FEASIBILITY AND ACCEPTABILITY OF A MOTHER-DAUGHTER INTERVENTION TO ADDRESS DISORDERED EATING BEHAVIOR AMONG ADOLESCENT GIRLS LIVING WITH TYPE 1 DIABETES MELLITUS

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ABSTRACT

Disordered eating behavior (DEB) is an important health problem among adolescent girls in the United States. DEB has been correlated with the subsequent development of clinically diagnosed eating disorders and with other psychological illnesses. Adolescent females with Type-1diabetes (T1DM) are at higher risk for DEB and have a two-fold higher incidence of disordered eating behavior (DEB) than their non-diabetic counterparts. Individuals with T1DM have the unique ability to omit insulin as a weight reduction strategy. DEB in T1DM adolescent females significantly increases the risk for premature nephropathy, neuropathy, retinopathy, and death. Despite strong evidence to support the association between DEB and negative health outcomes, little research has focused on interventions that lower the risk of DEB among adolescent girls with T1DM. The purpose of this study was to develop and test the feasibility and acceptability of a mother-daughter intervention to address

three of the major risk factors for DEB: low self-esteem, poor body image, and maternal-daughter communication. Participants in this study were ten mother-daughter dyads for a total of 20 participants (n = 20). Intervention development was guided by feminist, cognitive behavioral, and current diabetic theoretical frameworks and input from a mother-daughter dyad with the daughter having T1DM. Data was collected from participants on intervention effectiveness and overall acceptability. Feasibility and acceptability of the intervention was high in both mothers and daughters. Positive gains noted by participants included increased knowledge of mother-daughter communication, self-esteem, and deciphering media messages. Participants' goals after intervention included improved communication at home, increased scrutiny of media messages, and improved diabetes care. A pre/post-test design was utilized to examine changes in depression, self-esteem, body image, mother-daughter relationship, and disordered eating risk from pre to post-intervention. Encouraging changes in the clinically desired direction were seen on body image and disordered eating risk post-intervention. The next step in this program of research is to refine the intervention and then conduct a controlled pilot study with a larger sample size.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing, have examined a dissertation titled, "Feasibility and Acceptability of a Mother-Daughter Intervention to Address Disordered Eating Behavior Among Adolescent Girls Living with Type 1 Diabetes Mellitus," presented by Terri Lynne Schmitt**,** candidate for the Doctor of Philosophy degree**,** and certify that in their opinion it is worthy of acceptance.

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DEDICATION

To husband Brian Schmitt who never ceases to amaze me and to my sons, Connor and Jacob, and to my daughter, Taylor who are my never ending comic relief.

CHAPTER 1

INTRODUCTION

Disordered eating behaviors (DEBs) are unhealthy and maladaptive eating behaviors, which do not occur at a frequency to meet the criteria for a formal *DSM-IV-TR* eating disorder diagnosis (Olmsted, Colton, Daneman, Rydall, & Rodin, 2008). For adolescent females with Type 1 Diabetes (T1DM), even infrequent DEBs can increase the risk of negative health outcomes (Gobel-Fabbri et al., 2008). Insulin omission, which results in the purging of glucose calories through the urine, is a unique and frequent DEB found among adolescents with T1DM (Nielson, 2002; Nielson, Emborg, & Molback, 2002). Early identification of adolescent females who are at risk for DEB is critical to limit or prevent negative health outcomes. Adolescent females with T1DM who engage in DEBs are difficult to identify and treat, but key areas where early prevention measures can be implemented are noted throughout research (Olmsted et al., 2008).

Approximately 300,000 of the 10.5 million adolescent girls living in the United States have a clinically diagnosable eating disorder with twice that number exhibiting DEBs (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007; Hudson, Hiripi, Pope, & Kessler, 2007; Stice, Marti, Shaw, & Jaconis, 2009; U.S. Census Bureau, 2008). DEB, or sub-clinical disordered eating as it is sometimes called, is a growing public health concern; however, it is not generally treated in clinical practice (Budd, 2007; Hudson et al.; Stice, 2002). Adolescent females with T1DM have a two-fold higher incidence of DEB than their non-

diabetic counterparts (Hsu, Chen, Lin, & Lin, 2009; Jones, Lawson, Daneman, Olmsted, & Rodin, 2000; Nielsen, 2002; Pinar, 2005).

Among adolescent populations, DEBs are associated with the subsequent development of eating disorders and psychological illnesses including depression, anxiety, increased suicidal attempts, functional impairment, and obsessive compulsive disorders (Budd, 2007; Littleton & Ollendick, 2003; Stice et al., 2009). Dual diagnosis of T1DM and DEB places adolescent girls at high risk for negative health outcomes secondary to diabetic microvascular complications, including nephropathy, retinopathy, and premature death (Affento et al., 1997; Bryden et al., 1999; Crow, Keel, & Kendall, 1998; Daneman, Olmsted, Rydall, Maharaj, & Rodin, 1998; Goble-Fabbri et al., 2008; Neilson et al., 2002; Neumark-Sztainer et al., 2002; Olinder, Kernell, & Smide, 2009; Takii et al., 1999; Takii et al., 2008).

Indentified risk factors that predict or increase the risk for development of DEBs in adolescent girls with T1DM include low self-esteem, poor body image, increased drive for thinness, elevated body mass index (BMI), depression, psychological disease, negative family cohesion/communication, maternal weight/shape concerns, and poor maternal-daughter relationship (Colton et al., 2007; Engstrom et al., 1999; Goebel-Fabbri et al., 2008; Kahn & Montgomery, 1996; Neumark-Sztainer et al., 2002; Pollock-Barziv & Davis, 2005). Research suggests that T1DM adolescents with DEB score differently on measures of depression, self-esteem, body-image, and family relationships than T1DM girls without DEB (Olmsted et al., 2008). However, adolescents with T1DM who are at risk for or are already engaging in DEBs generally score within 'normal' ranges on standardized screening measures, suggesting that identifying T1DM adolescents with DEB by the use of depression or body image questionnaires with standard population norms may not be helpful in

identification (Olmsted et al., 2008). Adolescent girls without DEBs have less depression, higher body image, and higher self-esteem scores on standardized testing, further suggesting that having a healthy body image, elevated self-esteem, functional family relationships, and lack of depression may actually protect diabetic girls from developing DEB behavior (Olmsted et al., 2008).

These key psychosocial risk factors are potential points for preventative intervention in adolescent girls with T1DM. However, despite strong evidence about risk factors associated with DEB, no evidenced-based clinical prevention strategies and only one intervention trial were found in an exhaustive review of the literature that addressed the prevention of DEB in this population (Ackard et al., 2008; Affenito & Adams, 2001; Bryden et al., 1999; Colton et al., 2007; Olmsted et al., 2008; Colton, Olmsted, & Rodin, 2007; Crow et al., 1998; Engstrom et al., 1999; Goebel-Fabbri, 2009; Goebel-Fabbri et al., 2008; Howe, Jawad, Kelly, & Lipman, 2008; Hsu et al., 2009; Jones et al., 2000; Kahn & Montgomery, 1996; Neumark-Sztainer et al., 2002; Nielsen, 2002; Nielsen et al., 2002; Olmsted, Daneman, Rydall, Lawson, and Rodin, 2002; Olmsted et al., 2008; Pinar, 2005; Pollock-Barziv & Davis, 2005; Takii et al., 1999; Takii et al., 2008). The single intervention trial that has been published examined an intervention within a group of T1DM females with already developed DEB behavior and found these DEBs difficult to treat, with gains only in eating attitudes and not long term metabolic control (Olmsted et al., 2002). Early prevention of DEB through the enhancement of protective risk factors is an area of potential long-term health benefit that has yet to be researched.

Purpose

The purpose of this study was to develop and test a mother-daughter group intervention for feasibility and acceptability. The intervention aimed to reduce DEB risk through enhancement of known protective factors among T1DM adolescent girls. The proposed intervention, Beautiful YOU Team Intervention (BEYOUTI), was designed to increase knowledge about DEBs among adolescent females living with T1DM, to enhance self-esteem and body image, and to improve the mother-daughter relationship through improved communication skills. Poor self-esteem, body image, and mother-daughter relationship are three of the major risk factors for DEBs in this population (Goebel-Fabbri, 2009; Olmsted et al., 2008). This study is the first step in a program of research that aims to translate evidence about known risk factors for DEB into a clinical intervention strategy to reduce risks for DEB and improve physical and emotional outcomes for adolescent girls living with TIDM.

Specific Aims and Research Questions

This aims of this study were (1) to develop a mother-daughter group intervention, BEYOUTI, to increase knowledge about DEBs, enhance self-esteem, body image, and mother-daughter communication; and (2) to conduct a pilot study to examine the feasibility and acceptability of the intervention. Outcome measures included acceptability among both mothers and daughters, feasibility of intervention design and measures, and alteration of risk factors to include depression, poor mother-daughter relationship, poor body image, and low self-esteem. The following research questions guided this research study: (1) Is it feasible

and acceptable to implement a mother-daughter group intervention to prevent DEB development among T1DM adolescent girls receiving care in a hospital-based pediatric endocrinology practice? (2) What is the impact of the intervention on depression, perceptions of the mother-daughter relationships, body image, and self-esteem?

Assumptions

Theoretical frameworks of feminist, cognitive behavioral, and T1DM DEB theory guided the proposed mother-daughter intervention. The hypothesis guiding this study was that effective mother-daughter communication is a protective factor that reduces the risk for DEB in the adolescent girl with T1DM (Littleton & Ollendick, 2003; Stice, 2002) and diabetes, family, sociocultural gender/body messages, weight gain associated with insulin, and dietary management all interact to increase the risk of DEB (Gobel-Fabbri, 2009). An intervention logic model was utilized to guide intervention design and to assist in the application of information from the theoretical frameworks and review of literature. Based on the foundational theoretical frameworks, the following assumptions were made:

(1) Low-self esteem, low body image, and ineffective mother-daughter communication contribute to the development of DEB behavior in adolescents with T1DM.

(2) Mothers of adolescent girls with T1DM lack information and/or may be unaware of the relationship between insulin omission, DEB behavior and the negative effects of body image, self-esteem, and mother-daughter communication on DEB.

(3) Adolescent girls with T1DM lack information and/or may be unaware of the relationship between insulin omission, DEB behavior and the negative effects of body image, self-esteem, and maternal relationship on DEB.

(4) Guided mother-daughter interactions focusing on body image, self-esteem and communication will positively affect these variables; body image, self-esteem, maternal-daughter relationship, depression, DEB risk, and insulin omission.

(5) Adolescent girls with T1DM and their mothers want to reduce the risk of developing DEB.

Limitations

Limitations of this study included the small sample size. A single pediatric endocrinology practice in the Midwest was used and felt to be adequate to meet intervention aims of development, feasibility, and acceptability of a mother-daughter intervention. Another limitation of this study was that biomarkers such as hemoglobin A1c and BMI were not used as outcome variables. These were considered, but because these markers would not change in the short time period from pre to post-intervention, it was felt that these markers were not appropriate for measurement of the intervention's development and feasibility. Certainly, biological measures would be necessary for subsequent longitudinal research to examine the efficacy of the intervention. While BMI was collected as a baseline measure, it was also a self-reported measure at the post-intervention time point and did not seem to contribute significantly to an understanding of the feasibility or acceptability of the intervention.

Having mothers present during data collection was also a limitation of the research because of the potential for hindering honesty in responses by adolescent participants. Adolescent participants were encouraged to complete questionnaires in an area that was separate from their mothers, but availability of private areas to separate mother-daughter

dyads at intervention sites was limited. Therefore, the PI emphasized the private nature of questionnaire responses in both verbal and written format and provided physical space between mothers and daughters to increase confidentiality. A final limitation of the study was selection bias. Those who agreed to participate might have different characteristics than those who did not agree to participate. This limitation could not be controlled for, but recruitment was aimed at all individuals who met study criteria.

CHAPTER 2

REVIEW OF LITERATURE

Adolescence, Diabetic Girls, and the Risk for DEB

Eating disorders primarily affect young women and adolescents, with lifetime prevalence three times higher in women than in men (Hudson et al., 2007). The mean age of onset of eating disorders in the female population ranges from 18 to 21 years, with some exhibiting DEBs as young as age 10 (Hudson et al.). BMI, perceived social pressure to be thin, exposure to media body image ideals, modeling of body image, and internalization of thin ideals all increase rates of DEB in females (Stice, 2002). Further, in general adolescent populations, relapse rates of DEB range from 33 to 41% depending on type of DEB behavior (Stice et al., 2009).

Adolescent girls with Type-1 diabetes have a two-fold higher incidence of DEB than their non-diabetic counterparts (Hsu et al., 2009; Jones et al., 2000; Nielsen, 2002; Pinar, 2005). There is some variability in reported rates of DEB among adolescent T1DM girls, ranging from no difference when compared to the general population of adolescent girls, to as much as four times greater (Ackard et al., 2008; Howe et al., 2008; Pinar, 2005). Even in research that reports reduced rates of eating disorders and DEBs among adolescents with T1DM, insulin omission is still present (Ackard et al.). The combination of T1DM and DEB places adolescent females at higher risk for negative health outcomes such as blindness, renal failure, acute ketoacidosis, and premature death (Affenito et al., 1997; Bryden et al., 1999;

Crow et al., 1998; Daneman et al., 1998; Goble-Fabbri et al., 2008; Neilson et al., 2002; Neumark-Sztainer et al., 2002; Olinder et al., 2009; Takii et al., 1999; Takii et al., 2008)

Insulin Omission

Insulin omission for weight loss is exclusive to adolescents with T1DM (Crow et al., 1998; Neilson, 2002). Insulin omission rates as high as 30% have been noted in females with T1DM and as high as 73% in individuals with T1DM and an eating disorder (See Table 1) (Goebel-Fabbri et al., 2008; Takii et al., 1999). Individual stories confirm a high degree of insulin omission, with some girls missing insulin for days at a time and others skipping more than half of their scheduled doses (Maharaj, Rodin, Olmsted, Connolly, & Daneman, 2003; Peveler et al., 2005; Takii et al., 2002).

Where insulin omission is present there is a significant risk for life threatening complications and mortality among DEB females with T1DM (Goebel-Fabbri et al., 2008; Takii et al., 2008). The majority of research in the T1DM female population supports elevated HbA1c levels in the presence of either an eating disorder, insulin omission or both (Affenito et al., 1997; Gobel-Fabbri et al., 2008; Kichler, Foster, & Opipari-Arrigan, 2008; Meltzer et al., 2001; Neumark-Sztainer et al., 2002; Peveler et al., 2005; Pinar, 2005; Pollock-Barziv & Davis, 2005). DEB is correlated with significant rises in HbA1c, which in turn cause more rapid development of diabetic complications (Colton et al., 2007; Daneman et al., 1998; Goebel-Fabbri et al., 2008; Howe et al., 2008).

Individuals who omit insulin for weight loss purposes have increased rates of diabetic ketoacidosis, hospitalizations for acute illness, nephropathy, retinopathy, neuropathy and

premature death (Bryden et al., 1999; Colton et al., 2007; Crow et al., 1998; Goebel-Fabbri et al., 2008; Nielsen, 2002; Nielsen et al., 2002; Peveler et al., 2005; Takii et al., 2002; Takii et al., 2008). Duration of insulin omission behavior is the defining factor in the development of nephropathy and retinopathy in T1DM females with eating disorders (Takii et al., 2008). Adolescent girls with T1DM and disordered eating not only develop complications of diabetes at higher rates, but also develop them more quickly (Takii et al. 1999; Takii et al., 2008). Despite the fact that there is clear evidence that DEB is prevalent among populations of adolescent girls with T1DM and that it leads to high rates of secondary complications and has well-known risk factors, no standard interventions exist to alter risk factors (Goebel-Fabbri, 2009).

Table 1

Published Rates of Insulin Omission

Article	Rates of Insulin Omission
Ackard et al. (2008)	7.4% reduction in insulin, 10.4% omission
Crow et al. (1998)	14 to 37.5%
Daneman et al. (1998)	14% at baseline, 34% at year 4 follow up
Goebel-Fabbri et al. (2008)	30% at baseline
Maharaj et al. (2003)	50% High Risk Group, 20.7% Moderate Risk Group
Nielsen (2002)	40% in those with disordered eating
Neumark-Sztainer et al. (2002)	17.7% of females, 2.8% of males
Peveler et al. (2005)	36% (compared to 26% w/disordered eating)
Pinar (2005)	4x's more common in those w/disordered eating
Takii et al. (1999)	73% in ED population
Takii et al. (2002)	56%

Factors Related to DEB in T1DM

Mental representation of self: Self-esteem and body image

Self-esteem is "a favorable or unfavorable attitude toward the self " (Rosenberg, 1965, p. 15). T1DM females with bulimia feel more ineffective than when compared to girls without bulimia (Kahn & Montgomery, 1996). Low self-esteem scores on psychometric questionnaires predict DEB variance in this population (Colton et al., 2007; Maharaj et al., 2003; Olmsted et al., 2008).

