

**FACTORS ASSOCIATED WITH INITIATING DISCUSSION OF REPRODUCTIVE
HEALTH ISSUES BETWEEN TEEN GIRLS WITH TYPE 1 DIABETES AND THEIR
MOTHERS**

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University of Pittsburgh, 2007

Objectives: To: 1) describe and examine the associations between general communication (GC) and intention to initiate discussion about reproductive health (RH) issues within mother-daughter dyads; 2) describe mothers' knowledge and attitudes of diabetes and RH and mothers' perceived available social support; 3) identify variables associated with mothers' intention to initiate discussion and actual discussion of RH issues with their daughters with type 1 diabetes; and, 4) explore mothers' perspectives about RH discussions.

Design: This study of mothers used a sequential explanatory mixed method design. *Phase 1*, the quantitative study, utilized a repeated-measures (baseline, 3-month) correlational design as part of a larger randomized-controlled preconception counseling intervention study with diabetic adolescent girls. Mothers did not receive an intervention. Forty-four mothers participated; with a mean age of 45.3 years (SD=5.3, range 34-57.1) and 82% (n=36) were Caucasian. *Phase 2*, a qualitative descriptive study, used open-ended semi-structured telephone interviews with mothers. Ten mothers were selected by criterion-related purposeful sampling from the phase 1 sample. Qualitative content analysis techniques were used to analyze the qualitative data.

Results: Mothers reported high levels of GC and moderate levels of intention to initiate RH discussions with their daughters. Few (55%) reported having actual RH discussions. Mothers' intention was significantly associated ($r=.579$, $p<.05$) with GC. Overall, mothers lacked knowledge about diabetes and RH, had strong attitudes and high perceived social support. There were significant ($p<.05$) time effects for mothers' knowledge, perceived barriers to their daughter preventing an unplanned pregnancy, and actual RH discussion. Five themes regarding mothers' perspectives of RH discussions were identified: 1) awareness 2) knowledge; 3) triggers for initiating discussions; 4) fears/concerns; and, 5) comfort level with discussions. Mothers were aware that their daughters should preplan pregnancies. They knew that an unplanned pregnancy may have detrimental maternal/fetal effects. A major trigger for initiating discussions was a steady boyfriend. Overall, mothers were not comfortable with RH discussions.

Conclusions: Mothers lacked knowledge about RH and only half of the mothers initiated RH discussions with their diabetic daughters. Mothers could benefit from an intervention that provides information about diabetes and RH, and guidance on communication skills.

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PREFACE

I dedicate this dissertation to my parents, Mary Elizabeth and Joseph Ferons. Their endless hard work and sacrifice to provide for us has always been an inspiration to me. I am very fortunate and thankful that my mother is alive and well to share in this very special time in my life. I only wish my father were here as well. I also want to express immense gratitude to my husband, Ron, and my family; David, Leslie, Mary Ann, John, John, Liz, Kate, Claire and Emily for their love, encouragement and unending support, which was instrumental in helping me to complete this arduous process.

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1.0 INTRODUCTION

1.1 SIGNIFICANCE

Pregnancy during adolescence is considered to be high risk (Porter, 1988); type 1 diabetes increases those risks exponentially for maternal and fetal complications (Coustan, 1995; Rosenstock, Strecher, & Becker, 1988). To prevent maternal and fetal complications (e.g., birth defects) in a woman with diabetes, her blood glucose must be tightly regulated prior to conception and throughout the pregnancy (Kitzmiller, Buchanan, Kjos, Combs, & Ratner, 1996). The American Diabetes Association (ADA) recommends that all women with diabetes of childbearing age be counseled about the potential fetal and maternal complications associated with unplanned pregnancies through preconception counseling (American Diabetes Association, 2007). Many of these complications are potentially preventable by practicing effective reproductive health behaviors and instituting preconception counseling. It is of the utmost importance that adolescent women with diabetes learn about how diabetes can affect their reproductive health and a pregnancy.

Adolescent girls with type 1 diabetes are at risk for unplanned pregnancies and complications related to an unplanned pregnancy (Charron-Prochownik, Sereika et al., 2001). They need to have accurate information in order to make well informed reproductive health choices in order to prevent unplanned pregnancies. Parents, especially mothers, can provide this

necessary information. Parents can be influential figures in the life of the adolescent (Lefkowitz, Kahlbaugh, Kit-fong Au, & Sigman, 1998). They can be accessible and willing sources of information, which can be a significant factor in the knowledge, attitudes and sexual behavior of the adolescent (Lefkowitz, Sigman, & Kit-fong Au, 2000). Mothers can be a prime source of information; however, mothers' knowledge about diabetes and reproductive health is not known.

1.2 PROBLEM STATEMENT

Adolescents are known to engage in risk-taking behaviors, such as participation in early and unprotected sex (Burns, Barber, Brady, & Dunn, 1996). Twenty-five percent of 15-year old American adolescent girls report having had sex at least once; and, 77% of 19-year old American girls report having had intercourse at least once (Hogan, Sun, & Cornwell, 2000; Terry & Manlove, 2000). These behaviors may result in negative consequences and significant health concerns such as pregnancy (Miller, Forehand, & Kotchick, 2000). Reports of sexual activity among adolescents with a chronic disease range from 28-51% (Britto et al., 1998; Suris, Resnick, Cassuto, & Blum, 1996).

A recent study among 80 adolescent females between 16-20 years of age with type 1 diabetes demonstrated a sexual activity rate of 40%, with only 15% reporting use of effective combination birth control methods (Charron-Prochownik, Sereika et al., 2001). It was reported that these adolescents with type 1 diabetes engaged in early and unsafe sexual practices, were unaware of potential complications, and were at high risk for unplanned pregnancies (Charron-Prochownik, Sereika et al., 2001).

Fortunately, parental involvement, such as mother-daughter reproductive health communication, has shown to decrease the risk of negative developmental outcomes and prevent high-risk behaviors in adolescents, such as unprotected sex (Anderson, Brackett, Ho, & Laffel, 1999; Resnick et al., 1997). Although many studies have investigated reproductive health communication between mothers and their adolescent children, no studies have examined reproductive health communication that takes place between a mother and her adolescent daughter with type 1 diabetes. Nor have any studies been conducted that examine a mother's knowledge about the effect of diabetes on reproductive health.

1.2.1 Purpose

The primary purposes (Phase 1) of this mixed method study were to: 1) describe and examine the associations between general communication and intention to initiate discussion about reproductive health issues within mother-daughter dyads; 2) describe mother's knowledge of diabetes and reproductive health and mother's social support; and 3) identify constructs, as conceptualized by the Health Belief Model, associated with intention to initiate and actual discussion of reproductive health issues between mothers and their adolescent daughters with type 1 diabetes. A secondary aim (Phase 2) was to explore mothers' perspectives (e.g., timing, who initiated, triggers) about initiating reproductive health discussions with their adolescent daughters with diabetes.

