Then for the things they have done, circle the number that describes how helpful these things were. Give insulin means pump or injection. There are 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 of the time					All the 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		0	1	2	3	4
Showed you how to figure insulin dose.	0	1	2	3	4		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		0	1	2	3	4
Answered your questions about figuring insulin dose.	0	1	2	3	4		0	1	2	3	4		0	1	2	3	4

Appendix D



Human Research Protection Office

Barnes Jewish Hospital
St. Louis Children's Hospital
Washington University

IRB ID #: 201403145

To: Neil White

From: The Washington University in St. Louis Institutional Review Board,
WUSTL DHHS Federalwide Assurance #FWA00002284
BJH DHHS Federalwide Assurance #FWA00002281
SLCH DHHS Federalwide Assurance #FWA00002282

Re: Transitioning Teens with Type 1 Diabetes from Pediatric to Adult Health Care

Approval Date: 06/09/14

**Next IRB Approval
Due Before:** 04/09/15

Type of Application:

- ☐ New Project
☐ Continuing Review
☒ Modification

Type of Application Review:

- ☐ Full Board:
Meeting Date:
☒ Expedited
☐ Exempt
☐ Facilitated

Approved for Populations:

- ☒ Children
☒ Signature from one parent
☐ Signature from two parents
☐ Prisoners
☐ Pregnant Women, Fetuses, Neonates
☐ Wards of State
☐ Decisionally Impaired

Source of Support:
University of Missouri Research Board

Appendix E



The Edward Mallinckrodt Department of Pediatrics
Division of Endocrinology & Diabetes

Paul W. Hruz,
MD, PhD
Division Director

Ana Maria
Arbelaez, MD
Abby S. Hollander,
MD
Bess A. Marshall,
MD
Jennifer Sprague,
MD
Michelle Vanstone,
MD
Neil H. White,
MD, CDE

Washington University
St. Louis Children's Hospital
Pediatric Diabetes Clinic

Dear Teen and Parent,

The pediatric diabetes outpatient clinic at Washington University/St. Louis Children's Hospital will be providing an opportunity for you to participate in a program about the transition of teenagers with type 1 diabetes from pediatric diabetes health care to adult diabetes health care. If you are 15-19 years old with type 1 diabetes for at least one year you may be eligible to participate in this research study. The program will consist of 4 weekly sessions to assist both the parent and teen in making this important transition.

Brief descriptions of the four sessions are as follows:

Session 1 focuses on the introduction of the study and the team. A review of the pathophysiology of T1D including nutrition will be presented. Parents and adolescents will be together.

Session 2 focuses on the day-to-day management of T1D. This includes problem-solving surrounding episodes of hypoglycemia and hyperglycemia, and insulin administration. Review of how smoking, drugs, and alcohol affect those with diabetes. Problem-solving on how exercise and activity affect diabetes management and incorporating stress management techniques. Parents will have a separate concurrent support session covering the same topics.

Session 3 focuses on preparation in managing T1D independently for the adolescent who may be beginning employment, moving out of the parental home to live independently or leaving for college. This includes how to order supplies, communicate with the doctor, preparing Individual Education Plans (IEP) for standardized testing, disclosure of diabetes to employers or teaching staff at university. Parents will have a separate concurrent support session covering the same topics.

Session 4 focuses on reproductive health. This session will be presented using the READY-Girls curriculum and The WISE GUYS curriculum. Females and the males will be in separate rooms. Females will learn about how diabetes affects the mother, fetus, and infant post delivery. For the males, basic male reproductive health will be covered. Parents will have a separate concurrent support session covering the same topics.

If you are interested in participating, we will provide more information at your upcoming clinic visit. If you have just visited the clinic and won't be returning for several months and would like to participate, please contact **Becky Meyer PhDc, RN-BC** at (314) 454-8478 who is working with Dr. Neil White to complete this project.

Thank you for your consideration.