Body image, perception of the physical self, is noted in conventional psychological literature as a significant contributor to DEB in the general population (Cash & Pruzinsky, 2002). T1DM adolescent girls with DEB report higher levels of body image and weight dissatisfaction (Engstrom et al. 1999; Kichler et al., 2008; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Pinar, 2005). Drive for thinness, which is highly supported by general eating disorder research, was found to be stronger in girls with both DEB and diabetes (Cash & Pruzinsky; Engstrom et al.; Kahn & Montgomery, 1996). Weight preoccupation is also dominant in T1DM adolescents with disordered eating (Pollock-Barziv & Davis, 2005).

Both physical and mental development affects development of body image (Grogan, 2010). Age is one standard with which to mark physical and mental development. Age of diagnosis with T1DM, if close to onset of puberty, appears to increase the risk for DEB and eating disorder development (Takii et al., 2011). Overall, poorer mental representation of self, including self-concept, self-esteem, and body image are risk factors for DEB in T1DM adolescent girls (Colton et al., 2007; Engstrom et al. 1999; Kichler et al., 2008; Maharaj et al., 2003; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Pinar, 2005).

BMI

Intensive insulin therapy does produce weight gain (Kaufman, 2006). This effect of insulin has been considered an obstacle for compliance in both adult and adolescent diabetic patients (Daneman, 2002; Kaufman; Rodin et al., 2002). Elevated BMI is strongly correlated with DEB in T1DM adolescent girls (Colton et al., 2007; Engstrom et al. 1999; Olmsted et al., 2008). In a one-year longitudinal study, BMI actually predicted new onset DEB (Colton et al., 2007). Maternal weight is also associated with DEB, with mothers who weigh more being more likely to have daughters who have participated in high risk weight loss behaviors that include insulin omission (Maharaj et al., 2003). Thus, girls who engage in insulin omission are more likely to have elevated BMI's and have mothers with elevated BMI's.

Psychological symptoms

There are nine-fold greater odds for adolescent girls with T1DM and DEB to display psychological symptoms (Pollock, Kovacs, & Charron-Prochownik, 1995). T1DM adolescents who engage in DEB are more likely to be depressed, anxious, ineffective at coping, and perfectionists (Gobel-Fabbri et al., 2008; Grylli et al., 2005; Pollock-Barziv & Davis, 2005). Increased scores on both depression and anxiety inventories are found in T1DM girls with diabetes, with depression scores being a significant predictor of DEB (Colton et al., 2007; Gobel-Fabbri et al., 2008; Olmsted et al., 2008; Takii et al., 1999).

Family Interactions and Maternal Characteristics

Adolescent girls with T1DM and disordered eating are more likely to have family communication issues, to have mothers with weight concerns, and to report poorer mother-daughter relationships than T1DM girls without DEB. T1DM girls with DEB are more likely to express negative family cohesion and home communication, to have poorer perceptions of family communication, and to feel less trust within the family and greater alienation (Kichler et al., 2008; Neumark-Sztainer et al., 2002; Maharaj et al., 2003). Mothers of diabetic girls with DEB are more likely to have weight-shape concerns, to have increased body weight, to be currently on a diet, and to be more controlling of girls' expressions of autonomy (Maharaj et al., 2003). There is correlation between maladaptive maternal eating attitudes and poor maternal-daughter relationships in T1DM adolescent girls with DEB (Colton et al., 2007).

Identifying Girls at Risk for DEB and Intervention

Low self-esteem, elevated BMI, depression, maternal weight/shape concerns, and maternal communication serve as both risk factors and identifiers of adolescent girls with T1DM who are at risk for DEB (See Table 2). Identifying girls who are at risk for DEB can be complex. Recent longitudinal research suggests that T1DM adolescents with DEBs do score differently on measures of depression, self-esteem, body image, and family relationships than T1DM girls without DEB (Olmsted et al., 2008). However, a review of standardized measures scoring systems and pre-determined psychometric 'cut off' levels shows T1DM girls with DEBs score within the 'normal' range although near the limit of how 'normal' is defined in population norms on these psychometric measures (Olmsted et al., 2008). Adolescent girls living with T1DM who do not develop DEBs score quite low on

ratings of depression, as well as having a better body image, higher self-esteem, and better relationships with their mothers, further suggesting that a healthy body image, elevated self-esteem, functional family relationships, and lack of depression may actually protect the adolescent T1DM from developing DEBs (Olmsted et al., 2008).

Table 2

Risk Factors Associated with DEB in T1DM Adolescent Females

Risk Factor	Measured As
Self-Esteem	• Feeling Ineffective • Low Self-Concept • Low Self-Esteem (Colton et al., 2007; Kahn & Montgomery, 1996; Maharaj et al., 2003)
Body Image	• Body Image • Drive for thinness • Weight preoccupation (Engstrom et al. 1999; Kahn & Montgomery; Kichler et al., 2008; Neumark-Sztainer et al., 2002; Pinar, 2005; Pollock-Barziv & Davis, 2005)
BMI	• Elevated BMI (Colton et al., 2007, Engstrom et al.; Maharaj et al.)
Depression	• Depression • Signs of Psychological Disease (Colton et al., 2007; Gobel-Fabbri et al. 2008; Takii et al. 1999)
Family/Maternal Relationships	• Negative family cohesion/negative home communication • Feeling less trust and greater alienation within the family • Mothers: maternal weight-shape concerns, increased body weight, currently on a diet and more controlling, maladaptive eating attitudes • Poor maternal-daughter relationship (Maharaj et al.; Kichler et al.; Neumark-Sztainer et al., 2002)

The physiologic measure of HbA1c significantly elevates after the onset of DEB and may be useful to the clinician as a biological screening marker, in conjunction with elevated BMI, to identify girls who already participate in DEBs within a pediatric endocrinology practice (Olmsted et al., 2008). In longitudinal research, poor body image, depression and elevated BMI were predictive of DEB onset in adolescent females living with T1DM. Researchers concluded that modification of psychosocial risk factors could be critical in the prevention of DEB behavior (Olmsted et al., 2008). Such factors provide a sound place for prevention intervention research.

Mother-Daughter Relationship

In females, desire for thinness, weight/shape concerns, and self-esteem drive DEB (Cash & Pruzinsky, 2002). In general adolescent populations negative maternal feedback about figure, maternal eating behaviors, and maternal food attitudes are predictive of daughter's body image (Cooley, Toray, Wang, & Valdez, 2008). An adolescent with a mother who has a history of an eating disorder or high body image concern is more likely to have DEB (Field et al., 2008).

Among adolescent girls with T1DM, maternal behaviors and relationship contribute to risk for DEB (Colton et al., 2007; Kichler et al., 2008; Maharaj et al., 2003). Adolescent girls with T1DM and DEB are more likely to report ineffective family communication (Kichler et al., 2008; Neumark-Sztainer et al., 2002), have mothers with greater concerns about weight or eating (Colton et al., 2007; Maharaj et al., 2003), and have poor perceptions of mother-daughter relationships (Maharaj et al., 2003). An intervention targeting the mother and daughter dyad could enhance communication, improve daughters' perceptions of family

cohesion, raise mothers' awareness of DEBs in T1DM, create more positive self-esteem and body image for both mothers and daughters and prevent the onset of DEB. Such an intervention is currently not available.

Overall research points to connections between the development of DEBs in T1DM adolescent girls and body image, self-esteem, and maternal relationship. Early prevention, through education and family skill building, is an excellent place to begin intervention research to decrease the prevalence of DEBs and thus improve quality of life, family functioning, and diabetes management, as well as preventing long-term negative health outcomes.

Theoretical Frameworks

Diabetic theoretical frameworks underpinning DEB are grounded in feminist and cognitive behavioral theories. In constructivist feminist theory, body image is engendered through interactions and relationships, being constructed from social interactions, cultural influences, and changing gender ideals (Bohan, 1993). Engendered messages of an 'ideal body' prompt adolescent girls to scrutinize their bodies to evaluate how they measure up to internalized standards, thus creating an objectified body consciousness (Calogero, Davis, & Thompson, 2005; McKinley, 1998; McKinley, 1999). Body objectification is learned through sociocultural influences in constructivist feminist theory. In body objectification, culture teaches women to view their bodies as objects and to evaluate and describe themselves by physical traits (Aubrey, 2010). Media drives culture and objectification through visual emphasis on women's bodies, which fuels body evaluation and improvement.

Women, both mothers and daughters, gain a sense of self-worth based on their internalized body ideal and proximity to achieving it.

In DEB, the interactions between cognitive processes, emotions and behaviors are affected by history and experiences in a continual reciprocal feedback loop which results in specific behaviors to control weight (Cash & Pruzinsky, 2002). For adolescent girls with T1DM, cognitive processes and emotions about their body are influenced by multiple factors, including cultural socialization, interpersonal relationships, physical characteristics and personality attributes all of which are associated with DEB (Cash & Pruzinsky). These frameworks emphasize the importance of both family and media influence on the development of sense of self that drives both body image and self-esteem, which in Western cultures are highly tied together.

Diabetic Frameworks

Daneman et al., 1998 published a proposed framework for understanding DEB in T1DM adolescent females based on research within the population and foundational knowledge of cognitive behavioral theory. Goebel-Fabbri (2009) also proposed a more recent framework for understanding DEB in T1DM female populations, expanding on the framework presented by Daneman and colleagues (1998). Both frameworks remain without an official name within the literature, are based on foundations in cognitive behavioral and feminist theory, and display similar structures.

For this study, these two diabetic frameworks were combined to create a more complete model for understanding DEBs among adolescent females living with T1DM. Antecedents of the combined diabetic framework are (a) that T1DM disease management is

complex and causes a predisposition of weight and food awareness, and (b) that personal history, family relationships/support, and sociocultural messages drive body image ideals (Daneman et al., 1998). Three main constructs, 'weight gain' related to T1DM management and insulin administration, 'perceived dietary restrictions' based on T1DM education and meal plans, and deliberate 'insulin omission' as a unique method for weight loss, interact both with antecedents, which include body image, self-esteem, and maternal-relationship, and with each other to increase the risk of DEB, ultimately resulting in poor metabolic control and diabetes-related complications (Daneman et al., 1998). Within this proposed research, this framework serves as an understanding of intervention within antecedents to prevent poor health outcomes (see Figure 1). Figure 1 is a compilation of both diabetic frameworks, designed to frame screening, intervention, and outcomes targeted by this proposed research.

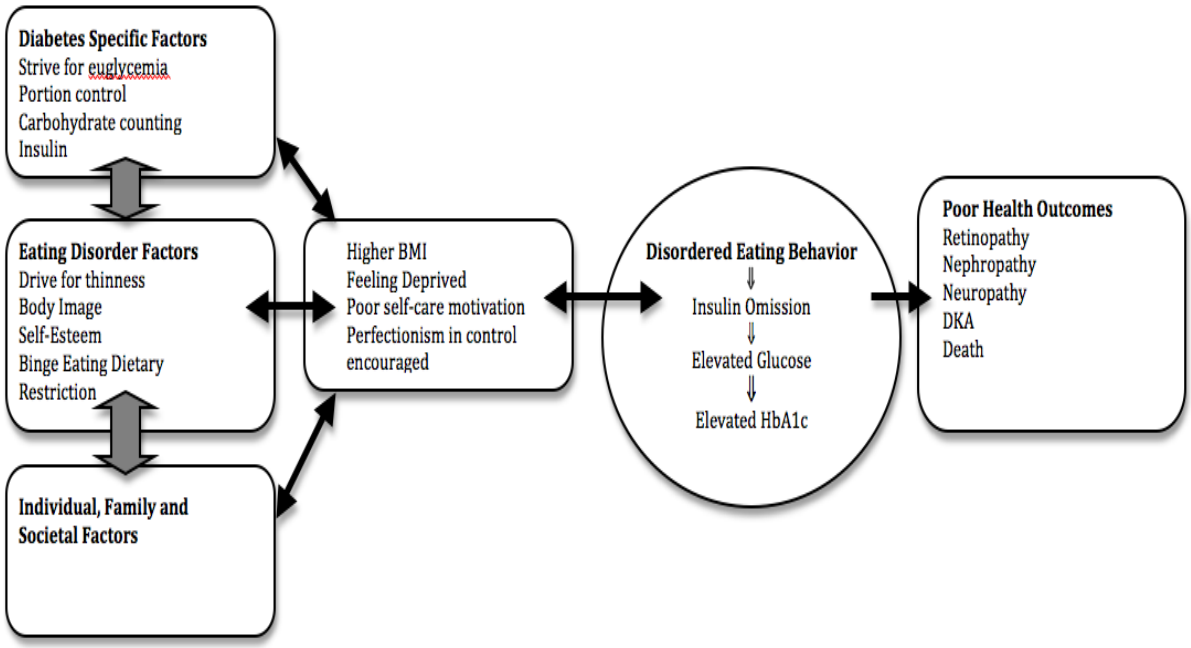

Figure 1. Framework for DEBs in T1DM Adolescent Females

Mother-Daughter Intervention Development and Feasibility

The evidence supporting incidence of DEB in adolescent girls with T1DM is substantial (Ackard et al., 2008; Bryden et al., 1999; Colton et al., 2007; Daneman et al., 1998; Goebel-Fabbri et al., 2008; Howe et al., 2008; Hsu et al., 2009; Jones et al., 2000; Nielsen, 2002; Pinar, 2005; Takii et al., 2002; Takii et al., 2008). Omission of insulin, the unique weight loss behavior of this group, has irrefutable negative health outcomes (Bryden et al., 1999; Daneman et al., 1998; Nielsen, 2002; Takii et al., 2002; Takii et al., 2008). To date, there is strong correlation between DEB and the key risk factors of body image, self-esteem, depression, maternal weight and shape concerns, and maternal-daughter relationship difficulties, yet identification of these girls by means of psychometric scoring numbers alone makes identifying at-risk girls problematic (Olmested et al., 2008). Currently, there are no clinical screening or intervention standards for health care providers who care for adolescent girls with T1DM. Further, intervention treatment after development of DEB is difficult (Olmsted et al., 2002). Skill building within the entire population to strengthen body image, self-esteem, and maternal communication may protect T1DM girls from developing DEBs (Olmsted et al., 2008).

Developing an Intervention Addressing Body Image, Self-Esteem, and Communication

Body image is associated with one's perceptions, emotions, interpretation, and feelings concerning one's physical body (Grogan, 2010). A high and positive self-esteem has been strongly tied to an improved body image (Grogan, 2010). Research within adolescent female populations strongly links sociocultural factors, such as media messages,

to internalization of thin ideals, disordered eating behavior, and to low self-esteem (Clay, Vignoles, & Dittmar, 2005; Field et al., 2008; Grogan, 2010). Media images create body image and self-esteem issues in young women (Aubrey, 2010; McCabe & Ricciardelli, 2001).

In general adolescent populations, interventions focused on prevention and psychological improvement have been shown to have a positive effect on a multitude of methods and topics (Tennant, Goens, Barlow, Day & Steawart-Brown, 2007). One large scale educational intervention aimed at general adolescent and pre-adolescent female populations focusing on self-esteem, self-efficacy, body image, and social support was successful in improving body image, perceived social support, and self-efficacy, but not self-esteem (Steese et al., 2006). This intervention was 10 lessons in length and required time commitment and access to the adolescents for all lessons.

Parenting interventions through an educational group format aimed at improving psychological the health of children have also proved beneficial for emotional and behavioral issues in children (Tennant et al., 2007). Increased perception of social support in adolescents is tied to family communication and relationships (Steese et al., 2006). Despite an awareness of the significance of maternal relationship, body objectification, and disordered eating on development of DEBs in daughters, interventions targeting mothers-daughters are lacking.

A mother-daughter intervention, targeting T1DM adolescent girls and their mothers, seemed a logical first step. The intervention would address the prevention of DEBs by focusing on strengthening body image, self-esteem, and maternal communication. Input from both mothers and daughters was critical in the development of such an intervention in

order to enhance participation, increase feasibility, and accommodate the research populations' specific needs. If risk factors for development of DEB can be altered and DEB risk lowered among adolescent girls living with T1DM through mother-daughter intervention, long-term health outcomes of this population may be improved.

Logic Model for Organization of an Intervention

The logic model is a method of creating a conceptual framework to plan and implement health promotion processes (Goodstadt, 2005). Within implementation of a program to promote health the logic model integrates explanatory factors and variables that affect processes. This model also outlines steps of the initiative and highlights desired outcomes (Goodstadt). The logic model is a useful visual tool to incorporate theoretical frameworks into specific populations and actions (W.K. Kellog Foundation, 2004). An intervention logic model was utilized to guide intervention design and to assist in application of information from the theoretical frameworks and review of literature. The logic model designed for this research clarified purpose for the intervention and outlined aims for eventual impact (See Appendix A).