1.2.2 Specific Aims / Research Questions

The **specific aims** and **research questions** of this study are listed as follows:

Phase 1

Specific Aim #1 Examine the bivariate associations between general communication and intention to initiate reproductive health discussion by subject type (mothers and adolescent girls with type 1 diabetes) within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 1 What is the association between general communication and intention to initiate reproductive health discussion for mothers and for their adolescent girls with type 1 diabetes within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Specific Aim #2 Examine the agreement between mothers and daughters within dyads on general communication and intention to initiate reproductive health discussion within each treatment group (IG, CG) at each time point.

Question # 2a What is the agreement between mothers and daughters on general communication within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Question # 2b What is the agreement between mothers and daughters on intention to initiate reproductive health discussion within each treatment group (IG, CG) at either time point (baseline, 3-months)?

Specific Aim #3 Examine the bivariate associations between the dependent variables of mother's intention to initiate and actual discussion of reproductive health discussions and the independent variables of mother's knowledge of diabetes and reproductive health, mother's perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of her daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy,

and mother's social support of her daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 3a What are the bivariate associations between the dependent variable of mother's intention to initiate reproductive health discussions with her adolescent daughter and the independent variables of: mother's knowledge of diabetes and reproductive health, mother's perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of her daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of her daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Question # 3b What are the bivariate associations between the dependent variable of mother's actual discussion of reproductive health issues with her adolescent daughter and the independent variables of: mother's knowledge of diabetes and reproductive health, mother's perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of her daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of her daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Specific Aim #4 Compare differences over time (baseline to 3-months) between mothers in each treatment group (IG, CG) on knowledge of diabetes and reproductive health, perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, perception of her daughter's severity to pregnancy/pregnancy-related complications, perception of benefits and barriers of her daughter preventing an unplanned pregnancy, social support of her daughter

preventing an unplanned pregnancy, intention to initiate reproductive health discussion with her daughter, and actual discussions reproductive health issues with her daughter.

Question # 4 Are there any differences over time (baseline to 3-months) between mothers of adolescents in the IG or those in the CG on knowledge of diabetes and reproductive health, perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, perception of her daughter's severity to pregnancy/pregnancy-related complications, perception of benefits and barriers of her daughter preventing an unplanned pregnancy, social support of her daughter preventing an unplanned pregnancy, intention to initiate reproductive health discussion with her daughter, and actual discussions of reproductive health issues with her daughter?

Specific Aim #5 Compare treatment groups (IG vs. CG) on mothers' knowledge of diabetes and reproductive health, mother's perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of her daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support of her daughter preventing an unplanned pregnancy, intention to initiate reproductive health discussion with her daughter, and actual discussions of reproductive health issues with her daughter at each time point (baseline, 3-months).

Question # 5 What is the difference between the treatment groups (IG vs. CG) for mothers' knowledge of diabetes and reproductive health, mother's perception of her daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of her daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support of her daughter preventing an unplanned pregnancy, intention to initiate reproductive health

discussion with her daughter, and actual discussions of reproductive health issues with her daughter at each time point (baseline, 3-months)?

Phase 2

Specific Aim #6 Explore mothers' perspectives (e.g., timing, who initiated, triggers, etc.) about initiating reproductive health discussions with their adolescent daughters with diabetes.

Question # 6 What are mothers' perspectives about initiating reproductive health discussions with their adolescent daughters with diabetes?

1.3 DEFINITION OF TERMS

The following definitions apply to terms employed in this dissertation:

Adolescent – a young woman between the ages of 13-19 years as defined in the parent study.

Adolescents will be split into two groups, young adolescents (13-16 years) and older adolescents (17-19 years) for analysis as there is a difference of development between these age groups.

Mother – natural, step or adoptive mother with whom the female adolescent with type 1 diabetes lives.

Type 1 Diabetes – autoimmune diabetes mellitus diagnosed during childhood or adolescence.

Mother-Daughter Communication – mother's or daughter's self-report of verbal interaction with each other. General communication will be measured with The Parent-Adolescent Scale (PAC).

Knowledge – factual information about diabetes and reproductive health issues (pregnancy, birth control and sexuality) and general family planning.

Health Belief Model (HBM) – conceptual framework of the study. Constructs of the HBM will be measured as follows:

Perceived Susceptibility – mother’s perception of her daughter’s susceptibility to an unplanned pregnancy or pregnancy-related complications.

Perceived Severity – mother’s perception of the severity of complications should her daughter have an unplanned pregnancy.

Perceived Benefits – mother’s perception of the benefit of her daughter preventing an unplanned pregnancy and seeking preconception counseling.

Perceived Barriers – mother’s perception of the barriers her daughter may face in preventing an unplanned pregnancy or seeking preconception counseling.

Mother’s social support – mother’s perception of the availability of her supportive behaviors (emotional, appraisal, informational, and instrumental) to be given to her daughter for seeking preconception counseling and obtaining birth control.

Intention to initiate reproductive health discussions – mother’s self-report of intending to initiate discussion with her adolescent daughter about diabetes and reproductive health issues (e.g., pregnancy, birth control, and, sexuality), and, diabetes and preconception counseling. Daughter’s self-report of intending to initiate discussion with her mother about diabetes and reproductive health issues (e.g., pregnancy, birth control, and, sexuality), and, diabetes and preconception counseling.

Actual discussion of reproductive health issues – mother’s self-report of actual discussions that have taken place with her adolescent daughter about diabetes and reproductive health issues (e.g., pregnancy, birth control, and, sexuality), and, diabetes and preconception counseling.

1.4 SIGNIFICANCE TO NURSING

All adolescents, including those with diabetes, can participate in risky behaviors, such as early and unprotected sex (Charron-Prochownik, Sereika et al., 2001; Feldman & Elliott, 1997). However, an unplanned pregnancy resulting from such behavior is a major problem for an adolescent with diabetes as there is a much greater risk for complications (Felig, Razzaq, Sykora, Hux, & Anderson, 2006; Steel, 1985). Adolescents with diabetes must be made aware of these potential complications and how to prevent them; however, educating adolescents alone is not enough. Mothers can also be key figures in the dissemination of reproductive health information. Maternal involvement in the education process has been shown to have positive effects on the health outcomes in adolescent daughters (Anderson et al., 1999; Resnick et al., 1997). However, there is a gap in the literature that involves mothers in the education process of adolescents with diabetes about reproductive health issues.