Becky Meyer PhDc, RN-BC
Doctoral Student, UMSL
(314) 454-8478

Washington University School of Medicine at
Washington University Medical Center,
660 South Euclid Avenue, Campus Box 8116,
St. Louis, Missouri 63110,
Clinical Office: (314) 454-6051, Fax: (314) 454-6225

St. Louis Children's Hospital is a member of **B/C** HealthCare™

FOR IRB USE ONLY
IRB ID #: 201403145
APPROVAL DATE: 04/10/14
RELEASED DATE: 04/10/14
EXPIRATION DATE: 04/09/15

Appendix F

FOR IRB USE ONLY
IRB ID #: 201403145
APPROVAL DATE: 08/06/14
RELEASED DATE: 08/06/14
EXPIRATION DATE: 04/09/15

We Need Your Help!!

**Are you between the ages of 15 and 19?
Do you have type 1 diabetes?**

Teens age 15-19 with type 1 diabetes are wanted for participation in a program on transitioning from pediatric diabetes care to adult diabetes care. This research study is being conducted by Washington University in St. Louis/St. Louis Children's Hospital and the University of Missouri St. Louis. Participants will attend 4 weekly sessions on diabetes management and preparation for adult health care. Participation involves attending four 1-1.5 hour weekly sessions in the evening starting soon. You will be compensated for your time. All information you provide as part of this project will be strictly confidential.

***For more information, please call:
Becky Meyer RN at 314-454-8478***

**First session starts Sept. 10th,
future sessions to follow**

Appendix G

Demographic Form

Name: _____

Date of Birth: _____

Parent's names: _____

Address: _____

Telephone: H: _____ C: _____

Email: _____

Height: _____ Weight: _____

Age at diagnosis: _____ Years with diabetes: _____

Insulin delivery: Shots _____ Pump _____

How many times a day do you perform glucose testing: _____

Have you been hospitalized for diabetes care since diagnosis: Y _____ N _____

If yes, how many times: _____ Reason for hospitalization(s): _____

What was your last HbA1c: _____

Have you ever had to use glucagon Y _____ N _____

Have you ever needed help with a low Y _____ N _____

How many times a year do you see the diabetes doctor: _____

Are you planning on leaving the home for college: _____

Appendix H

FOR IRB USE ONLY
IRB ID #: 201403145
APPROVAL DATE: 04/10/14
RELEASED DATE: 04/10/14
EXPIRATION DATE: 04/09/15

Transitioning Teens with Type 1 Diabetes from Pediatric to Adult Health Care

Phone Script

Hello, my name is Becky Meyer and I am a nurse conducting a project on the transition from the pediatric diabetes doctor to the adult diabetes doctor through Washington University/Children's Hospital. I am working along with Dr. Neil White.

Recently, you received a letter in the mail inviting you to participate in this research study called "Transitioning Teens with Type 1 Diabetes from Pediatric to Adult Health Care".

I am calling to verify that you have type 1 diabetes greater than or equal to 1 year and that you are between the ages of 15-19.

Are you interested in participating in this study?

If so, may I have your address to send you a copy of the consent form to review.
My contact information is (314) 454-8478 and you may call me at any time with questions about the study. If you decide you want to participate, I or a member of the research team will also review the study and consent form with you prior to the first session.

Thank you.

Appendix I

FOR IRB USE ONLY

IRB ID #: 201403145
APPROVAL DATE: 12/03/14
EXPIRATION DATE: 04/09/15

Website Posting for vfh.wustl.edu or rpr.wustl.edu

PURPOSE OF THE STUDY:

The purpose of this study is to transition adolescents from pediatric to adult diabetes care.

WHO IS NEEDED?

1. Participants must have type 1 diabetes
2. Participants must be 15 to 19 years old
3. Participants must have a parent or guardian willing to provide transportation to appointments

WHAT IS INVOLVED IF I PARTICIPATE?