CHAPTER 3

METHODS

Introduction

Despite evidence acknowledging the problem of DEBs (Gobel-Fabbri, 2009), subsequent negative health outcomes (Gobel-Fabbri et al., 2008; Nielson et al., 2002; Takii et al., 2002; Takii et al., 2008), and insulin omission (Maharaj et al., 2003; Neumark-Sztainer et al., 2002; Peveler et al., 2005; Takii et al., 2002) among adolescent females with T1DM, prevention interventions for this population have yet to be developed and researched (Gobel-Fabbri, 2009; Olmsted et al., 2008). In general adolescent female populations, an acknowledgement of media driven issues of self-esteem and body image in the development of DEBs has led to research on interventions to improve self-esteem, body image, and perceived social support. However, some of these interventions have lengthy time requirements and still have not incorporated the education and involvement of mothers (Steese et al., 2006).

This study was conducted as a first step toward addressing the multiple factors that contribute to the development of DEBs in adolescent girls with T1DM. A mother-daughter intervention was developed that aimed to enhance protective factors that may prevent development of DEBs in T1DM adolescent females. The mother-daughter BEYOUTI intervention development occurred through the application of theoretical frameworks and research evidence in cooperation with T1DM adolescent females and their mothers. Focus areas of the intervention were education about DEBs, deciphering media, improving self-

esteem and improving mother-daughter communication. This dissertation study examined the feasibility and preliminary impact of the mother-daughter intervention entitled BEYOUTI.

Research Design

BEYOUTI was developed in conjunction with adolescent an adolescent female with T1DM and her mother. The feasibility and acceptability of BEYOUTI intervention were evaluated using a pre/post-test, no control group design with a cohort of mother-daughter dyads. There were three data collection time points for this group: pre-intervention/baseline, immediately post-intervention, and 6-weeks post-intervention. Data collection included verbal and written feedback that assisted in determining acceptability, feasibility, and change in study variables. Psychosocial measures and variables of interest in decreasing risk of DEB development that were measured were self-esteem, body image, depression, maternal relationship, and insulin omission behavior.

Protection of Human Subjects

Risks associated with participation in either the focus group or the intervention portions of this study included mild psychological distress from discussion of topics related to the physical body and mother-daughter relationship. If distress occurred participants were encouraged to let the PI know so that arrangements could be made to refer the participant to the practice social worker of the pediatric endocrinology team. No other risks were noted. Human subjects were reminded that they could bypass answering questions that made them uncomfortable and that they could halt participation in the research and withdraw any

previous responses at any time. Participants were notified prior to participating that DEB screening scores on the Eating Attitudes Test-26 (EAT-26) indicating possible DEB, based on standard scoring, would be reported to the pediatric endocrinologist.

All questionnaires and intervention data collected in paper and pencil format and questionnaires were stored in a locked cabinet. Transcribed data from the focus group was stored in electronic format on the PI's computer and password protected. Participant numbers were utilized and no identifiers were linked to data. All data will be maintained in a locked cabinet by the PI for a period of seven years and then destroyed per Social Science IRB protocols. All study personnel had completed required human subjects training and Health Insurance and Portability and Accountability Act (HIPAA) education specific to the University and Hospital system requirements.

Sampling

Both the University of Missouri Kansas City Social Sciences IRB and the University of Missouri Hospital IRB provided IRB approval prior to any recruitment of subjects for study participation. Adolescent females living with T1DM and their mothers were recruited from a large pediatric hospital-based endocrinology practice in the Midwest, with a potential participant pool of over 900 diabetic patients. Approximately 30% of patients seen in this practice were expected to meet inclusion criteria for the proposed study. Inclusion criteria for enrollment were (a) diagnosis of T1DM for at least 18 months, (b) female gender, (c) 13 to 18 years old, (d) ability to fluently speak/read English, and (d) mother available to participate and able to fluently speak/read English. The physiologic honeymoon period that can occur after diagnosis, which can affect HbA1c readings and blood glucose control, has

usually ended after the 18-month time period. The 18-month time period criterion also provides girls and their mothers time to have developed habits regarding their diabetes management and a better understanding of the disease and its daily management requirements.

Potential participants for both intervention development and intervention implementation were identified by chart review by the physician co-investigator and research assistant. All potential participants were recruited via a brochure provided by the PI or research assistant to potential participants while waiting on their clinic appointments. The recruitment brochure described the research study and outlined requirements and contact information for the PI. The PI was available during clinic hours to explain the research further and to review the informed consent process with potential participants. Brochures were handed out to 32 potential participants for intervention, and three potential participants for participation in intervention development. All met study criteria for participation.

Two mother-daughter dyads were interested in intervention development and filled out interest forms. These two dyads did not participate in the intervention implementation. Of the two mother-daughter dyads who expressed interest in intervention development, one pair participated in intervention development.

Twenty-four mother-daughter dyads expressed interest in intervention implementation and filled out interest forms. The sample size determination was based on the "rule of thumb" statistical theory for pilot studies (Johanson & Brooks, 2010). Of the 24 dyads that expressed interest in intervention feasibility and acceptability, 10 participated in the study.

Measures

Data collected during intervention development with the mother and daughter who participated was recorded as fields notes taken by the PI. All information was stored in Microsoft Word Document format and secured. Pre- and post-intervention data was collected using paper and pencil questionnaires, which included a page for recorded height and weight, and open-ended questions concerning the intervention. Completion of the questionnaires took 10 to 20 minutes. All measures for this study were previously tested for reliability and validity (see Table 3) and were used in multiple research studies with general adolescent and/or adolescent diabetic populations. Outcome measures were; Body Esteem Scale (BES) as a measure of body image, Rosenberg Self Esteem Scale as a measure of self-esteem, Major Depression Inventory (MDI) as a measure of depression, and the Inventory of Parent and Peer Attachment (IPPA) maternal scale as a measure of mother-daughter relationship. Predictor variables were; Eating Attitudes Test (EAT-26) as a measure of eating disorder risk and insulin omission questions developed by the researcher as a measure of intentional insulin omission. BMI was collected as a descriptor of the population.

The EAT-26 is a 26-item likert scale self-report questionnaire used to measure disordered eating risk. Generally, the EAT-26 is used as the initial step and screening tool in a two-step process for eating disorder screening. The EAT-26 has the following subscales; Dieting, Bulimia and Food Preoccupation, and Oral Control. Internal consistency of the EAT-26 is high, with Chronbach's alpha of 0.90 in anorexia nervosa comparison groups and Chronbach's alpha of 0.83 within adolescent female comparison groups (Garner, Olmsted, Bohr, & Garfinkel, 1982). The scale has been used in numerous studies with adolescents to

identify those at risk for disordered eating, is within the public domain and is written at a 5th grade reading level (Tompson & Smolack, 2001).

Table 3

Evaluation Measures/Questionnaires

Risk Factor	Questionnaire	Items	Reliability/Validity
DEB Risk	Eating Attitudes Test-26 (EAT-26)	26	α = 0.90, Good construct validity (Garner et al., 1982)
Self-Esteem	Rosenberg Self-Esteem Scale	10	α = 0.80, Good construct validity (Haborg, 1993)
Body Image	Body Esteem Scale (BES)	23	α = 0.92 Test-retest correlations - 0.89 Appearance, 0. 92 Weight, 0.83 Attribution (Mendelson et al., 1997)
Depression	Major Depression Inventory (MDI)	12	Consistent correlation to Beck depression inventory Good reliability, sensitivity and specificity (Bech et al., 2002)
Maternal Relationship	The Inventory of Parent and Peer Attachment (IPPA)	25 (Maternal scale)	Mother α = 0.87 Test-retest reliability: 0.93 (Armsden & Greenberg, 1987)
Insulin Omission	Research specific self-report items	2	-Yes/No item-omitting insulin -self-report # of insulin omissions -open ended question as to why
BMI	BMI	Calculation of Height/Weight	Standard measure of obesity (CDC, 2008)

The Body Esteem Scale (BES) is a 23-item likert scale self-report questionnaire that was used to measure body image. The Alpha of the entire scale is 0.92 and test-retest correlations by sub-scale are Appearance 0.89, Weight 0.92 and Attribution 0.83 (Mendelson, White, & Mendelson, 1997). The Rosenberg self-esteem scale, a 10-item likert scale self-report questionnaire was used to measure self-esteem. The Chronbach's alpha of this scale is 0.80 with good construct validity (Hagborg, 1993). The Major Depression Inventory (MDI) is a 12-item likert scale self-report questionnaire that was used to measure depression. The instrument is available for use in the public domain and is shorter than the Beck Depression inventory with consistent correlation to this instrument and good reliability, sensitivity, and specificity (Bech, Rasmussen, Raabaek, Noerhom, & Abildgarrd, 2002).

The Inventory of Parent and Peer Attachment (IPPA) is a 75-item likert scale self-report questionnaire that has subscales of maternal, paternal, and peer relationships. Only the 25-item mother subscale was used with an alpha level of 0.89 and test-retest reliability of 0.93 (Armsden & Greenberg, 1987). Permission to use this scale and copies of all instruments can be found in appendix B. Insulin omission was measured in two additional questions added to the instrument packet. This scale was chosen and administered to both mothers and daughters at all time points to evaluate mothers' relationships with their own mothers and to expose mothers to the same questionnaires as daughters.

Mothers and daughters completed all of the psychometric measures, with the exception of the insulin omission measure, which was completed only by the daughter. Additional information about the intervention (see Table 4) was also collected pre and post intervention in written format. The PI recorded as field notes the verbal responses from mothers and daughters and any additional feedback given by them, as field notes.

Table 4

Qualitative Questions

Questionnaire	Question
Pre-Intervention	▪ What do you hope to gain from the intervention today?
Immediately Post-Intervention	▪ What is the most important thing you are taking from today?
	▪ After learning what you did today, what is one goal that you are going to try to do at home?
	▪ Would you like to make any recommendations about this mother/daughter intervention for future classes or research?
6-Week Post-Intervention	▪ After the intervention, has your behavior or actions changed at home and if so, how?
	▪ After the intervention you set a home goal. What was that goal and how is it going?
	▪ Would you like to make any recommendations about this mother/daughter intervention for future classes or research?

Research Ethics and Intervention Development and Implementation

Both the University of Missouri Kansas City Social Sciences IRB and the University of Missouri Hospital IRB provided IRB approval prior to any recruitment of subjects for study participation. Written informed consent was obtained from all mothers and written assent was obtained from each daughter prior to intervention development or implementation. All participants were informed of participation requirements, risks and rights when interest brochures were provided, at the time of consent, and immediately prior to intervention.

Intervention Development

A mother-daughter dyad assisted in the development of the BEYOUTI intervention. The meeting with the dyad took place at a Midwest suburban public establishment where seating for participants and the PI could be comfortably established with workspace. One week prior to meeting, the dyad was e-mailed a copy of the potential intervention outline, purpose, objectives, and questions concerning development of the intervention. The dyad reviewed the proposed outline and content of the intervention, viewed any media that could be presented in the intervention, and suggesting refinements to content and activities. Feedback from this dyad guided the development of the intervention, including questions and activities, ordering of activities, time structuring, and suggestions for obtaining maximum participation during the intervention from both mothers and daughters. Suggestions and revisions proposed by the mother and daughter were made prior to the first intervention.

Intervention Implementation

The intervention was implemented at two different locations on different days of the week to enhance participation. The intervention consisted of a single two-hour session with interactive, educational, and skill building activities, and included four content focus areas. Content areas were on the topics of (a) DEBs in T1DM (b) deciphering media messages, (c) body-image and self-esteem building, and (d) open communication. Each content area was limited to 15 to 35 minute intervals and included educational information, open discussion time within the group, and specific mother-daughter activities. All participants were provided paper and pencil to assist in participation in communication activities and to keep notes throughout the intervention. As it was considered private, participants did not share

their written work from both the investigator and other participants in the intervention. During the intervention session, participants could share openly with other members of the group or chose to speak only individually to their mothers.

Procedures

Study personnel included the PI, a physician co-investigator who was the treating physician at the pediatric endocrinology site, and a nurse-practitioner research assistant also from the pediatric endocrinology site. The research assistant was trained by the PI on study procedures and completed all human subjects and HIPAA training modules required by the study site. The research assistant identified possible adolescent females who met recruitment criteria and assisted in providing information to possible participants about the study.

Once potential mother-daughter participant dyads were identified, and informational brochures provided, potential mother-daughter participants who were interested and willing to participate contacted the PI via personal face-to-face contact at the recruitment site, phone, or e-mail and provided contact information through an information sheet that was used to set up dates and times for intervention.

Written informed consent was obtained from mothers and written assent was obtained from daughters prior to beginning the intervention session. All participants were informed of their right to refuse to participate at any time throughout the intervention, of the minimal risks involved, and of their right to revoke consent at any time. Participants were also informed that refusal to participate in this study would not impact their clinical care in any way. Written consent forms included a statement informing participants that EAT-26 scores

of 20 or higher, based on standardized scoring, would be reported to their primary diabetes care provider for follow-up and further evaluation.

Mothers and daughters completed a set of questionnaires immediately prior to the intervention session and another set of immediately after the intervention session ended. At six-weeks post intervention, the same set of questionnaires and post card to enter the gift certificate drawing were mailed to all mother and daughter participants separately with a stamped-addressed return envelope. Reminders to fill out the 6-week post questionnaire were re-mailed to participants who had not returned surveys after two weeks. Each individual mother and daughter participant received the opportunity to enroll in a drawing for a $50 gift card at the completion of all data collection. As a thank you for participating, each participant was given a small gift bag at the time of intervention with small items like a pen, calculator, magnet, hand lotion, and note cards. The cost of these bags was approximately $10 per bag. Light refreshments of bottled water and sugar free snacks were served at the intervention session.

Data Analysis

An identification number was used on all questionnaires. Consent forms for all participants were kept separately from questionnaires. No identifying data were collected on questionnaires or in field notes kept by the PI.

Qualitative and Field Note Data

Field note and qualitative data were transcribed verbatim and then analyzed by the PI using an inductive qualitative content analysis process (Elo & Kyngas, 2008). In this

process, data is organized and examined for frequent themes and then coded into categories derived from those themes (Elo & Kyngas). Data from both field notes and questionnaire open-ended questions were reviewed for themes and then grouped into categories. Frequency of recurring themes was also calculated. Specifically qualitative data were analyzed for statements of acceptability of the BEYOUTI intervention and information that could be used to refine the intervention. Descriptive analysis of the nominal yes/no insulin omission question was completed, while qualitative analysis of answers as to reasons for insulin omission was also completed using the inductive qualitative content analysis process.

Quantitative Data

Data from the EAT-26, Rosenberg self-esteem scale, BES, MDI, and maternal scale of the IPPA were entered into a database using the Statistical Package for the Social Sciences (SPSS) 19.0. Individual missing item responses were replaced with the item average for that group, i.e. daughters' pre-intervention or mothers' post-intervention, provided that no more than 10% of item responses were missing. If greater than 20% were missing on any one item it was to be removed from analysis. Each individual questionnaire response was totaled per participant. Questionnaire and sub-scale totals were utilized for data analysis. Descriptive statistics were used to analyze demographic and health characteristic data (i.e. age, race, and age at diagnoses with diabetes).

The variables analyzed were the EAT-26, Rosenberg Self-Esteem Scale, BES, MDI, and mother subscale of the IPPA and their corresponding subscales. Descriptive statistics and change in average variable measures was analyzed pre- and post-intervention. Paired t-tests were conducted to study pre- and post-intervention effect. All statistical tests were two-

tailed with a significance level of 0.05. BMI was analyzed by descriptive statistics only from pre-intervention questionnaires.

CHAPTER 4

RESULTS

Adolescent girls with T1DM and their mothers were recruited from a Midwest pediatric endocrinology practice. Two mother-daughter dyads met inclusion criteria and expressed interest in assisting with the development of the intervention. Neither of these two dyads participated in intervention implementation. A single dyad participated in intervention development.

Of the 32 potential participant dyads, 24 expressed interest in mother-daughter intervention implementation, feasibility, and acceptability testing and completed contact information. Of the 24 interested dyads, two had inaccurate addresses. Twenty-two dyads were successfully contacted about intervention implementation. Of these 22 dyads one mother-daughter dyad reported they were no longer on speaking terms nor living together, three dyads reported illness of mother or daughter on the scheduled day of intervention, three dyads canceled due to school or work obligations, and five dyads simply did not show for intervention. This left 10 mother-daughter dyads that participated in the intervention. Four mothers and one daughter did not return six-week post survey questionnaires.

Development of the Intervention

The BEYOUTI intervention was developed in collaboration with one mother-daughter dyad. Intervention development included creating and then reviewing the proposed outline and content for the intervention, selecting and viewing media for presentation in the

intervention, and creating interactive activities and discussion for each content area. The mother-daughter dyad involved in intervention development reviewed content, outlines, media, and proposed activities. Feedback from this dyad guided discussion questions, activities, and ordering of activities to ensure maximum participation.