This study was both timely and crucial to protecting and promoting reproductive health of adolescent females with type 1 diabetes. In this study, reproductive health discussion among mothers and their adolescent girls with type 1 diabetes was examined to provide the foundation for future studies designed at improving this mother-daughter communication.

2.0 REVIEW OF THE LITERATURE

2.1 INTRODUCTION

Adolescence is a time of growth and development (McManus, 2002). It is a period of significant physical growth coupled with cognitive and emotional development when children begin the transition to adulthood and begin to take on the responsibilities of adult life. However, for a child with diabetes it is a wavering period of development between childhood and adulthood that is not conducive to the everyday challenges of diabetes (Charron-Prochownik & Arslanian, 1997). It is an unstable, impulsive, and explorative period of time (Charron-Prochownik & Becker, 1998) when rapid biological changes occur that may have an effect on diabetes control (Roemer, 2003).

During adolescence knowledge and skills are acquired for establishing an adult role. For adolescents with diabetes, some knowledge and skills become essential for survival. It is imperative for adolescent females with diabetes to begin to understand how diabetes affects their reproductive health and the need to preplan a pregnancy through preconception counseling (American Diabetes Association, 2007; Kitzmiller et al., 1991). Parents, especially mothers, can play a pivotal role in the adolescent's acquisition of the essential knowledge and skills to have a healthy reproductive life. Parents are accessible and willing sources of information, which can

be an influential factor in the knowledge, attitude and behavior of the adolescent (Lefkowitz et al., 2000).

The information in this chapter will be presented on female adolescents as it pertains first to the general population, followed by the chronic illness population, and then specifically about adolescent girls with diabetes.

2.1.1 Adolescent Development

Adolescence is the transformation of the child-parent relationship from one-sided authority to one of cooperative negotiation (Steinberg, 1990). During this period, the adolescent grows toward interdependence within the family, not independence from the family (Steinberg, 1990). In a healthy family, the adolescent continues to seek parental advice and remains responsive to parental influence while parents give more freedom to the adolescent by recognizing her personal capabilities and needs (Steinberg, 1990). It is also a time when the parent can maintain a key position (van Wel, Linssen, & Abma, 2000) without being discarded (Steinberg, 1990).

For adolescents who are gaining independence, it is important for parents to continue to provide guidance and support (van Wel et al., 2000). Adolescents are protected from negative developmental outcomes and high-risk behaviors when there is parental involvement (Anderson et al., 1999; Resnick et al., 1997). Parents help to foster self-esteem, self-confidence, and good decision-making of their adolescents by communicating their values and attitudes, sharing information, and exchanging ideas with them (Advocates for Youth, 1995).

In regards to the onset of sexual activity, parents, especially mothers, play an important role in delaying this high risk behavior (Aspy et al., 2006; Doswell et al., 2003). In a report on the cross-sectional analyses of data from the National Longitudinal study on Adolescent Health,

a longitudinal study of adolescents in grades 7 through 12, an adolescent's delay of sexual intercourse was associated with significant family factors, such as high levels of parent-family connectedness (Resnick et al., 1997). A more detailed discussion of mother-child communication and reproductive health behavior can be found in section 2.1.4.

2.1.2 Diabetes and Adolescence

Type 1 diabetes is one of the leading chronic diseases in adolescents (Libman, Songer, & LaPorte, 1993). Approximately 13,000 new cases are diagnosed each year (LaPorte, Marsushima, & Chang, 1995). It is estimated that 0.26% of children less than 20 years of age have diabetes ("Center for Disease Control and Prevention Diabetes Program: National Diabetes Fact Sheet," 2002). It is also one of the largest and costliest chronic diseases of youth (LaPorte et al., 1995; Libman et al., 1993). Diabetes has the highest incidence as compared with other chronic diseases of this age cohort (LaPorte et al., 1995). The ratio of other chronic diseases of childhood compared with diabetes is as follows: childhood AIDS to diabetes – 1:15; childhood cancers to diabetes – 1:1.5; cystic fibrosis to diabetes – 1:5 (Libman et al., 1993).

Type 1 diabetes is a life-threatening disease in which children are dependent on insulin and life style changes for survival, and are required to learn and perform self-management skills the rest of their lives (Leonard, Skay, & Rheinberger, 1998). Basic survival skills for self-management include: following a daily dietary regimen, daily insulin administration, and blood glucose monitoring. Because type 1 diabetes poses new challenges, as a child develops, new skills and knowledge are required to manage the everyday demands.

Adolescents with diabetes are burdened with the developmental task of attaining independence while attempting to achieve self-management skills and incorporate diabetes into

their everyday lives (Charron-Prochownik & Arslanian, 1997). Diabetes care, however, may not be a top priority for adolescents. Furthermore, changing hormones due to puberty can have an effect on blood glucose and lead to poorer glucose control (Roemer, 2003). According to several researchers (Anderson et al., 1999; Grey, 1999), adolescence is the period of development for worsening glycemic control. The success of long-term self-management for these children and adolescents is greatly influenced by the role of their parents (Leonard et al., 1998). As found in a descriptive study by Ingersoll, Orr, Herrold, & Golden (1986) 41 adolescents with type 1 diabetes did not always assume responsibility for insulin adjustment when parental involvement was decreased.

Parents tend to begin to delegate responsibility of decision-making by incremental levels beginning in the early adolescent years (Anderson, Auslander, Jung, Miller, & Santiago, 1991; Leonard et al., 1998). For adolescents with diabetes this can be very challenging. Parental involvement was the focus of a longitudinal randomized control study conducted by Anderson et al. (1999) on 85 adolescents with diabetes (aged 10-15 yr, mean age 12.6 yr). The researchers evaluated an office-based intervention aimed at fostering parent-adolescent teamwork in regards to diabetes management with the major focus on preventing an increase in family conflict related to diabetes care. The adolescents were randomized into one of three groups: teamwork, attention control, and standard care (control). The teamwork group received the office-based intervention. Those in the attention control group received equal amounts of time and attention as those in the teamwork group, but without a focus on parental involvement. Adolescents in the standard care control group received routine clinical care without intervention from a research assistant. The 3 groups had no significant differences of demographic or baseline data. Those adolescents in the teamwork group reported a significantly greater decrease in family conflict

related to diabetes care by the end of the study. The adolescents in the teamwork group also demonstrated a greater trend to improving metabolic control as demonstrated by their HbA_{1c} results.

Parental support was also an influential factor in another study of 51 adolescents aged 13-17 years (mean age 15.1 yr) with type 1 diabetes (Kyngas, Hentinen, & Barlow, 1998). Compliance in adolescents with diabetes was dependent upon the adolescents' perception of their parent's actions. If the perception was of "disciplined control" (parents asking many questions about self-care and forcing the adolescent to take better care of themselves), adolescents were less compliant. However, if the parents were perceived to be supportive and encouraging (parents showing a natural interest and acceptance of the child as a unique individual), adolescents were motivated to comply.