1. **Duration:** There will be weekly study visits for 4 weeks. Visits will last 1 to 1.5 hours each.
2. **Tests/procedures:** This study may help transition responsibility of diabetes management from the parents to the adolescents using a comprehensive, interactive, collaborative, and proactive plan that optimizes health and meets the complex needs of the adolescent. Participants and their parents will complete surveys before and after the study sessions.
3. **Risks:** Risks will be discussed with volunteers as part of the informed consent process.
4. **Benefits:** Benefits will be discussed with volunteers as part of the informed consent process.
5. **Compensation:** Participants will receive up to 40 dollars in gift cards to Target for their time and effort.

WHO IS THE PRINCIPAL INVESTIGATOR (PI)?

Dr. Neil White

WHERE WILL THE STUDY TAKE PLACE?

Washington University

I'M INTERESTED! WHO DO I CONTACT FOR MORE INFORMATION?

Volunteer for Health

314-362-1000

Appendix J

FOR IRB USE ONLY

IRB ID #: 201403145

APPROVAL DATE: 12/03/14

EXPIRATION DATE: 04/09/15

Facebook.com (RPR fanpage posting)

ICTS website posting at icts.wustl.edu

Facebook allows up to 420 characters (with spaces)

Characters = 377

Teenagers needed! Dr. Neil White is conducting a research study to transition adolescents from pediatric to adult diabetes care. Participants must have type 1 diabetes and must be 15 – 19 years old. There will be weekly study visits for 4 weeks. Visits will last 1 to 1.5 hours each. Up to \$40 in Target gift cards is provided. Contact Becky @ ram8784@bjc.org or 314-454-8478.

Appendix K

FOR IRB USE ONLY

IRB ID #: 201403145

APPROVAL DATE: 12/03/14

EXPIRATION DATE: 04/09/15

Center Watch website ad

<http://www.centerwatch.com/>

A Washington University research study seeks teen participants with type 1 diabetes.

Study Purpose:

The purpose of this study is to transition adolescents from pediatric to adult diabetes care. There will be weekly study visits for 4 weeks. Visits will last 1 to 1.5 hours each. This study may help transition responsibility of diabetes management from the parents to the adolescents using a comprehensive, interactive, collaborative, and proactive plan that optimizes health and meets the complex needs of the adolescent. Participants and their parents will complete surveys before and after the study sessions. Risks and benefits will be discussed as part of the informed consent process. Participants will receive up to 40 dollars in gift cards to Target for their time and effort.

Inclusion Criteria:

1. 15 - 19 years of age
2. Type 1 diabetes
3. Parent or guardian willing to provide transportation (if adolescent is unable to drive)

Exclusion Criteria:

1. Type 2 diabetes

Study Contact Information:

Becky Meyer

314-454-8478

ram8784@bjc.org

Appendix L

FOR IRB USE ONLY

IRB ID #: 201403145

APPROVAL DATE: 12/03/14

EXPIRATION DATE: 04/09/15

BJC Today Newspaper ad

Volunteer for Health

Do something extraordinary



Do Something Extraordinary

Are you a candidate for a study? Following is information on several studies now recruiting volunteers at Washington University School of Medicine.

For more, visit <http://vfh.wustl.edu> or call 314-362-1000

Purpose:

The purpose of this study is to transition adolescents from pediatric to adult diabetes care.

Who is needed?

1. Participants must have type 1 diabetes
2. Participants must be 15 to 19 years old
3. Participants must have a parent or guardian willing to provide transportation to appointments

What is involved if I participate?

There will be weekly study visits for 4 weeks. Visits will last 1 to 1.5 hours each. This study may help transition responsibility of diabetes management from the parents to the adolescents using a comprehensive, interactive, collaborative, and proactive plan that optimizes health and meets the complex needs of the adolescent. Participants and their parents will complete surveys before and after the study sessions.

What are the benefits of participating?

Benefits will be discussed as part of the informed consent process.

What are the risks of participating?

Risks will be discussed as part of the informed consent process.

Is compensation provided?

Up to \$40 in Target gift cards is provided for time and effort.

Principal investigator:

Dr. Neil White

Where will the study take place?

Washington University School of Medicine