The mother-daughter dyad reviewed and approved proposed content areas for relevancy to the topic. The dyad also reviewed content delivery methods and verbalized some concern with questions of a more personal nature that could possibly cause daughters to be reluctant to speak openly. The dyad suggested that these topics/questions be trialed in the first intervention and if discussion did not flow easily; that either questions be cut or mothers and daughters be separated if mechanics of the environment allowed. The dyad felt handouts providing website URLs and take home information were needed. Resources from established self-esteem building and media education websites targeting girls were reviewed and approved by the mother-daughter dyad as handouts (See Appendix C).

Table 5 includes content areas, information, discussion, and activities for each focus area. No information was removed from content based on feedback from the mother-daughter dyad assisting with intervention development. An addition to discussion topics was made in the communication content area based on suggestions from the mother-daughter dyad. The dyad felt that it was important to encourage mothers and daughters to participate in home 'safe times' discussions in which daughters could share feelings and information openly without fear of punishment, 'nagging', or judgment and during which mothers would "really listen". Suggested revisions were made prior to first intervention.

Table 5

Intervention Design

Component/ Time	Theoretical Construct	Content/Audiovisual	Discussion	Activities
DEB/Insulin Omission 15 minutes	▪ Diabetic theory-specific factors interact with family/society and increase DEB risk	▪ DEB in T1DM ▪ Insulin Omission	▪ Time for questions	▪ No structured activities
Deciphering Media 30 minutes	▪ Constructivist Feminist Theory-media/society messages increase DEB risk	▪ Dove Campaign for Beauty video 'Evolution' ▪ NOW PowerPoint, Love Your Body	▪ How did viewing the video/ PowerPoint make you feel? ▪ What did you learn? ▪ What does media sell to girls?	▪ Media Activity: View current print advertising targeting women; describe the product/ messages conveyed
Body Image and Self-Esteem 20 minutes	▪ Constructivist Feminist theory-media/society messages increase DEB risk ▪ Cognitive Behavioral theory- cognitive processes/history affect actions, increase DEB risk	▪ Dove PSA video	▪ Moms: How do you feel about yourself? ▪ Does your daughter hear you? ▪ Do you listen to your daughters? ▪ Daughters: Do you think your mothers like themselves?	▪ Writing Activity: 3 things you like about yourself and mother/daughter ▪ Writing Activity: 3 things you are good at and mother/ daughter is good at ▪ Writing activity: What do you need from mother/ daughter when you /are being negative?
Communication 15 minutes	▪ Diabetic theory-specific factors interact with family/society and increase DEB risk	▪ List of things adolescents wish their parents knew ▪ "What it is like to be a teenager"	▪ Do you have a 'safe' time to talk at home? ▪ Moms share 1 thing about their adolescence.	▪ Writing Activity: Write down 1 thing learned, 1 goal for home, and 1 thing to teach/point out to friends/peers

Intervention Implementation

In an effort to increase participation and ease intervention execution and to decrease conflict with participant schedules the BEYOUTI intervention was designed as a single two-hour session. Mother-daughter communication was the center of emphasis throughout each focus area of the intervention. Mothers and daughters were asked to participate in specific activities and to communicate openly with each other throughout the intervention. Each participant was encouraged to write down responses to discussion questions and to reflect on answers throughout the intervention.

The two-hour intervention session consisted of interactive, educational, and skill building activities. Audiovisual content was included to keep participants engaged and to provide multiple content delivery methods for learning. Intervention content focused on the topics of (a) DEBs in T1DM, (b) deciphering media messages, (c) body-image and self-esteem building, and (d) open communication. Each component included information, an open discussion time within the group, and specific mother-daughter activities.

In diabetes specific DEB theory, family, society, and environment are mediators for DEBs (Goebel-Fabbri, 2009) and body objectification learned through media influences DEB behaviors (Aubrey, 2010). Thus, information to assist adolescents and their mothers in better deciphering media messages was included. Educational information on deciphering media included the video *Evolution* from the Dove's campaign for beauty, a PowerPoint based on the National Organization for Women's Love Your Body campaign, and an activity where print media images were evaluated for product placement and additional messages being promoted. Print magazines included *Teen Vogue, Seventeen, People, Vogue, Women's Day,* and *J-14.* The media selections in this section were well received. Participants denied

having previously viewed either the video or the PowerPoint. Many participants noted the evaluation of the print media as a favorite activity.

Family, society, and environment factor into self-esteem which affects body objectification that leads to cognitive behavioral actions to achieve an 'ideal' body (Cash & Pruzinski, 2002). Within a diabetes specific theoretical framework, poor self-esteem can affect body objectification and lead to increased risk of DEBs. In the body image and self-esteem building component, a second Dove PSA video, highlighting how daughters feel about themselves and their bodies, was shown. This media selection had also not previously been viewed by any of the participants and was well received.

To assist in changing the mediator of family, particularly maternal relationship, communication was chosen as an intervention area. Content for the communication component included a review of things that adolescents wish their parents knew and a qualitative reading about difficulties of adolescence (Aspen Education Group, 2010; Heart of the Matter, 2010). Discussion activities included goal setting for home communication, having a 'safe' communication time, and mothers sharing one thing either in written form or verbally with their daughters that they had not shared with their daughters previously. Participants said they appreciated the inclusion of audiovisual media, the qualitative readings from other adolescents, and the opportunity to communicate in writing through the intervention.

Demographic Data

The mother-daughter dyad who participated in intervention development was not unlike the participant group sample in demographics. The mother in this dyad was Caucasian. The daughter was of mixed Caucasian and African American descent.

Intervention implementation participants all identified themselves as Caucasian. Daughter participants ranged in age from 14 to 17 years with a mean age of 15 years 4 months (median 15.5 years; mode 14.5 years; SD 1.16 years). Age of diagnosis with diabetes among the daughters ranged from 2 to 13 with a mean age at diagnosis of 8 years 11 months (median 7.5; mode 10; SD 3.48 years). Mother participants who reported ages ranged in age from 36 to 47 years with a mean age of 41 years 3 months, n=5 of mothers reporting age.

Question 1: Feasibility and Acceptability

Is it feasible and acceptable to implement a mother-daughter group intervention to prevent DEB development among T1DM adolescent girls receiving care in a hospital-based pediatric endocrinology practice?

Attrition

Evaluation of intervention feasibility and acceptability was gleaned from two primary sources: field notes of the PI taken during intervention implementation and qualitative verbal and written feedback about the intervention from participants. All of the 24 mother-daughter dyads that filled out interest forms were receptive to the intervention. Attrition from time of enrollment to actual intervention was 42%.

Acceptability of Study Measures

The majority of participant responses to completing outcome measure questionnaires were positive and participants felt that the amount of time it took to complete the questionnaires, 10 to 15 minutes, was acceptable. Outcome measures were EAT-26, a measure of DEB risk; the Rosenberg self-esteem scale, a measure of self-esteem; the Body Esteem Scale (BES), a measure of body image; the Major Depression Inventory (MDI), a measure of depression; and the maternal relationship scale of the Inventory of Parent and Peer Attachment (IPPA), a measure of mother-daughter relationship. There was one area of suggested refinement by mothers; removal of the IPPA mother relationship subscale to be taken by mothers. Two mothers did not fill out the mother subscale of the IPPA as their mothers were no longer living and had not been for some time. One mother commented on the post intervention questionnaire, "Although I understand the questions about my relationship with my mother, I wonder if questions about my relationship with my daughter would be more effective?" In verbal feedback after intervention, mothers suggested using scales noting family support and targeting communication skills or how mother's felt about daughter relationship.

Acceptability of the Intervention

Mother and daughter feedback regarding the BEYOUTI intervention was quite positive with 70% of participants responding positively on post intervention questionnaires (See Table 6). Verbal feedback provided by participants after the intervention included statements such as "This was a real eye opener," and "We have never talked about these things before." Mothers and daughters suggested that the intervention should be replicated,

if not for research then to serve more general educational purposes for T1DM girls and their mothers. Most felt this was an approach that all mothers and daughters living with T1DM could benefit from to improve daughters' self-esteem, to help them decipher media messages, and to enhance communication between mothers and daughters. Mothers and daughters also suggested a larger venue such as the Juvenile Diabetes Research Foundation (JDRF), ADA, and Parent Teacher Association (PTA) meetings for future intervention. They also suggested that the age for the target audience be lowered to the pre-adolescent years in order to "catch them before any of this starts." Feedback on BEYOUTI was positive and many participants encouraged continuation of the information in some format.

Table 6

Results of Feasibility Data Provided as Written Feedback by Participants

Area	Intervention Condition
Attrition	▪ Attrition 42% from baseline interest
Measures	▪ Time to complete questionnaires acceptable
	▪ Mothers felt IPPA mother subscale did not serve a significant purpose
	▪ Mothers suggested use of a social support, communication, or daughter relationship tool instead
	▪ Positive changes with some measures despite small sample size
Intervention	▪ 70% responded positively regarding intervention content
	▪ 95% set a positive goal based on intervention content
	▪ Mothers suggested a larger venue through family activities sponsored by a diabetes organization
	▪ Mothers suggested target audience be expected to include preadolescents

(n = 20)

Question 2: Impact of the Intervention

What is the impact of the BEYOUTI intervention on depression, perceptions of the mother-daughter relationships, body image, and self-esteem?

Outcome Measure Change for All Participants

Descriptive statistics and paired t-test comparisons were used to examine outcome measures at three time points: pre-intervention, post intervention, and six-week post intervention. Significance was set at $p < 0.05$ for all paired t-test comparisons. Changes in the clinically desirable direction were found on several of the outcome measures of interest to this study. Mean change of average outcome measure is noted in Tables 7 and 8. For outcome measures, first analysis was of all participants together, both mothers and daughters, except for the IPPA maternal relationship scale, which was totaled for daughters only based on feedback from participants.

For all participants, EAT-26 scores decreased immediately post-intervention and further decreased at six-weeks post-intervention. BES scores also remained higher throughout post-intervention testing. There was a decrease in Rosenberg self-esteem scores and an increase in MDI scores at the six-week post-intervention time point for all participants, both mothers and daughters. An outlier was noted on each of these measures, which was thought to skew results. When the outlier was removed, the difference in scores at the six-week post-intervention time point for the Rosenberg self-esteem scale dropped to –0.41 and the MDI only increased by only +0.79 in total and by only +0.05 on in the daughter group. However, given the small sample, outlier results likely had a greater effect on average scores.

Table 7

Mean Change of Outcome Measures Immediately Post Intervention

Variable / Measure	Pre-intervention Mean	Pre-S.D	Post-intervention Mean	Post-S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale	23.55	6.21	24.14	6.58	+ 0.58	-1.737	0.099
MDI	7.57	6.49	7.35	6.69	-0.22	0.811	0.428
BES*	51.6	21.08	55.34	21.00	+ 3.74	-2.682	0.015
EAT-26	5.95	3.53	5.25	3.11	- 0.70	1.113	0.279

n = 20
*significant in paired t-test $p < 0.5$

Paired t-tests. To examine changes from pre- to post-intervention on all outcome measures for all participants, paired t-tests were used. The mean BES was significantly higher post-intervention compared to pre-intervention with a t-score of $t = -2.682$, $df = 19$, $p = 0.015$. There was also a significant decrease in mean EAT-26 six-weeks post-intervention with a t-score of $t = 2.382$, $df = 15$, $p = 0.032$ (See Table 8). No other significant results in paired t-test analyses were found. However, the changes in the clinically desired direction on the outcome measures of body image, as measured by BES, and DEB risk, as measured by EAT-26, are promising.

Table 8

Mean Change of Outcome Measures Six-Week Post Intervention

Variable / Measure	Pre-intervention Mean	Pre-S.D	6-week Post Mean	6-week Post S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale	23.00	6.77	21.75	8.15	-1.25	1.692	0.111
MDI	8.09	7.02	9.56	11.64	+1.47	-1.025	0.321
BES	49.73	22.19	52.52	25.07	+ 2.79	-1.641	0.122
EAT-26^*	6.13	3.62	4.13	3.36	- 2.00	2.382	0.032

n = 16
*significant in paired t-test $p < 0.5$
^ n=15, one daughter did not fill out return EAT-26

Outcome Measures Subscale Change for All Participants

Descriptive statistics and paired t-test comparisons were also used to examine changes at the following time points; pre-intervention, immediately post-intervention, and six-weeks post-intervention for subscales of outcome measures. The BES, EAT-26, and IPPA maternal scale outcome measures all had subscales which were as follows: BES Appearance, BES Weight, and BES Attribution; EAT Dieting, EAT Bulimia and Food Preoccupation, and EAT Oral Control; IPPA Trust, IPPA Communication, and IPPA Alienation. Of these subscales, three showed consistent change in the clinically desired

direction at both immediately post intervention and six-weeks post-intervention time points, BES Appearance, BES Weight, and EAT Dieting (See Tables 9 & 10).

Table 9

Mean Change of Subscale Outcome Measures Immediately Post Intervention

Variable / Measure	Pre-intervention Mean	Pre-S.D	Post-intervention Mean	Post-S.D.	Change	t-score	*p-value*
BES-Appearance*	23.87	9.90	26.42	10.85	+2.55	-3.090	0.006
BES – Weight	17.08	9.04	18.20	8.29	+1.12	-1.589	0.128
EAT – Dieting	4.55	3.71	3.95	3.05	-0.60	1.121	0.276

n = 20
*significant in paired t-test $p < 0.5$

The BES Appearance, BES Weight, and EAT Dieting subscales showed change in the desired direction from baseline to the immediate post-intervention and six-week post-intervention time points and are presented in Tables 9 and 10. Both BES Appearance and BES Weight showed increases in the desired direction for all participants at both the immediate post- and six-week post-intervention time points. In paired t-test comparisons the BES Appearance subscale was significantly higher post-intervention, with a t-score of $t = -3.090$, $df = 19$, $p = 0.006$. This subscale was probably a significant driver of the total immediate post-intervention BES changes and indicated a significant improvement in appearance body image.

Table 10

Mean Change of Subscale Outcome Measures Six-Week Post Intervention

Variable / Measure	Pre-intervention Mean	Pre-S.D	6-week Post Mean	6-week Post S.D.	Change	t-score	*p-value*
BES-Appearance	23.21	10.73	24.81	11.20	+1.60	-1.841	0.085
BES – Weight	16.48	9.36	17.81	9.99	+1.33	-1.875	0.080
EAT – Dieting^*	4.73	3.88	2.87	2.77	-1.96	2.536	0.024

n = 16
*significant in paired t-test $p < 0.5$
^ n=15, one daughter did not fill out return EAT-26

There was also a significant decrease on the EAT-26 Dieting subscale at six-weeks post-intervention, with a t-score of 2.536, $df = 14$, $p = 0.024$, indicating a reduction in DEB risk related to dieting. No other significant results in paired t-test analyses for variable subscales were found. However, the change in the clinically desired direction on the BES Appearance and EAT Dieting subscales measures is also promising. IPPA maternal relationship scales were only totaled for daughters based on feedback from participants and were not included in outcome measure subscale analysis for all participants.

Outcome Measure Results by Group

Daughters' Results. Analysis of mean scores for Rosenberg self-esteem, MDI, BES, EAT-26, and IPPA maternal relationship scale outcome measures among daughters showed a non-significant increase in BES scores at both the immediately post-intervention and six-

week post-intervention time points, although the six-week time point increase was not as high as the immediate post intervention increase (See Tables 11 & 12). In paired t-test comparisons of pre-intervention and post-intervention means, none of the paired t-test comparisons for daughters had statistical significance at the $p < 0.05$ level other than the Rosenberg self-esteem scale at the six-week post intervention time point, which was not significant once the outlier was removed.