The importance of parental support was also seen in a descriptive study of 157 youths with diabetes and their mothers (Hanson, DeGuire, Schinkel, & Kolterman, 1995). An association between optimal health outcomes and a family-centered approach to the child's diabetes care was reported. Family-centered approach appears to foster positive family functioning and lead to less family stress.

Although "parental" support has been highlighted, mothers tend to be the primary care givers and therefore a dominant factor in the life of the adolescent. In a qualitative study conducted on 20 adolescents with diabetes (10 females and 10 males), in all cases it was the mother who was most involved in assisting the adolescent with his/her diabetes care (Williams, 1999). Similarly, in a study by Anderson, et al. (1991), on shared responsibilities of diabetes-related care between parents and children, in 95% (n=428) of the families, it was the mother who participated in the diabetes-related care.

From these studies, we can gather that parental involvement and support fosters positive outcomes and is a necessary component in managing the adolescent's diabetes. These studies indicate the importance of continued parental, especially maternal, involvement in the life of the adolescent with diabetes. It is the responsibility of the health care provider of these adolescents to initiate the support of mothers, which is considered to be crucial (Kyngas et al., 1998). Mothers and health care providers need to collaborate (Kelton, 1999) in order to help foster good diabetes control as the adolescent moves from childhood into adulthood.

2.1.3 Maternal-adolescent Reproductive Health Communication

In the general population, parental interest in participating in reproductive health education of their children is strong, however, the actual level of involvement is moderate (Fox & Inazu, 1980). In a recent review of the literature, Kirby (2002) found that some studies report that parent-child communication about sex can have a positive effect on the adolescent's delay of initiation of sex and contraceptive use, while others report it to be a negative influence. Leland and Barth (1993) found that, in general, adolescents who had talked with their parents about sex were more likely to delay sex initiation, use condoms and have fewer pregnancies. Several investigators reported that mother-daughter communication in the general population will include more information on reproductive health issues than that of father-daughter, which exists but is infrequent (Fox & Inazu, 1980; Lefkowitz et al., 1998; Lefkowitz et al., 2000; Leland & Barth, 1992). In a study by Aspy, et al. (2006) it was found that agreement between adolescents and their parents regarding reproductive health communication had a positive effect on the adolescent's reproductive health behavior. It has also been reported by Doswell, et al. (2003)

that a teen's intention to abstain from early sexual behavior was strongly correlated with a mother's subjective norm.

More recent studies have begun to use interventions to increase communication about reproductive health issues between adolescents in the general population and their parents. In a longitudinal intervention study of 582 adolescents, with an age range of 11 -14 years, and their mothers (n=110), the effects of two programs on the adolescent's use of condoms and mother's sex-based communications were examined (Dilorio et al., 2006). At 24-months post-intervention, a higher percentage of sexually active adolescents in both intervention groups reported the use of a condom at last intercourse when compared with adolescents in the control group. It was also reported that mothers in both treatment groups indicated a greater intent to discuss and more comfort in discussing sex-based topics than those in the control group.

Although there have been many studies examining the role of parent-child and mother-daughter reproductive health communication concerning sexual activity, to date there are no published reports of maternal involvement in reproductive health communication, awareness or education with adolescent daughters who have a chronic illness or diabetes. However, a pilot feasibility study was conducted by this researcher in which 3 mother-daughter dyads participated in a non-randomized intervention (Feron & Charron-Prochownik, 2004). The intervention was a fundamental preconception educational CD-rom developed for adolescent girls with diabetes. Mothers were assessed at baseline and immediate-post viewing of the CD-rom. Baseline knowledge of diabetes and reproductive health (e.g., pregnancy, birth control and sexuality) scores for mothers ranged from 64-84%. Two of the dyads viewed the CD-rom together, while for the control dyad the CD-rom was viewed by the daughter only. Overall, there was a difference between pre and post viewing of mothers' total knowledge of diabetes and

reproductive health. For mothers who watched the CD, the difference of knowledge scores increased pre to post from 8-36%. Although mothers are a primary source of reproductive health information, these mothers lacked specific knowledge with regards to its relation to diabetes.

Much of the research on mother-daughter reproductive health communication has been conducted using self-report measures (Jordan, Price, & Fitzgerald, 2000; Miller, Norton, Fan, & Christopherson, 1998; Miller, Kotchick, Dorsey, Forehand, & Ham, 1998; Whitaker & Miller, 2000; Whitaker, Miller, May, & Levin, 1999). However, there has been little research conducted using qualitative methods to examine parent-adolescent reproductive health communication in the general population. No qualitative research has been conducted among mothers of adolescents with a chronic illness, including diabetes, regarding reproductive health issues.

2.1.4 Diabetes and Reproductive Health Communication

Diabetes affects all aspects of human sexuality (Anderson & Wolf, 1986; Legro & Dunaif, 1997; LeMone, 1993). This is an especially important issue for adolescent women who are developing secondary sexual characteristics and transitioning into womanhood. It has been reported that menstrual irregularities, such as, primary amenorrhea and oligomenorrhea, are twice as common among women with diabetes as among non-diabetic control women (21.6 vs. 10.8%) (Kjaer, K., Hagen, C., Sando, S. H., & Eshoj, O., 1992). These irregularities are associated with poor glycemic control and low body mass index (Kjaer, Karen et al., 1992; Schroeder, Hertweck, Sanfilippo, & Foster, 2000). Furthermore, blood glucose levels around and during menstruation may be higher (Poirier & Coburn, 1997). This is a result of the hormonal changes that occur with the menstrual cycle (Poirier & Coburn, 1997). Tight glycemic control is related to improved menstrual regulation in diabetic adolescents (Schroeder et al., 2000). Adolescent

women must be made aware of these facts, so they can monitor glycemic changes prior to and during menstruation, and become proactive in managing their diabetes to maintain glycemic control and improve outcomes.

In a retrospective review of 46 charts of insulin-dependent diabetic girls (10-18 years of age), it was found that 81% had regular menstrual cycles and 19% had menstrual disturbances (Schroeder et al., 2000). The adolescents with regular menstrual cycles had significantly ($P < .05$) better metabolic control (Odds ratio of 7.3, 95% CI when the HbA1c was >10). Higher HbA1c levels were associated with more menstrual disturbances.

Diabetes can also have an effect on a woman's sexual function (Enzlin et al., 2002; LeMone, 1993; Poirier & Coburn, 1997). However, unlike men, little has been written about diabetes-related female sexual dysfunction. Diabetes may alter sexual functioning by: fluctuating blood glucose levels (hypo- and hyper- glycemia); increasing the incidence of vaginal infections, e.g. yeast, (that could affect interest in and comfort during intercourse); and decreasing vaginal lubrication (necessitating the use of lubricants during intercourse) (Enzlin et al., 2002; LeMone, 1993; Poirier & Coburn, 1997). Furthermore, persistent hyperglycemia may cause neurological and vascular complications that could interfere with physical sexual functioning (e.g., losing sensation in genital area) (LeMone, 1993; Poirier & Coburn, 1997). It is imperative to establish a knowledge base necessary to meet the reproductive health care needs of women (LeMone, 1993) and avoid preventable problems.

Sexual activity involves physical exertion and can result in a low blood glucose reaction (hypoglycemia) (Poirier & Coburn, 1997). Women with diabetes are advised to plan for sexual activity as they would any other exercise. Conversely, hyperglycemia affects energy levels and interest in sexual activity (LeMone, 1993; Poirier & Coburn, 1997). Most of these problems can

be prevented with glycemic control (Nankervis, 1998). These problems are not limited to older women, they affect adolescents as well. Being made aware of the benefits of glycemic control at an early age has the potential to motivate young women to achieve control and prevent these problems from occurring.

2.1.5 Adolescent Sexuality and Risk-taking Behavior

Adolescence is a time when risk-taking behaviors emerge, such as participation in early and unprotected sex (Feldman & Elliott, 1997). In a 2003 national survey, called “Youth Risk Behavior Surveillance System (YRBSS)”, of 15,214 students in grades 9-12 (public and private schools), 43% of high school white females reported having had sexual intercourse (Grunbaum et al., 2004). Of those sexually active, 43% had an onset of sexual debut by the tenth grade and 3% had an onset of sexual intercourse before the age of 13 years (Grunbaum et al., 2004). Thirty-three percent reported being currently sexually active (i.e., sexual intercourse within 3 months of the survey). Fifty-seven percent reported condom use and 27% used birth control during their last sexual intercourse.

The statistics are similar for adolescents with a chronic condition. The Minnesota Adolescent Health Survey was conducted among 36,284 general students in grades 7-12 during the 1986-1987 school year (Suris et al., 1996). A sub-sample of 1,068 students (609 females) reported having a non-visible disability (e.g., diabetes, asthma, seizure disorder) (Suris et al., 1996). Of these 609 females (mean age 14.9 yr), 37% were sexually active, with a mean age at the time of their first intercourse of 13.9 years. Up to 25% of the females reported not using any birth control. Similarly, Britto, et al. (1998) reported that 115 adolescents (51% female) with cystic fibrosis (mean age 15.5 yr, SD 1.6 yr) and 199 adolescents (50% female) with sickle cell

disease (mean age 16.2 yr, SD 1.6 yr) had sexual activity rates of 28.3% and 51.3%, respectively. The mean age of first intercourse for the female adolescents with cystic fibrosis was 15.7 years of age and for those with sickle cell disease it was 14.8 years of age. Condom use at last intercourse was reported to be 58% for all the sexually active adolescents with cystic fibrosis and 81% for those with sickle cell disease. Eighty-one percent and 91%, respectively, reported contraception use at last intercourse.

Similar patterns were noted in adolescent girls with type 1 diabetes. In a descriptive multi-site phone survey of 87 adolescent girls with diabetes with an age range of 16 to 22 years (mean 17.86 yr, SD 1.26) it was found that 43% had been sexually active (Falsetti et al., 2003). Mean age at the time of sexual debut was 15.8 years (SD=1.2 yr, range=14-18 yr). Seventy-three percent of these adolescents reported use of a condom at each sexual encounter. Thirty percent reported the use of combination methods for birth control (i.e., condom with another method).

In a randomized-controlled, repeated measures study of 47 adolescent girls with diabetes with an age range of 16-19.9 years (mean age 17.4 yr), 32% were sexually active (Charron-Prochownik, Becker, Sereika, Ferons, & Reddinger, 2002). This preliminary report did not include information on birth control use. In summary, from these studies, adolescents with diabetes have similar sexual risk-taking behaviors as those adolescents with other chronic illnesses and adolescents in the general population.

Risk-taking sexual behaviors may result in negative consequences, such as an unplanned pregnancy and complications (Burns et al., 1996). Approximately 400,000 American adolescents in the general population become pregnant each year (Abma, Martinez, Mosher, & Dawson, 2004; Hamilton, Martin, Ventura, Sutton, & Menacker, 2005), with approximately 80%

being unplanned (Henshaw, 1998). It was reported from the National Survey of Family Growth 2002 data that there is a 13% probability that an adolescent girl in the general population will become pregnant by age 20 years (Abma et al., 2004).

For adolescents with a chronic illness, the findings of unplanned pregnancy are inconsistent, depending upon the illness and the country from which the sample was drawn. Pregnancy rates for 59 American adolescent girls with cystic fibrosis (mean age 15.5 yr) and 99 American adolescent girls with sickle cell disease (mean age 16.2 yr) were 0% and 22% respectively (Britto et al., 1998). In a national study conducted by the French National Institute of Health (Choquet, Pediaevsky, & Manfredi, 1997) on a subsample of French adolescents with a chronic illness, (n=706; mean age 16.2 yr, SD 2; 51.% females) the pregnancy rate was 2.9%.

Pregnancy rates for adolescents with diabetes were consistent with those of the general population. In the previously reported multi-site phone survey by Charron-Prochownik and colleagues (Falsetti et al., 2003), 11% of the diabetic adolescent girls had reported having at least one unplanned pregnancy. Pregnancy during adolescence is considered to be high risk (Porter, 1988), and diabetes makes it an even higher risk for maternal and fetal complications. An unplanned pregnancy in a woman with diabetes has a greater risk of pregnancy-related complications than that of a woman without diabetes (Elixhauser et al., 1993; Miller et al., 1981; Steel, 1985).

One major reason for unplanned pregnancies is the lack of awareness. In a report by Sawyer, et.al. (1995), 34% of 55 women with cystic fibrosis (mean age 23.7 yr) were not aware of the harmful effects that a pregnancy could have on their respiratory health. Two percent actually thought it may improve their lung disease while another 2% thought it would have no effect. Similar findings were reported on adolescents with diabetes whereby the adolescents had

limited awareness of how diabetes can affect their reproductive health, and of the risks of unplanned pregnancies to maternal and fetal complications (Charron-Prochownik, Sereika et al., 2001). Sixty-five percent of the adolescents in the sample were not aware of the importance of preplanning a pregnancy with preconception counseling, or the role of tight metabolic control prior to pregnancy in preventing these complications (Charron-Prochownik, Sereika, Wang et al., 2006).