Table 11

Mean Change of Outcome Measures Immediately Post Intervention for Daughters

Variable / Measure	Pre-intervention Mean	Pre-S.D	Post-intervention Mean	Post-S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale	23.50	8.20	23.85	9.00	+ 0.35	-0.724	0.487
MDI	8.44	8.64	8.10	9.10	-0.34	0.707	0.497
BES	56.66	23.32	59.27	25.18	+ 2.61	-1.670	0.129
EAT-26	4.70	3.80	4.90	3.60	- 1.10	-0.215	0.834
IPPA	78.48	23.09	80.00	23.87	+1.52	-0.783	0.454

n = 10
*significant in paired t-test $p < 0.5$

Table 12

Mean Change of Outcome Measures Six-Week Post Intervention for Daughters

Variable / Measure	Pre-intervention Mean	Pre-S.D	Post-intervention Mean	Post-S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale*	22.89	8.45	20.44	10.57	-2.45	2.408	0.043
MDI	9.27	8.73	12.33	15.12	+3.06	-1.266	0.241
BES	56.73	24.73	57.56	29.88	+ 0.83	-0.322	0.756
EAT-26^	5.38	4.00	4.63	4.44	- 0.75	0.600	0.567
IPPA	79.31	24.32	76.07	25.29	- 3.24	1.037	0.330

n = 9
*significant in paired t-test $p < 0.5$
^ n=8, one daughter did not fill out return EAT-26

Mothers' Results. Analysis of mean scores for Rosenberg self-esteem, MDI, BES, and EAT-26 outcome measures among mothers showed changes in the desired clinical direction on all outcome measures (See Tables 11 & 12). An increase in BES scores was noted at the immediate post-intervention time point and was increased significantly at the six-week post intervention time point. MDI scores had a small, sustained decrease, which was not significant. Just as Rosenberg self-esteem had a small, sustained non-significant increase. EAT-26 scores were lower at the immediate post-intervention time point, but also

Table 13

Mean Change of Outcome Measures Immediately Post Intervention for Mothers

Variable / Measure	Pre-intervention Mean	Pre-S.D	Post-intervention Mean	Post-S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale	23.60	3.75	24.40	3.17	+ 0.80	-1.714	0.121
MDI	6.70	3.56	6.60	3.24	-0.10	0.361	0.726
BES	46.54	18.38	51.40	16.22	+ 4.86	-2.079	0.067
EAT-26	7.20	2.90	5.60	2.67	- 1.60	2.021	0.074

n = 10
*significant in paired t-test $p < 0.5$

Table 14

Mean Change of Outcome Measures Immediately Post Intervention for Mothers

Variable / Measure	Pre-intervention Mean	Pre-S.D	6-Week Post Mean	6-Week Post S.D.	Change	t-score	*p-value*
Rosenberg Self-Esteem Scale	23.14	4.41	23.43	3.36	+ 0.29	-0.354	0.736
MDI	6.57	4.08	6.00	2.83	-0.57	0.795	0.457
BES*	40.71	15.74	46.05	17.17	+ 5.34	-2.838	0.030
EAT-26*	7.00	3.21	3.57	1.62	- 3.43	3.827	0.009

n = 7
*significant in paired t-test $p < 0.5$

had a larger significant decrease at the six-weeks post-intervention indicating a decrease in DEB risk.

To examine the variable changes for mothers from pre intervention to post-intervention time points paired t-tests were run on the variables Rosenberg self-esteem, MDI, BES, and EAT-26 and subscales of the BES and EAT-26. Significant results were found for the EAT-26 at six-week post intervention, for the BES Appearance subscale at the immediate post intervention time point, and the EAT Dieting, BES Appearance, and BES Appearance subscales at six-weeks post intervention. For mothers, mean EAT-26 scores were significantly lower at six-weeks post-intervention, with a t-score of 3.827, $df = 6$, $p = 0.009$. The EAT Diet subscale also showed a significant decrease at six-weeks post intervention in mothers, with a t-score of 2.97, $df = 6$, $p = 0.025$. Mothers' scores on the EAT-26 appeared to be the driving factor for significant change in the Dieting subscale at six-week measures that was found in total participant variable comparisons.

In mothers, the mean of BES Appearance subscale was significantly higher in both post-intervention and six-weeks post intervention time points, with t-scores of $t = -2.901$, $df = 9$, $p = 0.018$ for immediate post-intervention and $t = -5.031$, $df = 6$, $p = 0.002$ six-weeks post intervention. The mean of BES Weight subscale was significantly higher at the post-intervention time point with a t-score of $t = -2.569$, $df = 6$, $p = 0.042$. Overall, changes in the desired direction for body image and DEB risk were strongest in mothers. The changes noted in the clinically desired direction on the EAT-26, BES, and MDI total scores, as well as BES Appearance and EAT Dieting subscales measures, are promising as well.

Insulin Omission and BMI

The unique form of DEB behavior in T1DM adolescent females is insulin omission. No instrument has been developed to analyze rates of insulin omission or root causes for it. For this study, T1DM adolescents were asked on each questionnaire if they had ever omitted insulin and how many times. At the pre and immediate post-intervention time points daughters were asked how many times they had omitted insulin in the last 3 months and at the six-week post-intervention time point they were asked, "How many times in the last six weeks?" At pre and immediate post intervention time points 70% of girls, seven of n=10, indicated that they had missed an insulin dose in the previous 3 months and 67% that they had missed an insulin dose at the six-week post intervention time point.

No participant reported missing more than three doses (range 1 to 3). The most common reason for missing dosing was forgetting to take insulin, and the most common insulin noted was glargine insulin. One participant noted pump failure as a reason for missing insulin doses. None of the daughters reported frequent insulin insulin omission behavior nor purposeful insulin omission, although one girl did note on her responses that, "We forgot about my Lantus and sometimes I don't feel like giving myself a shot."

BMI for both mothers and daughters was calculated at baseline. Mean BMI for daughters was 25.78 with a standard deviation of 3.65. Mean BMI for mothers was 32.09 with a standard deviation of 7.39. BMI averages for both groups are higher than current suggested parameters for optimal health (normal range = 18.5 to 25) (CDC, 2008; CDC, 2011).

Findings from Qualitative Data

Open-ended questions were asked on all questionnaires, and participants had the opportunity to write their responses to the following questions. On pre-intervention questionnaires participants were asked, "What do you hope to gain from intervention?" On immediate post intervention questionnaires, participants were asked to share what they had gained from the intervention. Participants were also asked to set one goal after intervention that they would work on at home and at the six-week post intervention time point participants were asked if behaviors had changed at home and if goal implementation had occurred. Four themes emerged in responses at all three time points; improved communication, becoming media savvy, improved self-esteem, and improved diabetes care.

Theme 1: Improved Communication

Throughout open-ended questionnaire responses at all time points, communication was a dominant theme. On pre-intervention questionnaires one daughter looked forward to getting to know her mother better. Mothers overwhelmingly responded that they had a desire to improve communication and better their relationships with their daughters.

The theme of improved communication emerged in the responses from both mothers and daughters on immediately post-intervention questionnaires, with emphasis on open communication and participants better trying to see the other person's perspectives as noted priorities. One mother wrote, "I need to talk with my daughter more and find out how she is really feeling." A daughter wrote that she was more hopeful about "the whole idea of communication" and that she and her mother could "better understand each other."

At the six-week post-intervention time point, participants were asked about whether they had met intervention goals at home. The majority of mothers set goals of improving open communication with their daughters. Mothers commented that they wanted to be more positive listeners and provide ample time for daughters to express their feelings. Daughters set goals of desiring to communicate more frequently with mothers. Several participants noted that they had improved communication within their family. Daughters reported they were talking more openly with mothers, and mothers reported they were trying to be "better" listeners. One daughter wrote, "I try to be more open with my mom about everything. Even though I was open before, it helped me to know that I can even be more open with her." A mother expressed, "My goal was to listen/hear more of what was being said. Although it is a challenge sometimes, we are making progress."

Theme 2: Becoming Media Savvy

The theme of becoming media savvy was prominent in the immediately post- and six-week post-intervention time points. Several participants recognized that magazine and television advertising was not an honest representation of a person's body. Post-intervention goals set by participants reflected this theme. One daughter set a goal not purchasing fashion magazines. Daughters also set goals of looking at media advertising more closely for subliminal messages that might affect their body image, improved diabetes care, and improving hemoglobin A1c goals. One daughter responded that, "…when I look through magazines its funny how they try to sell other things than the product." Verbal field note responses echoed this theme with many participants agreeing that learning to decipher media should be presented to a wider audience and younger girls. Two girls verbalized that they

were going to take this information and apply it to various school service projects and to educate their younger sisters.

Theme 3: Improved Self-Esteem

The theme of self-esteem was present throughout pre- and post-intervention questionnaire responses. On pre-intervention questionnaires one daughter expressed a desire to learn that she was not different from other girls. Both mothers and daughters noted improved personal self-esteem and recognition of personal importance as post intervention gains. One daughter wrote that she discovered that she was not different, "and not awful" from attending the intervention with her mother. Another daughter enthusiastically commented, "I've played more softball and my attitude is changing and getting better! And everyone has noticed."

Theme 4: Improved Diabetes Care

On pre-intervention questionnaires daughters responded more frequently about hopeful improvements in diabetes care. Daughters' responses included learning about diabetes, eating healthier, and consequences of eating disorders. In the immediate post-intervention responses two daughters set goals of improving home diabetes management and HgbA1C levels. Both mothers and daughters noted knowledge of the long-term impact of DEBs on health outcomes in adolescent females with T1DM as a post-intervention gain.

Overall field notes and written responses about the intervention included statements about prior of lack of knowledge about rates and impact of DEBs and insulin omission for adolescent girls living with T1DM, nor the importance of mother-daughter communication, self-esteem, media, and body image in regards to DEBs prior to participating in this study.

Many voiced concerns, based on their new knowledge of DEBs in adolescent females living with T1DM, about the long-term impact of DEBs on health outcomes. Most participants expressed appreciation for the intervention and information presented. Participants felt the intervention provided a mechanism for improved communication between mothers and daughters and that the knowledge they had gained on all topic areas was important.

CHAPTER 5

DISCUSSION

The BEYOUTI intervention was developed to address the risk for DEBs among adolescent females living with T1DM. The intervention aimed to enhance self-esteem, body image, and mother-daughter relationship through communication, three of the major risk factors for DEB in this population (Goebel-Fabbri, 2009; Olmsted et al., 2008). Findings from this feasibility study showed that participants were enthusiastic about the intervention and that outcome measures changed in the clinically desired direction from pre- to post-intervention. This appears to be the first study that aimed at the development of a mother-daughter intervention to prevent DEBs among adolescent females living with T1DM. While limitations are present, findings were encouraging and warrant further research.

Summary and Conclusion

The purpose of this study was to develop and test the feasibility and acceptability of a mother-daughter intervention, BEYOUTI, which aimed to prevent DEBs among adolescent females living with T1DM. Participants in this study found the intervention to be both feasible and acceptable. The single two-hour intervention session design provided participants with information on DEBs in T1DM, deciphering media, body image, self-esteem, and improved mother-daughter communication. BEYOUTI was developed by the PI, in conjunction with a mother-daughter dyad in which the adolescent daughter was living with T1DM.

Participants were highly enthusiastic about the intervention. Participants provided positive verbal feedback regarding interactive components of the intervention, audiovisual supplements, and involvement of both mothers and daughters in the intervention design. Even though some daughters noted a degree of trepidation about spending time with their mothers at the outset of the intervention, which may be a cultural variant, written and verbal responses post intervention were overwhelmingly positive.

The primary goal of this study was intervention development and to examine feasibility and acceptability of the intervention by the target population. Outcome measures of interest to this study were the EAT-26 a measure of DEB risk, the Rosenberg self-esteem scale a measure of self-esteem, the Body Esteem Scale (BES) a measure of body image, the Major Depression Inventory (MDI) a measure of depression, and the maternal relationship scale of the Inventory of Parent and Peer Attachment (IPPA) a measure of mother-daughter relationship. Findings showed changes in the clinically desired direction on several outcome measures from pre to post intervention time points.

BES scores, a measure of body image, showed improvement for all participants at both the immediate post intervention and six-week post intervention time points. A decrease in EAT-26 scores, a measure of DEB risk, for all participants at the six-week post intervention time point was also promising. Although the sample size was small, making significant interpretation of statistics difficult and giving more weight to outliers, several paired t-test results showed statistically significant changes post intervention. Mothers had some of the most significant changes in outcome measures at the post intervention time points, which may be critical in changing home environments and in their ability to assist their daughters in building up traits that may prevent the development of DEBs.

Qualitative findings indicated that the intervention was well received by the target population and that participants found the intervention valuable and helpful. Participants reported gains from the intervention, which included improved communication, improved ability to decipher media, and improved self-esteem. At the post intervention time point the majority of mothers set goals of improving communication with their daughters. Daughters also set goals of improved communication, but also desired better scrutiny of media messages, and improvement in their home diabetes management. All of these goals target some aspect of the desired outcomes. Interestingly, some daughters set post intervention goals to improve diabetes care and hemoglobin A1c values when these were not the focus of the education. However, both areas are critical in prevention of negative health outcomes related to DEBs among adolescents with T1DM. At the six-week post-intervention tiem point, both mothers and daughters affirmed that communication at home was improved.

The adolescent females that participated in this study had a higher return rate of six-week post questionnaires than their mothers (nine as compared to the six returned by mothers). Including both mothers and daughters in the intervention appeared to enhance post intervention goals at home. Several of the participating daughters noted that they and their mothers were working on communication improvement at home after the intervention.

In conclusion, the BEYOUTI intervention was found to be feasible and findings indicated a high acceptability by both mothers and their daughters living with T1DM. Findings from this study may be helpful to health care providers who are caring for adolescent females with T1DM as a point of possible intervention. Education about DEBs in T1DM along with family skill building to strengthen factors such as mother-daughter communication, body image, and self-esteem may prevent the development of DEBs in this

population and thus prevent negative health outcomes associated with DEBs among adolescent females living with T1DM. Findings from this study may also inform future research that focuses on prevention education in this population. Prior to this research there were no interventions targeting prevention of DEBs within this population. This program of research appears to be unique in its aim to prevent the development of DEBs among adolescent females living with T1DM. This study provides important information and the results are promising. The next step in the program of research is to refine the intervention and to determine effect size in a controlled pilot study.

Limitations

This study had some limitations that can be addressed through future research. The primary limitation was the small sample. The original enrollment goal was 20 mother-daughter pairs and although 24 mother-daughter dyads filled out informational sheets and expressed interest in the study only 10 pairs ultimately participated in the study. The long length of time from recruitment to intervention participation and the use of only one study site likely limited the sample size. However, 10 dyads were adequate for evaluating feasibility and acceptability of the intervention. As participants suggested, future research recruitment strategy may be improved through large planned activities for this population such as diabetes camps or other organized diabetes events.

Another limitation of the study was the homogeneity of the sample, which was entirely Caucasian. Thus, other ethnic groups may not find the intervention acceptable. Adding diversity to the sample population would be a goal for future studies. Also, this study used no biophysical outcome measures and only followed study participants for six-

weeks post intervention. Future studies should use biomarkers, such as HgbA1c, and follow participants for a longer period of time.

The research also appeared to have more affect on significant changes in desired outcome measures for mothers. A larger sample size is needed not only to verify findings, but involvement of more adolescents in refinement of the intervention and inclusion of content and activities that are relevant to daughters is suggested. Longitudinal research is also suggested, as it may be that effect on mothers may in fact change home environmental factors and maternal relationship enough to have lasting effect on daughters within a household or family. Finally, a sensitive measure is needed to examine changes in communication at home for both daughters and mothers. Future research should include a measure of communication or home environment.

Recommendations for Future Research

For the adolescent female living with T1DM, the risk of DEBs is higher than in general adolescent populations (Hsu et al., 2009; Jones et al., 2000; Nielsen, 2002; Pinar, 2005). DEBs among this population result in higher rates of negative health outcomes that include retinopathy, nephropathy, and premature death (Affenito et al., 1997; Bryden et al., 1999; Crow et al., 1998; Daneman et al., 1998; Goble-Fabbri et al., 2008; Neilson et al., 2002; Neumark-Sztainer et al., 2002; Olinder et al., 2009; Takii et al., 1999; Takii et al., 2008). Insulin omission, the most common form of DEB among adolescent females living with T1DM causes both significant rises in HbA1c and negative health outcomes such as nephropathy, retinopathy, and premature death (Bryden et al., 1999; Goebel-Fabbri et al.; Maharaj et al., 2003; Takii et al. 1999; Takii et al., 2008). Given the high rate of DEBs and

insulin omission among adolescent girls with T1DM (Gobel-Fabbri et al.), the high rate of negative health outcomes (Gobel-Fabbri et al.), and the possible contribution of risk factors to strengthen or prevent onset of DEBs in this population (Olmsted et al., 2008), intervention research targeting prevention should continue.

Longitudinal research, which utilizes biophysical and psychosocial outcome measures, includes the family in intervention, and aims to strengthen preventive factors, must continue. An intervention like BEYOUTI, which targets both mothers and daughters, is an ideal way to move forward into longitudinal research in multiple settings to see if indeed development of DEBs can be prevented through strengthening protective factors, as has been suggested in previous research (Olmsted et al., 2008). Consideration should be given to implementing prevention interventions prior to adolescence, as development of strong mother-daughter communication and improved knowledge of risks may have more impact if provided earlier on in diabetes care. Pediatric diabetes centers with a strong foundation of research in the area of DEBs in adolescent females with T1DM would be ideal partners in development and execution of such research.

BEYOUTI was well received and implementation was feasible. With minor edits to instruments, some changes in recruitment procedures, and refinement of measures and discussion topics BEYOUTI would be ready for the next phase of this program of research: a controlled pilot study to determine effect size. The encouraging findings from this development, feasibility, and acceptability study suggest that more research is warranted.

Implications for Practice

Strong correlations between BMI, self-esteem, body image, maternal eating attitudes and body image, parental relationships, DEBs, and HbA1c elevations have been clearly established (Colton et al., 2007; Engstrom et al., 1999; Goebel-Fabbri et al., 2008; Kahn & Montgomery, 1996; Olmsted et al., 2008; Neumark-Sztainer et al., 2002; Pollock-Barziv & Davis, 2005). Health care providers who treat adolescent females living with T1DM need to recognize the importance of the mother-daughter relationship, the acceptability of receiving information about DEBs and risk factors, the strong desire of both mothers and daughters to improve their own health outcomes, and the strong desire of both mothers and daughters to improve their own relationship. Strengthening protective factors for prevention of DEBs in adolescent females with T1DM should begin early in their diabetes care and be included in all interactions with their health care providers. Simple educational activities can be provided in a multitude of settings and can be easily incorporated into the educational practices of pediatric endocrinology clinics. Involving the entire family in this process and strengthening mother-daughter relationships may be key to the prevention of DEB development.