Adolescents need guidance. Therefore, for an adolescent woman with diabetes, being made aware of the risks of pregnancy-related complications and the importance of planning a pregnancy is imperative to ensure the best possible outcome for herself and her baby. According to the ADA (2007), all women with diabetes of child-bearing age, starting at puberty, must receive preconception counseling and be educated about the risks of an unplanned pregnancy so that they may be empowered to be in control of their own reproductive health (Charron-Prochownik, Becker et al., 2001).

2.1.6 Diabetes and Pregnancy

According to the ADA (2007), unplanned pregnancies for women with diabetes could lead to abnormal blood glucose levels, which cause fetal and maternal complications. In order to decrease the risks of complications, normal blood glucose must be obtained prior to conception. However, the majority of women with diabetes continue to have unplanned pregnancies, without having adequate metabolic control prior to conception (American Diabetes Association, 2007; Felig et al., 2006; Kjaer, K., Hagen, C., Sando, S., & Eshoj, O., 1992; St. James, Younger, Hamilton, & Waisbrem, 1993).

The incidence of fetal congenital anomalies (e.g., cardiac, neurological, physical malformations) is greater in diabetic women with unplanned pregnancies than that of non-diabetic women (Felig et al., 2006; Steel, 1985). It has been demonstrated that these malformations of the infant occur before the seventh week of gestation (Mills, Baker, & Goldman, 1979). It has been found that congenital anomalies, along with an increased risk of certain maternal complications (e.g., hypertension, retinopathy) and pregnancy-related complications (spontaneous abortion, c-section, pre-eclampsia), are a direct result of poorly controlled diabetes prior to and early in the pregnancy of a diabetic woman (Elixhauser et al., 1993; Felig et al., 2006; Miller et al., 1981; Steel, 1985).

In a study of 116 women with type 1 diabetes who were seen initially during their first trimester of pregnancy, 13% (n=15) delivered infants with major congenital anomalies (Miller et al., 1981). This group of 15 had a significantly higher ($p<.001$) mean initial HbA1c level when compared with those who delivered infants without anomalies. In a cohort study of 1,532 women with pregestational diabetes, 9% had a diagnosis of hypertension during pregnancy (Felig et al., 2006). This was 4 times greater than women without pregestational diabetes. Only 50% of these women sought care by an endocrinologist during their pregnancy. Therefore, to prevent these fetal and maternal complications, education and excellent blood glucose management must begin prior to conception (Kitzmiller et al., 1991). This can be achieved through preconception counseling (Kitzmiller et al., 1991).

2.1.7 Diabetes and Preconception Counseling

Preconception Counseling has been shown to decrease the risks of congenital anomalies from 9% to 2% in women with diabetes (Kitzmiller et al., 1991; Willhoite et al., 1993). Preconception

counseling has also decreased the rate of pregnancy-related complications (e.g., spontaneous abortion) (Diabetes and pregnancy group France, 2003; McElvy et al., 2000) as well as reducing the number of unplanned pregnancies in women with diabetes (Steel, 1985). However, most women with diabetes do not receive preconception counseling. We must ask, “Why do women with pregestational diabetes continue to have unplanned pregnancies?”

In a prospective longitudinal study of 66 women with diabetes, 23 women became pregnant, only 6 (26%) preplanned their pregnancy (St. James et al., 1993). Factors associated with consistent birth control in this study were higher levels of social support for the use of birth control, more positive attitudes regarding sex and birth control and higher knowledge scores on the Maternal Diabetes Scale (Diabetes and pregnancy group France, 2003; McElvy et al., 2000; St. James et al., 1993). In another, multisite, case-control study of women with pregestational type 1 diabetes, factors associated with seeking preconception counseling to prevent an unplanned pregnancy were perceived benefits of preconception counseling, higher level of instrumental social support (i.e., aid given by another such as giving insulin injection), and reported encouragement of a health care provider to seek preconception counseling (Janz, Herman, Becker, Charron-Prochownik, & et al., 1995). Motivational cues, such as knowledge, social support and communication all seem to be important motivators for women with diabetes to seek preconception counseling.

Ideally, preconception counseling should begin at puberty so that the importance of planning a pregnancy is introduced at an early age, prior to sexual activity (American Diabetes Association, 2007; Charron-Prochownik, Becker et al., 2001; Charron-Prochownik, Sereika et al., 2001; Steel, 1985). Until recently, however, even though preconception counseling has made significant improvements in pregnancy outcomes for adult women with diabetes, there have not

been any programs specifically designed for adolescent women. READY-Girls is a preconception counseling program specifically designed for adolescent women with diabetes to increase awareness of the risks associated with unplanned pregnancies and increase health-promoting reproductive behaviors (e.g., preventing unplanned pregnancies and seeking preconception counseling) (Charron-Prochownik, 2003). In a randomized controlled study of 47 adolescent women with type 1 diabetes (mean age 17.4 yr) the effectiveness of the READY-Girls preconception counseling program was evaluated (Charron-Prochownik et al., 2002). The program was presented in the form of a CD-rom and book. It was found that the program had a moderate to large effect ($\eta^2=.062-.291$) immediately post-intervention with the CD having a greater effect over a 3-month period. The program appears to be a valuable intervention for adolescent women with diabetes, to help them make well-informed reproductive health choices.

In summary, one of the influential factors to minimize sexual risk-taking behaviors in adolescents is to increase their knowledge and awareness of the reproductive health behaviors necessary to prevent the negative consequences of an unplanned pregnancy (e.g., seeking preconception counseling). It is also imperative to sustain mothers' involvement for these positive outcomes (Anderson et al., 1999). Involving parents is a complementary approach in teaching children about reproductive health issues (Dilorio et al., 2006). Therefore, this study will utilize a conceptual framework, the Health Belief Model, to study mothers' perceptions about their daughters' diabetes and reproductive health, as well as communication between mothers and daughters about these same issues.

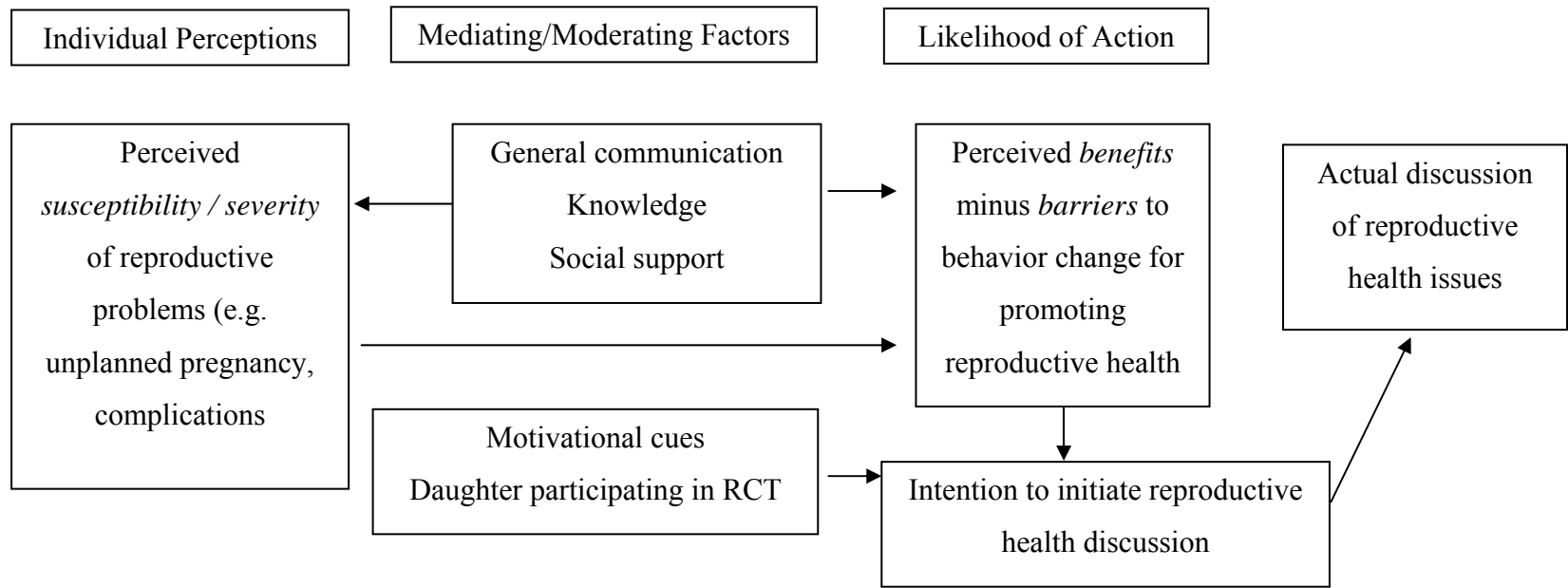
2.2 CONCEPTUAL FRAMEWORK

2.2.1 Health Belief Model

In this study, the Health Belief Model (HBM) was used as a conceptual framework. The HBM was originally developed in the 1950's by investigators in the U.S. Public Health Service to help explain the failure of people to accept preventive health behaviors such as screening tests for early disease detection and immunizations (Bates, Fitzgerald, & Wolinsky, 1994; Janz & Becker, 1984; Rosenstock, 1974). The HBM postulates that an individual is more likely to engage in a preventive health behavior to avoid a health problem/complication if she (1) feels personally susceptible to a health problem or complication, (2) perceives that the complication(s) would be serious, (3) considers the recommended behavior(s) to be beneficial in maintaining her health or would help to prevent the complication(s), and (4) believes that the benefits of following the preventive health behavior recommendations outweigh the barriers (e.g., cost and convenience) to performing the behavior(s) (Rosenstock, 1974; Strecher & Rosenstock, 1997). However, overt action may not occur unless there is an instigating event, or cue to action that sets the course of action in motion (Rosenstock, 1974). Cue to action may be internal (e.g., physical symptom) or external (e.g., having an adolescent daughter with diabetes for mothers) (Rosenstock, 1974; Sheeran & Abraham, 1996). Other factors embedded within the model that can potentially affect the perceptions of an individual and therefore, indirectly influence the health behavior include the following mediating/modifying variables: demographic (e.g., age, sex, education etc.); socio-psychological (e.g., socio-economic status [SES], social support, etc.), and structural (knowledge, communication, etc.) (Janz & Becker, 1984; Rosenstock, 1974).

Given the influence of beliefs/attitudes on behaviors (Rosenstock, 1974), this study postulated that mothers of adolescent women with diabetes would be more likely to speak with their daughters about diabetes and reproductive health issues if: 1) she perceived her daughter to be highly susceptible to the maternal and fetal complications that may occur with an unplanned pregnancy; 2) she perceived greater severity of these complications; and, 3) she perceived greater benefits of and lower barriers to her daughter preventing an unplanned pregnancy and planning a future pregnancy with preconception counseling (Charron-Prochownik, Sereika et al., 2001; Rosenstock, 1974; Strecher & Rosenstock, 1997). The cue to action was having an adolescent daughter with diabetes (Becker, 1985; Brock & Beazley, 1995; Conner & Norman, 1996). The mediating/modifying factors that could have potentially influenced mothers include the following: 1) demographics (age, and education) (Conner & Norman, 1996); 2) socio-psychological (SES, social support and religiosity) (Becker, 1985; Charron-Prochownik, Sereika et al., 2001; Conner & Norman, 1996; Janz & Becker, 1984; Laraque, McLean, Brown-Peterside, Ashton, & Diamond, 1997; St. James et al., 1993); and, 3) knowledge (diabetes and sexuality, diabetes and pregnancy, diabetes and birth control, and general family planning) and general communication (Charron-Prochownik, Sereika et al., 2001; Conner & Norman, 1996; Janz et al., 1995; St. James et al., 1993). See Figure 2.1.

**APPLICATION OF THE HEALTH BELIEF MODEL:
Actual Discussion of Reproductive Health Issues
(Strecher & Rosenstock, 1997)**



Health attitudes/beliefs are *italicized*.

Figure 2.1 Conceptual framework

The HBM has previously been used to examine parental beliefs and attitudes and the effects on the parents' behaviors. The HBM was used to examine parental health beliefs and compliance with the administration of penicillin in children with sickle cell disease. It was found that perceived barriers of adherence (i.e., obtaining medication refills and administering the medication) was a significant factor with the HBM accounting for 30% of the variance in adherence (Elliott, Morgan, Day, Mollerup, & Wang, 2001).

In addition, the HBM was used to examine parents' involvement in their ninth-grade adolescents' at-home sexuality education activities (Brock & Beazley, 1995). It was reported that perceived barriers were strongly correlated with parents' lack of involvement in their child's at-home sexuality education activities. Interestingly, parents who were uninvolved had significantly ($p < .01$) higher perceived susceptibility scores (they perceived their children to be at higher risk for pregnancy) than parents who were moderately and highly involved.