This study indicated that mothers and daughters have a desire to improve their health and will actively participate in activities outside of routine health care appointments to achieve this goal. Both mothers and daughters lacked knowledge about DEBs and insulin omission and their negative impact on health outcomes for the adolescent living with T1DM. Adolescent girls and their mothers have a desire for information about deciphering media, improving self-esteem and body image, and on improving home communication.

For health care providers who already treat adolescent females with both T1DM recognized risk factors for development of DEBs like depression, elevated BMI, poor self-esteem, poor body image, or difficulties in the mother-daughter relationship, early screening for DEBs and open conversations with patients and families should be encouraged. Ultimately, prevention will result in improved diabetes health outcomes for adolescent females, decreased overall health care costs, and possibly an improved quality of life.

Outcomes of this Study

In conclusion, the following goals of this study were met:

(1) Development a mother-daughter group intervention, BEYOUTI, to enhance mother-daughter communication, self-esteem, and body image.

(2) Feasibility of BEYOUTI was established through use of a single intervention session at two intervention sites.

(3) BEYOUTI was highly accepted by both mothers and daughters. Both groups responded positively to the intervention as evidenced by responses to pre/post questionnaires. Participants set home goals for decreasing risk factors at home.

(4) Changes in the clinically desired direction were seen on outcome measures of interest to the study. Improvement in body image as measured as BES was noted immediately post and at the six-week follow up. The measure of overall DEB risk, EAT-26 score, was lowered post intervention. Daughters showed improved IPPA scores, indicating better mother-daughter relationship at post-intervention. Mothers showed improvements in body image and decreases in DEB risk post-intervention.

APPENDIX A

MOTHER-DAUGHTER LOGIC MODEL

SITUATION	INPUTS	OUTPUTS		OUTCOMES -- IMPACT		
		Activities	Participation	Short Term	Medium Term	Long Term
Adolescent females with T1DM who experience problems with parental communication, in particular problems with their mother, and who perceive an altered body image and have low self-esteem are at increased risk for engaging in DEB. Insulin omission, a life-threatening weight reduction strategy that is unique to this population, is the most common DEB for this group of adolescents.	Nurse, Nurse Practitioner, hospital-based endocrinology clinics, diabetes care team. Campus based researchers to support intervention development, implementation and evaluation guidance and expertise. Funding resources to support intervention development and evaluation. Human and in-kind resources that support the intervention program.	Nurse Practitioner - led Mother and Daughter Intervention development: -Education about T1DM and disordered eating - Interactive activities focused on factors that are protective for disordered eating behavior: mother/daughter communication; self-esteem and perception of body image focused content.	Adolescent females with T1DM and their mothers who are: -At-risk for DEB -Unaware of physical or emotional health problems associated with disordered eating behavior -Have the potential to prevent disordered eating behavior and associated health problems.	Adolescent females with T1DM and their mothers increase knowledge about T1DM, insulin omission, and DEB; increased awareness of importance of self-esteem and body image on health; acquisition of skills to enhance mother-daughter communication.	Engagement in healthful behaviors increased Increased mother-daughter communication Enhanced self-esteem Improved perception of body image	Prevention/cessation of disturbed eating behaviors (i.e.: insulin omission) Improved glycemic control (i.e.: HgbA1C)

ASSUMPTIONS

Low-self esteem, low body image, and ineffective mother-daughter communication contribute to development of DEB. Mothers of adolescent girls with T1DM and Adolescent girls with T1DM lack information and may be unaware of the relationship between insulin omission and DEB behavior and the negative effects of body image, self-esteem, and maternal relationship on DEB. Guided mother-daughter interactions focusing on body image, self-esteem and communication will positively affect these variables; body image, self-esteem, maternal-daughter relationship, DEB risk, insulin omission, and HbA1c levels. Adolescent girls with T1DM and their mothers want to reduce risk for development of DEB.

EXTERNAL FACTORS

Health care system; Community; Media; Family

APPENDIX B

MEASURES

Rosenberg Self-Esteem Scale (Rosenberg, 1965)

The scale is a ten-item Likert scale with items answered on a four-point scale - from strongly agrees to strongly disagree. The original sample for which the scale was developed consisted of 5,024 High School Juniors and Seniors from 10 randomly selected schools in New York State.
Instructions: Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle **SA**. If you agree with the statement, circle **A**. If you disagree, circle **D**. If you strongly disagree, circle **SD**.

On the whole, I am satisfied with myself.	SA	A	D	SD
At times, I think I am no good at all.	SA	A	D	SD
I feel that I have a number of good qualities.	SA	A	D	SD
I am able to do things as well as most other people.	SA	A	D	SD
I feel I do not have much to be proud of.	SA	A	D	SD
I certainly feel useless at times.	SA	A	D	SD
I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
I wish I could have more respect for myself.	SA	A	D	SD
All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
I take a positive attitude toward myself.	SA	A	D	SD

The scale may be used without explicit permission. The author's family, however, would like to be kept informed of its use:
The Morris Rosenberg Foundation
c/o Department of Sociology
University of Maryland
2112 Art/Soc Building
College Park, MD 20742-1315

Major Depression Inventory

Please circle the answer that best describes you.

	No time at all	Some of the time	Less than half the time	More than half the time	Most of the Time	All the Time
Have you felt low in spirits or sad?	0	1	2	3	4	5
Have you lost interest in your daily activities	0	1	2	3	4	5
Have you felt lacking in energy and strength?	0	1	2	3	4	5
Have you felt less self-confident?	0	1	2	3	4	5
Have you had feelings of guilt?	0	1	2	3	4	5
Have you felt that life wasn't worth living?	0	1	2	3	4	5
Have you had difficulty in concentrating, e.g. when reading or watching television?	0	1	2	3	4	5
Have you felt very restless?	0	1	2	3	4	5
Have you felt subdued or slowed down?	0	1	2	3	4	5
Have you had trouble sleeping at night?	0	1	2	3	4	5
Have you suffered from reduced appetite?	0	1	2	3	4	5
Have you suffered from increased appetite?	0	1	2	3	4	5

***The MDI is a standardized depression instrument recommended by the World Health Organization and it is open to public use. No permission is needed for use in practice or research.

Body-Esteem Scale for Adolescents and Adults

Indicate how often you agree with the following statements ranging from "never" (0) to "always" (4). Circle the appropriate number beside each statement.

	Never	Seldom	Some-times	Often	Always
I like what I look like in pictures.	0	1	2	3	4
Other people consider me good looking.	0	1	2	3	4
I'm proud of my body.	0	1	2	3	4
I am preoccupied with trying to change my body weight.	0	1	2	3	4
I think my appearance would help me get a job.	0	1	2	3	4
I like what I see when I look in the mirror.	0	1	2	3	4
There are lots of things I'd change about my looks if I could.	0	1	2	3	4
I am satisfied with my weight.	0	1	2	3	4
I wish I looked better.	0	1	2	3	4
I really like what I weigh.	0	1	2	3	4
I wish I looked like someone else.	0	1	2	3	4
People my own age like my looks.	0	1	2	3	4
My looks upset me.	0	1	2	3	4
I'm as nice looking as most people.	0	1	2	3	4
I'm pretty happy about the way I look.	0	1	2	3	4
I feel I weigh the right amount for my height.	0	1	2	3	4
I feel ashamed of how I look.	0	1	2	3	4
Weighing myself depresses me.	0	1	2	3	4
My weight makes me unhappy	0	1	2	3	4
My looks help me to get dates.	0	1	2	3	4
I worry about the way I look.	0	1	2	3	4
I think I have a good body.	0	1	2	3	4
I'm looking as nice as I'd like to.	0	1	2	3	4

Attachment: Permission to use Body Esteem Scale

Subject	**Body Esteem Scale**
From	Beverley K. Mendelson
To	tschmitt2002@gmail.com
Sent	Wednesday, May 30, 2007 7:03 AM

Hello, Here are copies of the following:

- a paper on the latest version of the Body Esteem Scale for Adolescents and Adults (bescale);
- the manual for the measure (bemanual), which has a copy of the scale in Appendix 1;
- a paper that used an earlier version of the scale, but which may interest you nonetheless (beseimp).

If you have difficulty reading the files, please let me know what word processor (and version) you use.

If you end up using the measure, I would appreciate receiving a report of any research you conduct with it.

Thanks for your interest in our work.
BKM

EAT-26 Questionnaire: Fill in one response for each of the questions below.

	Always	Usually	Often	Sometimes	Rarely	Never
1. Am terrified about being overweight.	O	O	O	O	O	O
2. Avoid eating when I am hungry.	O	O	O	O	O	O
3. Find myself preoccupied with food.	O	O	O	O	O	O
4. Have gone on eating binges where I feel that I may not be able to stop.	O	O	O	O	O	O
5. Cut my food into small pieces.	O	O	O	O	O	O
6. Aware of the calorie content of foods that I eat.	O	O	O	O	O	O
7. Particularly avoid food with a high carbohydrate content (i.e. bread, rice, potatoes, etc.)	O	O	O	O	O	O
8. Feel that others would prefer if I ate more.	O	O	O	O	O	O
9. Vomit after I have eaten.	O	O	O	O	O	O
10. Feel extremely guilty after eating.	O	O	O	O	O	O
11. Am preoccupied with a desire to be thinner.	O	O	O	O	O	O
12. Think about burning up calories when I exercise.	O	O	O	O	O	O
13. Other people think that I am too thin.	O	O	O	O	O	O
14. Am preoccupied with the thought of having fat on my body.	O	O	O	O	O	O
15. Take longer than others to eat my meals.	O	O	O	O	O	O
16. Avoid foods with sugar in them.	O	O	O	O	O	O
17. Eat diet foods.	O	O	O	O	O	O
18. Feel that food controls my life.	O	O	O	O	O	O
19. Display self-control around food.	O	O	O	O	O	O
20. Feel that others pressure me to eat.	O	O	O	O	O	O
21. Give too much time and thought to food.	O	O	O	O	O	O
22. Feel uncomfortable after eating sweets.	O	O	O	O	O	O
23. Engage in dieting behavior.	O	O	O	O	O	O
24. Like my stomach to be empty.	O	O	O	O	O	O
25. Enjoy trying new rich foods.	O	O	O	O	O	O
26. Have the impulse to vomit after meals.	O	O	O	O	O	O

Inventory of Parent and Peer Attachment (IPPA) Maternal Subscale

This part asks about your feelings about your relationships with your mother. Indicate how often you agree with the following statements ranging from "Almost Never or Never True" (0) to "Almost Always or Always True" (4). Please read each statement and circle the ONE number that tells how true the statement is for you now.

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
1. My mother respects my feelings.	0	1	2	3	4
2. I feel my mother does a good job as my mother.	0	1	2	3	4
3. I wish I had a different mother.	0	1	2	3	4
4. My mother accepts me as I am.	0	1	2	3	4
5. I like to get my mother's point of view on things I'm concerned about.	0	1	2	3	4
6. I feel it's no use letting my feelings show around my mother.	0	1	2	3	4
7. My mother can tell when I'm upset about something.	0	1	2	3	4
8. Talking over my problems with my mother makes me feel ashamed or foolish.	0	1	2	3	4
9. My mother expects too much from me.	0	1	2	3	4
10. I get upset easily around my mother.	0	1	2	3	4
11. I get upset a lot more than my mother knows about.	0	1	2	3	4
12. When we discuss things, my mother cares about my point of view.	0	1	2	3	4
13. My mother trusts my judgment.	0	1	2	3	4
14. My mother has her own problems, so I don't bother her with mine.	0	1	2	3	4
15. My mother helps me to understand myself better.	0	1	2	3	4
16. I tell my mother about my problems and troubles.	0	1	2	3	4
17. I feel angry with my mother.	0	1	2	3	4
18. I don't get much attention from my mother.	0	1	2	3	4
19. My mother helps me to talk about my difficulties.	0	1	2	3	4
20. My mother understands me.	0	1	2	3	4
21. When I am angry about something, my mother tries to be understanding.	0	1	2	3	4
22. I trust my mother.	0	1	2	3	4
23. My mother doesn't understand what I'm going through these days.	0	1	2	3	4
24. I can count on my mother when I need to get something off my chest.	0	1	2	3	4
25. If my mother knows something is bothering me, she asks me about it.	0	1	2	3	4

Permission to Use IPPA:

Attachment IPPA Permission to Use

Mark T. Greenberg Ph.D.
Bennett Chair of Prevention Research
Director, Prevention Research Center
College of Health and Human Development

PHE 814 863-0112
FAX 814 863-7963
Email: mxg47@psu.edu

Dear Colleague:
Thank you for your request for information concerning the research that we have conducted on adolescents' perceived attachment to peers and parents. First, we have enclosed a copy of the article that you requested which appeared in the Journal of Youth and Adolescence in 1987. This article introduced the Inventory of Parent and Peer Attachment. We have also enclosed an information scoring manual that provides information on our factor analyses of the scales, information on reliability of the scales, and a scoring key.
Since the study reported in the1987 paper was carried out, we have revised the IPPA. In her dissertation, Gay Armsden modified the IPPA in order to separately assess perceived quality of attachment to mothers and fathers (instead of parents together). We have enclosed a copy of this unpublished measure, The IPPA (Mother, Father, Peer Version), and a page of scoring information. The measures have been used in a study of over 400 college students and Gay has found (with minor changes) that most of the same items fall on the same factors for mothers and father separately that we found in the factor analysis of parents together on the IPPA. We have included scoring for this version (both total score for Mother, Father, and Peer) as well as subscale scores.
If you have further questions, please feel free to call (814 863-0112) or e-mail Gay Armsden at (armsden@seanet.com), or write. If you decide to use our measures in data collection, please let us know. We would also appreciate a copy of papers that utilize the measure(s).

Sincerely,
Mark T. Greenberg, Ph.D.
Professor

Gay Armsden, Ph.D.
Research Consultant

APPENDIX C

INTERVENTION OUTLINE AND HANDOUTS

Mother-Daughter Intervention Outline: Preventing disordered eating, improving body image, self-esteem, and mother-daughter communication

INTERVENTION

1. Mothers and daughters arrive, are greeted, check in, get papers/handouts, and fill out the questionnaires they get SEPERATELY and anonymously.

2. Gather together in one room (no more than 5-6 pairs of mothers and daughters)

3. **TOPIC 1 – INFORMATION ON Eating disorder facts (Simple facts) Presented in Power Point slides with references. TIME – 15 minutes**

4. **TOPIC 2 – LEARNING TO BE MEDIA SAVVY – This presentation will be first a video, then a PowerPoint, then discussion and interactive game (in this order) – Time 30 minutes.**

- **Video 1** – DOVE campaign for beauty add on the magic of media. (FOR YOU TO VIEW IT GO TO - http://www.dove.us/#/features/
- **Powerpoint** – Love your Body campaign of the NOW organization.
- **Discussion:** How did viewing the video make you feel? What did you learn? How about the power point? What else does media sell to girls (think Pink)?
- **ACTIVITY:** Each Mom and Daughter will do the following activity on their own and then come together to compare:

Deconstructing Print Media

Purpose: To gain an understanding and look critically at images presented in magazines. Pick out 2 or so ads that stand out. List what product each ad is selling (in one column) and what other ideas are being sold (in the other column).

- Each mom will get a hand out on 5 tips to raising media savvy kids pertaining to both boys and girls.
- Each daughter will get a sheet on 10 tips on how the media packages 'girlhood' to girls.

5. **TOPIC 3 – FREE ME – SELF ESTEEM BUILDING** – Time 20 minutes.

- **Video from Dove** – Self-Esteem in Girls - http://www.youtube.com/watch?v=IWzbIVwGd1E
- **Talking Points/DISCUSSION:** Mom's, how do we feel about yourselves? Do our girls hear us? Do we talk to our girls and listen to them about their lives, concerns, and bodies or do we talk at them, are we too busy to even discuss it? Do they know our own concerns? Daughters – Do you think your mothers like themselves?
- **Activity:** Each participant will on their own write down three things I am good at and three things I like about myself. Also, each will write about the other – three things they think the other is good at and like about them. Then share with each other (mom/daughter)?
- **Activity 2:** DAUGHTERS - When I think I can't do something I need you to _____ for me? (Sky is the limit for what daughters can ask of mothers, can include 'leave me alone') BOTH – When I am being negative about myself will you _____ for me?

6. **TOPIC 4 – HEAR ME, a work on mother-daughter communication**– 15 minutes.

- Facts about Teens (Presented):

1. They want parents to 'listen' more and lecture less.
2. They wish parents could spend time in their shoes.
3. They want parents to be proud of them.
4. They want more trust and responsibility.
5. This generation is more depressed and is dealing with more information than any generation before them.
6. They need help and genuine understanding about the amount of stress they have in school, performing, friends, technology, communication, etc.
7. They wish their parents did not expect them to be perfect
8. The social aspect of their lives, whether public/private/ or homeschooled is BIG!

(Excerpt from an article where a teenager shared about her thoughts/wishes parents knew certain things.)

EXERPT - "I also wish my parents knew of the all the different maturity levels of kids in my school that I come in contact with, in classes, in the hallways, etc. Most people (ex. me and my friends) know how to deal with situations because we face them every day; we know what's right and wrong. But, there is so much peer pressure to break the rules and do what they know is wrong. Now it's more than just getting a gold star taken away or being put in time out; it's breaking the law and going to jail and getting expelled. All of these things can have a major effect on you and your life. I wish my parents knew how cruel some people can be and how hard it is to make friends that you can trust and keep a good reputation. Sometimes, no matter how hard you try, you could end up being the victim of rumors. The thing is, the rumors are almost never true, but it doesn't matter because people will spread them around just to have something to talk about. I know a girl at my school that is a very nice girl and she's had rumors spread about her all year. The most recent was that she's pregnant by some senior and that she sleeps around. People treat her horribly and you can see how upset it makes her. She's gone through a lot and dealt with all of the rumors and I look up to her for being so brave/strong about it; I know I would be devastated. I wish my parents knew how hard it is—in the social aspect of things just as much as the educational part." – From Heart of the Matter Online May 2010 - http://heartofthematteronline.com/what-teens-wish-their-parents-knew

- **Discussion:** Do you have a 'safe' time to talk at home where mothers listen, do not interrupt, do not judge, do not give advice, and keep the conversation completely private.
- Also, Mom's will share 1 thing (written or verbal) with their daughter about themselves and what that experience was like for the mom.

Handout 1
Tips for Parents: Self-Esteem and Body Image

Raising kids in a healthy environment is hard. Media grabs for their attention at every step. The following is a list of tips for parents from Lyn Mikel Brown, Sharon Lamb and mark Tappan and also some links to great websites and resources for parents and daughters.

Websites
List of resources from PackagingGirlhood.com -
http://www.packaginggirlhood.com/resources.html

Hardy Girls Healthy Women - http://www.hardygirlshealthywomen.org/content/tip-sheets

Dove Website with Features, Interactive Activities, and Videos for Mom's and Daughters -
http://www.dove.us

Five Tips for Raising Media Savvy Kids
Lyn Mikel Brown, Ed.D., Sharon Lamb, Ed.D., and Mark Tappan, Ed.D
Your child's world is changing every second, but the more things change, the more they stay the same. In *Packaging Girlhood: Rescuing Our Daughters from Marketers' Schemes* (Lamb & Brown, St. Martin's Press, 2006), we give examples of the kind of stuff your daughter faces every day in her world. In *Packaging Boyhood: Saving Our Sons from Superheroes, Slackers, and Other Media Stereotypes* (Brown, Lamb & Tappan, St. Martin's, 2009) we do the same for boys. While the messages are different for your son, they're still everywhere and just as narrow as those directed at your daughter.
Below we offer five tips for talking with your children about media and marketers' attempts to influence them. Are there paths through the forest of sexy diva princess pink shopping hotties or tough, wild, hard-partying, cocky players? There sure are. And whether you're a mom or dad, you can raise a child who can make her or his own way through the prefabricated, prepackaged, homogenized world that marketers are trying to sell.
1.) **Do your own work.** This is a lot harder than it might sound, which is why we put it first. Doing your own work means becoming familiar with what's out there. Watch what your children watch; listen to their music; read their books and magazines, so that you know what messages this world sends them. It also means being aware of your emotional response to the things you see. It's important that you take the time to name and understand what makes you so uncomfortable, so that you can take care of your own feelings before trying to understand theirs.
2.) **Listen to what your daughter or son likes and why they like it.** Ask them about their world. Don't assume you know why she loves shopping at Victoria's Secret, or why he loves playing *Halo*. You might be surprised by their answers. She may love the power she experiences when wearing those clothes or she may enjoy the grown up feeling they give her. He may like the freedom of getting out his aggression in a violent shoot-em-up game, or he may be really enthralled with the storyline and characters. Only when you understand where you child's really coming from can you talk about his or her desires and your concerns.

3.) **Bring them the world on your terms, from your broader view.** Reflect on what they say. Share your discomfort. Help them notice the bigger picture, for example, how looking hot like the latest teen idol can be fun but also connects her with a lot of other stuff she might not have noticed or thought about, or, how acting like a cool slacker dude may have a negative impact on his success in school and thus his future hopes and dreams. Wonder aloud about more general patterns you see, like how all those little purses hanging from everything might make girls think that all girls, even three year olds, are into shopping, or how the over the top action in every form of media might make boys think that they have to be wild and crazy all of the time.

4.) **Start Young.** You can help your four or five year old develop a vocabulary and a way of talking that will set the stage for conversations for years to come. What better way to introduce the word "stereotype" to your daughter or son than by walking through the girls' and boys' departments of any clothing store, or the "blue" and "pink" aisles of any toy store? If you question, they'll question. Model a way of seeing and talking about the different choices presented to your children. Ask her to imagine stories other than romance, shopping sprees, or saved by the prince versions she'll see over and over. Ask him to imagine stories other than superheroes or guys that need to fight to teach someone somewhere a lesson. Help your children notice when their world is becoming smaller and more limited, so they can step back and say, "That's silly. That's a stereotype. Real girls and boys aren't always like that."

5.) **Open up possibilities and create options.** Our job as parents is to encourage our daughters and sons to be all they can be and to introduce them to a world of possibilities. Increase the time you spend trying new activities that challenge your child's imagination. Seek mind-opening books, TV shows, and music that aren't marketed to "boys" or "girls" but to all kids. Defy pink. Resist explosions. And offer girls and boys the possibility of action without violence, pretty without sexy, and also, the full rainbow of colors.

Handout 2:
Packaging Girlhood: 10 Tips for Girls

By *Packaging Girlhood: Rescuing our Daughters from Marketers' Schemes* Sharon Lamb, Ed.D and Lyn Mikel Brown, Ed. D.

1. Face the Facts. Most girls want to believe that they are independent thinkers and that marketers and the media won't be able to influence them. But realize that marketers are spending billions of dollars every year to try and trick you and they wouldn't spend that much if it doesn't work and work often. So, perhaps the first thing a girl needs to do is to believe that somehow, someway those marketers may be getting under her skin. Once you realize that this is happening, it is harder and harder for the media and marketers to claim you.
2. Know The Same Old Same Old. The same old stereotypes are brought up and sold to you again and again. Do you see a girl on TV in pink with a bow in her hair and pearls? Do you see yet another movie that suggests girls are mean and can't get along? Do you see a girl watching while the boy gets to drive? Is the message in the book you're reading that a girl is nothing without a boyfriend? That she hates math? Does a makeover or shopping spree really fix everything? These are the same old stereotypes we see over and over again. We read about them. We hear them in lyrics of songs. Know them so you know how to resist them.
3. Think of Counter-Examples. One way to resist is through counter-examples. You may know girls who like and are good at math. You may have an aunt who's an engineer or who plays the horn in an orchestra. You may know specifically that girls really can get along when you think about you and your best friend. Remember these examples and bring them up when you hear the people around you reduce girls to stereotypes.
4. Look For Product Placement Invasions. This is tricky because the marketers are slipping in product information everywhere you look in subtle and almost undetectable ways. Don't be fooled. So, for example, if you're watching the new video of Cheaper by the Dozen 2 and you see the scene with Neutrogena makeup, yell (in your mind or out loud) PRODUCT PLACEMENT! And then swear not to buy that product.
5. Refuse To Type-Cast Yourself. Everywhere people may be asking you to sum yourself up as a girly girl, a tomboy, a goth, a prep, a jock. Don't do it. Keep in your mind a picture of yourself as a super complex human being. Make a list of all the things you are, do and love. See? No one can type cast you! When you see those magazine contests that ask you to type yourself by answering a bunch of questions, leave them be. They're not you--and they'll probably tell you to buy some product to fix whatever they think is wrong with you in the end.
6. Stop Calling Things Girly or Boy Stuff. If you participate in labeling things girl or boy you may end up calling all sorts of things that girls love to do and are good at "boy" things and giving messages to other girls and boys that the world is not open to them, that there's something wrong with them if they try things from the "other side."

7. Point Things Out to Other Girls. Now that you know, it's your responsibility to share these new things you're observing with other girls, boys and even your parents and teacher!
8. Don't Let the Media Turn You Away From Your Parents as Valuable Resources. Lots of media and marketers want to set up your parents as the opposition, as the ones who say no to fun. Then they can market to you directly and get you to buy things just to be rebellious. So teach your parents this way of seeing the world and get their true opinions of the music you listen to, the books and magazines you read, and the shows you watch.
9. Girlcott The Really Awful Stuff. If you see something really awful, like the Abercrombie and Fitch T-shirt that read "Who needs a brain when you have these" across the chest, start your own protest. Get other girls who are angry too and work together: send instant messages, set up a Facebook page posting your ideas, decide on a tactic whether it's a protest outside the store or a letter writing campaign, then do it. And remember to call the newspaper and tell them you're doing it too!
10. Enjoy Pink, Pretty, Glam Things on occasion, but never let it be the sum of who you are. We love chocolate but we don't eat it 24/7!!!

APPENDIX D

IRB DOCUMENTS

Institutional Review Board
Health Sciences Section

University of Missouri-Columbia

190 Galena Hall/ Dc074.00
905 Hitt Street
Columbia, MO 65212
PHONE (573) 882-3181
FAX (573) 884-4401
E-MAIL: irb@missouri.edu
WEB: www.research.missouri.edu/hsirb

July 21, 2010

Terri Schmidt MSN
2454 E. Greenwood
Springfield, MO65804

Dear Terri Schmidt,

Regarding your application for approval of the research project, ***Development and pilot testing of an intervention to reduce the risk for disordered eating behavior (DEB) among adolescent girls with Type 1 Diabetes Mellitus (T1DM)***, the Health Sciences Institutional Review Board (HS IRB) took the following action:

a. The principal investigator on this study is responsible for all aspects and conduct of this study.
b. Approved your study through expedited review [as codified under 45 CFR 46.110 (f) (6, & 7)] on July 20, 2010.
c. Found this Grant to impose minimal risk to the research participant.
d. Requires that the approved consenting personnel obtain the informed written consent of each research participant.
e. Reviewed and approved the final version of the consent form on July 21, 2010. Please use the approved consent displaying the signed IRB approval box when consenting patients.
f. Reviewed and approved the final version of the assent form on July 21, 2010. Please use the approved assent displaying the signed IRB approval box when obtaining assent.
g. Under 45 CFR, 46.404, written child assent required if determined capable by the investigator. One parent signature is required on the consent form.
h. Reviewed and approved any questionnaires or surveys that were submitted with your application.
i. Reviewed and approved any recruitment materials that were submitted with your application.
j. Reviewed and approved the HIPAA Authorization on July 21, 2010.
k. The HS IRB has determined that the degree of risk is such that the approval for this protocol will expire on July 20, 2011. A Continuing Review Report must be submitted a minimum of one month prior to this date.
l. Upon completion of the study a Completion Form must be submitted to the HS IRB office. If the closure is not documented on the Completion Form, you may close the study at the time of the annual review.

Please reference **IRB Project # 1170757** in all future communications regarding this project.

Pursuant to the HS IRB conflict of interest policy, investigators who are HS IRB members do not vote on protocols in which they are involved.

Death occurring in a study at this site must be reported to the HS IRB office within 24 hours of occurrence, whether or not the death is related to the study. All on-site serious adverse events meeting criteria must be reported to the HS IRB office within five (5) days of occurrence.

No change may be made in an approved protocol or recruitment materials unless the change is submitted to and approved by the HS IRB.

Do not depend on the HS IRB for your record keeping.

Sincerely,

Niels Beck, PhD
Chair

Comments Regarding Project #1170757

Review #93065

Comment Number: 300831 (04-05-2011)

Review Approved for Amendment sent on Apr 05, 2011:

To: tschmitt2002@gmail.com

CC: , hueskec@missouri.edu

Subject: HS IRB Project #1170757

Project Number:	**1170757**
Review Number:	**93065**
Project Title:	**Development and pilot testing of an intervention to reduce the risk for disordered eating behavior (DEB) among adolescent girls with Type 1 Diabetes Mellitus (T1DM)**
Principal Investigator(s):	**Schmitt, Terri L**
Primary Contact:	**Schmitt, Terri L**

Your amendment above has been approved. Please log into the eIRB to access any approved documents.

Comments Regarding Project #1170757

Review #93182

Comment Number: 307449 (06-23-2011)
Review Approved for CRR sent on Jun 23, 2011:
To: tschmitt2002@gmail.com
CC: , hueskec@missouri.edu
Subject: HS IRB Project #1170757

Project Number:	**1170757**
Review Number:	**93182**
Project Title:	**Development and pilot testing of an intervention to reduce the risk for disordered eating behavior (DEB) among adolescent girls with Type 1 Diabetes Mellitus (T1DM)**
Principal Investigator(s):	**Schmitt, Terri L**
Primary Contact:	**Schmitt, Terri L**
Review Interval:	**12 Month**
Approval Date:	**June 21, 2011**
Expiration Date:	**July 20, 2012**

Your continuing review above has been approved. Please log into the eIRB to access any approved documents.

Sincerely,

Niels Beck, PhD
Chair

UMKC SSIRB Approval

UMKC
UNIVERSITY OF MISSOURI
KANSAS CITY
Office of Research Services

November 10, 2010

Ms. Terri Schmitt
UMKC School of Nursing
2464 Charlotte Street
Kansas City , MO 64108

Dear Ms. Schmitt:

Your research protocol #SS10-12 entitled, "Disordered eating prevention in adolescent girls with Type 1 diabetes mellitus: a pilot intervention" was approved but restricted human subjects enrollment until revisions to several documents had been received and approved. Those revisions have subsequently been received.

The IRB grants full approval on the following documents:

-Research Protocol IRB #SS10-12
-Consent Form to Participate in a Research Study date stamped 11/10/10 to 8/19/11
-Consent Form to Participate in a Focus Group date stamped 11/10/10 to 8/19/11
-Assent Form to Participate in a Research Study date stamped 11/10/10 to 8/19/11
-Amendment #1 (Additional Site - Southwest Baptist University)
-Amendment #2 (Addition of Danita Rife to the Study Team)

This letter is to confirm that your application is now fully approved. You are granted permission to conduct your study as most recently described effective immediately. You must obtain signed written consent from all subjects. The stamped, approved Consent and Assent Forms must be utilized in your performance of this study. The study is subject to continuing review on or before 8/19/2011, unless closed before that date. It is your responsibility to provide a progress report prior to that date to avoid disruption of your research.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. If you have any questions, please feel free to contact me at 816-235-5370.

Sincerely,

Sheila Anderman, CIP, CIM
Research Protections Program Manager
UMKC Social Sciences
Institutional Review Board

UNIVERSITY OF MISSOURI-KANSAS CITY

March 11, 2011
Elctronic notification via e-mail

Terri Schmitt
UMKC School of Nursing
2464 Charlotte Street
Kansas City , MO 64108

Dear Ms. Schmitt,

Your Amendment dated: 01/31/2011 to research protocol IRB #SS10-12 entitled, "Development and pilot testing of an intervention to reduce the risk for disordered eating behavior (DEB) among adolescents with Type 1 Diabetes Mellitus (T1DM)" was given an expedited review by members of the UMKC Social Sciences Institutional Review Board.

The IRB approves your amendment dated: 01/31/2011 to research protocol IRB #SS10-12 as submitted. This is to confirm that your request has been approved. You are granted permission to conduct your study as revised effective immediately. The date for continuing review remains unchanged at 8/19/2011, unless closed before that date.

The IRB has approved the following changes:
-Removal of BMI greater than 85% as Inclusion criteria

Please note that any further changes to the study must be promptly reported and approved. Should you have any questions or require further information, please contact me at 816-235-6150; email: barrethr@umkc.edu.

Sincerely,

Rebekah Barreth, CIP
Compliance Officer
UMKC Social Sciences
Institutional Review Board

July 19, 2011
Electronic notification via e-mail

Terri Schmitt, MSN, APRN, FNP-BC
UMKC School of Nursing
2464 Charlotte Street
Kansas City , MO 64108

Dear Ms. Schmitt,

The UMKC Social Sciences Institutional Review Board has received the final progress report on your research protocol IRB #SS10-12 entitled, "Development and pilot testing of an intervention to reduce the risk for disordered eating behavior (DEB) among adolescents with Type 1 Diabetes Mellitus (T1DM)".

This letter is to confirm that your study is now closed. You may no longer have subjects enrolled and/or collect data under this protocol. Should you have any questions or require additional information, please feel free to contact me at 816-235-5927; fax 816-235-5602; email: umkcssirb@umkc.edu.

Sincerely,

SSIRB Administrative Office

APPENDIX E

CONSENT FORMS

CONSENT FORM TO PARTICIPATE IN A FOCUS GROUP

INVESTIGATOR'S NAME: **TERRI SCHMITT**
PROJECT # application 1170757

FOR HS IRB USE ONLY
APPROVED _____ HS IRB Authorized Representative Date **EXPIRATION DATE:** _____

Study Title: Disordered Eating Prevention in Adolescent girls with Type 1 Diabetes Mellitus: A Focus Group

INTRODUCTION

This consent may contain words that you do not understand. Please ask the investigator or the study staff to explain any words or information that you do not clearly understand.

This is a research study. Research studies include only people who choose to participate. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

Please take your time to make your decision and discuss it with your family and friends.

You and your daughter are being asked to take part in this study because your daughter has Type 1 Diabetes. We are looking for mother – daughter pairs where the daughters are between 13 to 18 years old and who have been diagnosed with Type 1, or Juvenile/Insulin dependent, diabetes for over 18 months.

This study is part of dissertation research for Terri Schmitt MSN, FNP-BC at the University of Missouri Kansas City.

In order for you and your daughter to participate in this study, it will be necessary to give your written consent.

WHY IS THIS STUDY BEING DONE?

The purpose of this research is to better understand how disordered eating risk (the risk a girl has of developing an eating disorder) in adolescent girls with Type 1 Diabetes can be affected through mother-daughter education.

This is a focus group to help design the intervention, meaning a small group of 4 to 6 people who work to lay out an education intervention to help teach adolescent girls and their mothers about self-esteem, body image, and communication.

This intervention is being developed because disordered eating is common in some adolescent girls with Type-1 Diabetes and currently there are no standards for prevention or screening for the development of disordered eating in adolescent girls with diabetes.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 6 people total (two to three mother-daughter pairs) will take part in this phase of study development at the University of Missouri. The focus group work time will only be a single 2-hour session.

WHAT IS INVOLVED IN THE STUDY?

Participants will be asked to attend and participate in a one-time 2-hour focus group to develop the intervention. You or your daughter may also contact the research team or be contacted after this one time focus group to clarify intervention activities that you help develop. Your participation is voluntary and all information provided will be kept anonymous at all times.

HOW LONG WILL I BE IN THE STUDY?

We think you and your daughter will be in the study for only the focus group.

You and your daughter can stop participating at any time. Your decision to withdraw from the study will not affect in any way your medical care and/or benefits.

If you decide to leave the study the information you have already provided will be kept anonymous and in a locked cabinet in the offices of Terri Schmitt FNP, until seven years after the study is completed.

WHAT ARE THE RISKS OF THE STUDY?

Attending the focus group may help enhance your and your daughter's feelings about yourself and your body. It may also make you or your daughter upset. If participating in the group does upset either of you, you may talk about your feelings afterwards, or you may stop participation at any time. It is likely that you or your daughter will not feel upset.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

If you and your daughter agree to take part in this study, there may or may not be direct medical benefit to you. You may expect to benefit from taking part in this research to the extent that you are contributing to medical knowledge. We hope the information learned from this study will benefit other adolescent girls with Type 1 Diabetes in the future.

The benefit of participation includes assisting researchers in understanding disordered eating in girls with Type 1 diabetes for future prevention and intervention. Participating in this study may or may not help you.

WHAT OTHER OPTIONS ARE THERE?

An alternative is to not participate in this research study.

WHAT ABOUT CONFIDENTIALITY?

You will get a copy of this form. The original signed form will be kept in a locked cabinet in the office of Terri Schmitt FNP, for at least 7 years. All study related documents will be labeled with a coded number to maintain confidentiality and all identifiable data will be removed. Only Terri Schmitt and her study team will have access to your information.

While every effort will be made to keep confidential all of the information you complete and share, it cannot be absolutely guaranteed. Individuals from the UMKC IRB and University of Missouri IRB (a committee that reviews and approves research studies), Research Protections Program and Federal Regulatory Agencies may look at records related to the study for quality improvement and regulatory functions. However, your name and contact information will not otherwise be attached to any of the study related documents.

WHAT ARE THE COSTS?

There are no costs to you.

WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

You and your daughter will receive a small gift bag worth approximately $10 upon attending the focus group.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary. You do not have to participate in this study. Your present or future care will not be affected should you choose not to participate. If you decide to participate, you can change your mind and drop out of the study at any time without affecting your present or future care in the University of Missouri system.

You will be informed of any significant new findings discovered during the course of this study that might influence your health, welfare, or willingness to continue participation in this study.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Health Sciences Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181 or the University of Missouri Kansas City Institutional Review Board at 816-235-1764.

You may ask more questions about the study at any time. For questions about the study or a research-related injury, contact Terri Schmitt at 417-209-2744.

A copy of this consent form will be given to you to keep.

WHERE CAN I GET MORE INFORMATION?

You can get more information at any time from:
Terri L. Schmitt MSN, APRN, FNP-BC
PhD Student UMKC School of Nursing
2454 E. Greenwood
Springfield, MO 65804
tschmitt2002@gmail.com
417-209-2744

SIGNATURE

I confirm that the purpose of the research, the study procedures, the possible risks and discomforts as well as potential benefits that I may experience have been explained to me. Alternatives to my participation in the study also have been discussed. I have read this consent form and my questions have been answered. My signature below indicates my willingness to participate in this study.

Subject/Patient*	Date
Legal Guardian/Advocate/Witness (if required)**	Date
Additional Signature (if required) (identify relationship to subject)***	Date

*A minor's signature on this line indicates his/her assent to participate in this study. A minor's signature is not required if he/she is under 7 years old. Use the "Legal Guardian/Advocate/Witness" line for the parent's signature, and you may use the "Additional Signature" line for the second parent's signature, if required.

**The presence and signature of an impartial witness is required during the entire informed consent discussion if the patient or patient's legally authorized representative is unable to read.

***The "Additional Signature" line may be used for the second parent's signature, if required. This line may also be used for any other signature which is required as per federal, state, local, sponsor and/or any other entity requirements.

"If required" means that the signature line is signed only if it is required as per federal, state, local, sponsor and/or any other entity requirements.

SIGNATURE OF STUDY REPRESENTATIVE

I have explained the purpose of the research, the study procedures, identifying those that are investigational, the possible risks and discomforts as well as potential benefits and have answered questions regarding the study to the best of my ability.

_____ _____

Study Representative**** **Date**

****Study Representative is a person authorized to obtain consent. Per the policies of the University of Missouri Health Care, for any 'significant risk/treatment' study, the Study Representative must be a physician who is either the Principal or Co-Investigator. If the study is deemed either 'significant risk/non-treatment' or 'minimal risk,' the Study Representative may be a non-physician study investigator.

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

INVESTIGATOR'S NAME: **TERRI SCHMITT**
PROJECT # application 1170757

FOR HS IRB USE ONLY
APPROVED _____ HS IRB Authorized Representative Date **EXPIRATION DATE:** _____

Study Title: Disordered Eating Prevention in Adolescent girls with Type 1 Diabetes Mellitus: A Pilot Intervention

INTRODUCTION

This consent may contain words that you do not understand. Please ask the investigator or the study staff to explain any words or information that you do not clearly understand.

This is a research study. Research studies include only people who choose to participate. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

Please take your time to make your decision and discuss it with your family and friends.

You and your daughter are being asked to take part in this study because your daughter has Type 1 Diabetes. We are looking for mother – daughter pairs where the daughters are between 13 to 18 years old and who have been diagnosed with Type 1, or Juvenile/Insulin dependent, diabetes for over 18 months.

This study is part of dissertation research for Terri Schmitt MSN, FNP-BC at the University of Missouri Kansas City.

In order for you and your daughter to participate in this study, it will be necessary to give your written consent.

WHY IS THIS STUDY BEING DONE?

The purpose of this research is to better understand how disordered eating risk (the risk a girl has of developing an eating disorder) in adolescent girls with Type 1 Diabetes can be affected through mother-daughter education.

This is a pilot study, meaning we are trying to figure out if mother-daughter education about disordered eating, body image, and self-esteem is possible in this population.

This research is being done because disordered eating is common in some adolescent girls with Type-1 Diabetes and currently there are no standards for prevention or screening for the development of disordered eating in adolescent girls with diabetes.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 40 people total will take part in this study at the University of Missouri, but only three to five mother-daughter pairs will participate in each session. The intervention will only be a single 2-hour session.

WHAT IS INVOLVED IN THE STUDY?

You and your daughter will be asked to fill out a questionnaire **that will take approximately 30 minutes of her time** immediately prior to the intervention, immediately after intervention, and six-weeks after the intervention. You may choose not to answer any of the questions at any time in these questionnaires. Also, medical records for the daughter will be accessed for only most recent height, weight measures, and hemoglobin A1c values. No other part of the medical record will be accessed.
All of the questionnaire information and data will be kept anonymous at all times.

HOW LONG WILL I BE IN THE STUDY?

We think you will be in the study for 6 weeks after the intervention. The last questionnaire set will be mailed separately to you and your daughter and all you have to do is fill them out and mail them back in the stamped envelope that will be provided.

You and your daughter can stop participating at any time. Your decision to withdraw from the study will not affect in any way your medical care and/or benefits.

If you decide to leave the study the information you have already provided will be kept anonymous and in a locked cabinet in the offices of Terri Schmitt FNP, until seven years after the study is completed.

WHAT ARE THE RISKS OF THE STUDY?

Attending the intervention may help enhance your and your daughter's feelings about yourself and your body. It may also make you or your daughter upset. If completing the

intervention or the questionnaires does upset either of you, you may talk about your feelings after answering questionnaires, or you may stop participation or answering questionnaires at any time. It is likely that you or your daughter will not feel upset.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

If you and your daughter agree to take part in this study, there may or may not be direct medical benefit to you. You may expect to benefit from taking part in this research to the extent that you are contributing to medical knowledge. We hope the information learned from this study will benefit other adolescent girls with Type 1 Diabetes in the future.

The benefit of participation includes assisting researchers in understanding disordered eating in girls with Type 1 diabetes for future prevention and intervention. Participating in this study may or may not help you.

WHAT OTHER OPTIONS ARE THERE?

An alternative is to not participate in this research study.

WHAT ABOUT CONFIDENTIALITY?

You will get a copy of this form. The original signed form will be kept in a locked cabinet in the office of Terri Schmitt FNP, for at least 7 years. All study related documents will be labeled with a coded number to maintain confidentiality and all identifiable data will be removed. Only Terri Schmitt and her study team will have access to your information.

While every effort will be made to keep confidential all of the information you complete and share, it cannot be absolutely guaranteed. Individuals from the UMKC IRB and University of Missouri IRB (a committee that reviews and approves research studies), Research Protections Program and Federal Regulatory Agencies may look at records related to the study for quality improvement and regulatory functions. However, your name and contact information will not otherwise be attached to any of the study related documents.

One of the questionnaires is a standard eating disorder screening, in an effort to keep your daughter safe, any score over 20 will be reported to your daughter's pediatric endocrinologist for follow-up. All of your daughter's responses will remain anonymous and nothing but her eating disorder risk score will be reported.

WHAT ARE THE COSTS?

There are no costs to you.

WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

You and your daughter will receive a small gift bag worth approximately $10 upon attending the intervention. Completion of all data collection points will also result in each of you being eligible for a $50 gift card as a thank you for participating.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary. You do not have to participate in this study. Your present or future care will not be affected should you choose not to participate. If you decide to participate, you can change your mind and drop out of the study at any time without affecting your present or future care in the University of Missouri system.

You will be informed of any significant new findings discovered during the course of this study that might influence your health, welfare, or willingness to continue participation in this study.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Health Sciences Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181 or the University of Missouri Kansas City Institutional Review Board at 816-235-1764.

You may ask more questions about the study at any time. For questions about the study or a research-related injury, contact Terri Schmitt at 417-209-2744.

A copy of this consent form will be given to you to keep.

WHERE CAN I GET MORE INFORMATION?

You can get more information at any time from:
Terri L. Schmitt MSN, APRN, FNP-BC
PhD Student UMKC School of Nursing
2454 E. Greenwood
Springfield, MO 65804
tschmitt2002@gmail.com
417-209-2744

ASSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

INVESTIGATOR'S NAME: TERRI SCHMITT
PROJECT # application 1170757
DATE OF PROJECT APPROVAL:

FOR HS IRB USE ONLY
APPROVED _____ HS IRB Authorized Representative Date **EXPIRATION DATE:** _____

Study Title: Disordered Eating Prevention in Adolescent girls with Type 1 Diabetes Mellitus: A Pilot Intervention

This is a study about adolescent girls with Type 1 Diabetes and their risks for developing disordered eating.

Why YOU are invited
You and your mother are invited to be in this study because you are between the ages of 13 to 18 and you have had Type 1 Diabetes for over 18 months.

What will happen?
You will come for a couple of hours one day to a meeting with your mom, you will be asked to read and fill out four questionnaires right before, right after, and six-weeks after this meeting. You will fill these questionnaires out separately from your mom, because your answers are kept private, even from your mom. It will take you about 15 to 20 minutes to fill out these questionnaires.

During this meeting you and your mom will work together in teams, with other mom's and their daughters, and learn more about diabetes, your body, and how you feel about yourself.

Also, if you agree to participate we will record your most recent height, weight, and HgbA1c level from your chart. This will be kept private and not reported individually to anyone.

Can anything bad happen to me?
Nothing bad can happen to you in this research. You could feel a little upset answering some of the questionnaires and if you do you can either not answer that question, stop answering

the questions all together, or talk to someone, like your mom, the research personnel, or your endocrinologist about it. However, it is likely you will not feel upset.

Can anything good happen to me?
The benefits include:

- Helping researchers in better understanding disordered eating in girls with Type 1 diabetes for future prevention and intervention.
- Maybe getting to know your mom a little better.
- Maybe getting to understand yourself and your body a little better.
- Participating in this study may or may not help you at all.

What if I don't want to do this?
If you say you do not want to be in the study, you just have to tell us. No one will be mad at you. You can also say yes, and later if you change your mind, you can quit the study. The choice is up to you and your mom. **Taking part in this study will not affect your medical treatment for your diabetes in any way.**

Who will know my answers, see my information?

Explain in simple terms that the subject's participation in the study will be kept confidential.

- We will do our best to make sure that your answers to these questions/your information are/is kept a secret. Only the research team will have them and they will take off all the information that might identify you.
- You will get to be separated from your mom when you fill out the questionnaire so that your answers will be private.
- You will also get the final questionnaire in a separate envelope than your mom so that your answers will be private.
- We also want to keep you healthy. If some of your questionnaire answers indicate that you might be inclined to have some disordered eating, then we will let your diabetes doctor (pediatric endocrinologist) know so that they can make sure you are healthy.

Who can I talk to about the study?
You can ask questions any time. You can ask now. You can ask later. You can talk to me or you can talk to someone else, like Dr. Bachrach
Do you have any questions about the study?

Do you want to be in the study?

☐ ***YES*** ☐ ***NO***

_____ _____

Signature of Child **Date**

REFERENCES

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VITA

Terri Lynne Schmitt was born in Missouri and raised in the Springfield Missouri area. She attended local schools and graduated from Kickapoo High School in 1991. She obtained her diploma nursing degree from St. John's School of nursing in 1995 to become a registered nurse. She went on to finish a Bachelor of Science in Nursing at Missouri State University in 1996 and a Masters of Science in Nursing as a family nurse practitioner in 2001.

Mrs. Schmitt began her career in nursing in the Neonatal Intensive Care Unit at St. John's Hospital in Springfield, Missouri and then spent time as a travel ICU nurse, returning to St. John's to become a member of the neonatal transport crew. Mrs. Schmitt also spent time working in pediatric urgent care and with the Springfield Public School system until she received her certification as a family nurse practitioner. Within her nurse practitioner career she focused on both pediatric and rural family health. She assisted in the development and establishment of the pediatric diabetes outreach clinic in the St. John's health in cooperation with the University of Missouri Columbia. She continues to maintain a practice in rural family health at the Conway Family Clinic in Conway Missouri and has taught for Southwest Baptist University, both in the ASN and now the BSN completion programs since 2004, where she was named New Faculty of the year in 2009 for her work in the RN to BSN program.

In her academic position Mrs. Schmitt has developed several courses for the online RN to BSN student including one on diabetes care across the lifespan. She assists on the educational technology committee, the college of nursing outcomes committee, and faculty senate. She also has had the privilege of leading international medical missions with the

college of nursing since 2009 and is faculty sponsor of the SBU Nursing Honor Society, which is in the process of applying for chapter status with Sigma Theta Tau International.

Mrs. Schmitt has presented at national, state, and local nursing conferences and currently has an article that will be published by the Nurse Practitioner Journal on disordered eating behavior in adolescent females. She is a past president, current web-master, and active member of the Theta Lambda chapter of the Sigma Theta Tau International Nursing Honor Society. She is also a member of the American Nurses Association, the Missouri Nurses Association, and the American Academy of Nurse Practitioners.