The HBM has also been used in studies examining preventive reproductive health behaviors in the general population of adolescents. In a review of the literature (Kirby, 2002), studies have reported that an adolescent's perceived risk to STDs or AIDS is antecedent to the adolescent's sexual initiation. Furthermore, the adolescent who perceived a greater susceptibility to becoming pregnant was more likely to use contraception (Kirby, 2002). In a study of 557 African-American adolescents, ranging in age from 12-23 years (mean age 15.9 yr, SD 1.8 yr), it was reported that the adolescent's perceived benefits and costs of a pregnancy predicted the use of condoms to avoid a pregnancy (Laraque et al., 1997). Additionally, social support of a parent for birth control use was a predictor of condom use (Laraque et al., 1997). In another study examining predictors of condom use to prevent HIV infection among youth in Ghana (Adih & Alexander, 1999), it was reported that perceived susceptibility to HIV infection, low level of

barriers and perceived social support were significant ($p<.001$) predictors of condom use (Adih & Alexander, 1999).

Among those with a chronic illness, the HBM has been used to examine the relationship between health beliefs of psychiatric outpatients and their adherence with antipsychotic drug regimens (Kelly, Mamon, & Scott, 1987). Perceived susceptibility, perceived barriers and cue to action were all significant ($p<.01$), with each explaining 10-12% of the variance in medication adherence.

The HBM has been utilized in a study to identify a relationship between the constructs of the model and reproductive health behaviors (preventing an unplanned pregnancy and seeking preconception counseling) of adolescent women with type 1 diabetes (Charron-Prochownik, Sereika et al., 2001). In this study of 80 adolescent women with an age range of 16 - <20 years (mean age 17.6 yr, SD 1.0 yr), there were two significant negative associations with preventing an unplanned pregnancy by using effective birth control methods, susceptibility ($p\leq.05$) and barriers ($p<.01$).

In a more recent, randomized-controlled, repeated measures study of adolescent women with type 1 diabetes with an age range of 13 - <20 years (mean age 16.7 yr, SD 1.7 yr) the HBM was used to examine the effects of a preconception counseling education program on health beliefs of seeking preconception counseling (Charron-Prochownik, Sereika, Hannan et al., 2006). It was reported that the adolescents in the intervention group had a significant interaction (group x time) effect for benefits of seeking preconception counseling; immediately post-intervention ($p<.001$) and 9-months post-intervention ($p=.03$). This group also had a significant ($p<.001$) decrease in their barriers to preconception counseling.

The HBM is a strong contributor to understanding preventive health behavior. Given that a mother's discussion of reproductive health issues with her adolescent daughter may promote better reproductive health outcomes in the adolescent with diabetes, the HBM was considered to be a suitable framework for this study.

2.2.2 Summary and Gaps in the Literature

It has been shown that preconception counseling can significantly reduce the incidence of maternal and fetal complications associated with an unplanned pregnancy of a woman with diabetes. In order for preconception counseling to be effective women must be aware of its existence and its components. If adolescent women are provided with the necessary information and support at an early age they will be more likely to prevent an unplanned pregnancy and seek preconception counseling prior to becoming sexually active. Mothers can be the source of this necessary information. Mothers, who feel their daughters with diabetes are susceptible to unplanned pregnancies and pregnancy-related complications, perceive these complications to be severe and see the benefits to and the barriers of their daughters seeking preconception counseling to prevent an unplanned pregnancy may be more likely to engage in reproductive health discussion with their daughters.

This study examined maternal knowledge and beliefs/attitudes of diabetes and reproductive health issues. The findings of this study can provide a basis for future intervention studies that will increase a mother's awareness, knowledge, attitude/beliefs, and intention to discuss and actual discussion of reproductive health issues, such as preventing an unplanned pregnancy and the need to seek preconception counseling, with her adolescent daughter with diabetes. This study has also provided implications for future research regarding actual content

of mother-daughter reproductive health sharing conversations. “Adolescents need someone who is knowledgeable about issues that concern them” (McManus, 2002, p.559). Mothers who are knowledgeable about diabetes and reproductive health issues can help to inform their daughters regarding the concerns of unplanned pregnancies and pregnancy-related complications.

Studies have been conducted about sexual activity with adolescents in the general population as well as those with a chronic illness and diabetes. From these studies, we know that adolescents are at risk for unplanned pregnancies and those with diabetes have similar risks when compared to those in the general population. Studies have also been conducted with adolescents in the general population that have found that there is a positive maternal influence on an adolescent’s sexual risk. However, there have been no studies that have looked at mothers’ influence on reproductive health behaviors with adolescent girls with diabetes. Nor have any studies used qualitative methods to examine reproductive health discussions among mothers and their adolescent daughters with diabetes, until now.

This study filled these gaps by examining mothers’ knowledge of diabetes and reproductive health, her intention to initiate reproductive health discussions and her actual discussion of reproductive health issues with her adolescent daughter with diabetes. This study was guided by the HBM in order to identify those constructs that were associated with a mother’s intention to initiate reproductive health discussions and actual discussion of those issues with her daughter. This study also used a qualitative design to examine a mother’s perspective about reproductive health discussions with her adolescent daughter with diabetes.

3.0 METHODS

3.1 STUDY DESIGN

A sequential explanatory mixed method design was used for this study. This study had 2 phases (quantitative and qualitative), each with a separate mode of data collection and analysis. *Phase 1* of this study utilized a repeated measures (baseline and 3-month), and correlational design to describe mother-daughter general communication, mother's knowledge of her daughter's diabetes and reproductive health, mother's beliefs/attitudes about her daughter's diabetes and reproductive health, mother-daughter intention to initiate discussion about reproductive health issues, and mother's actual discussion of these issues with her daughter. This study was part of a larger intervention trial where adolescent girls with type 1 diabetes between the ages of 13 to 19 years of age were recruited to participate in a randomized-controlled, clinical trial (RCT) that examined the effects of a newly developed CD-ROM preconception counseling educational program entitled "Reproductive Health Awareness for Teens with Diabetes (*READY-Girls*)" (Charron-Prochownik, Sereika, Hannan et al., 2006). Mothers did not receive an intervention, but they were identified as intervention group (IG) or control group (CG) based on their daughters' randomization in the RCT.

The *independent variables* for this study were mother-daughter general communication, mother's knowledge of diabetes and reproductive health, mother's health beliefs/attitudes of her

daughter's diabetes and reproductive health (mother's perception of her daughter's susceptibility/severity to unplanned pregnancy and pregnancy-related complications, mother's perception of her daughter's benefits of and barriers to preventing an unplanned pregnancy), and mother's social support of her daughter preventing an unplanned pregnancy. The ***dependent variables*** were mothers' intention to initiate discussion of diabetes and reproductive health issues with their daughters as they relate to preventing an unplanned pregnancy and pregnancy-related complications and mothers' actual discussion of these issues with their daughters.

Phase 2 of this study used a qualitative descriptive design that explored the mothers' perspectives about initiating reproductive health discussions with their adolescent daughters with diabetes (Creswell & Plano Clark, 2007). Within the context of this design, these data were intended to be supplemental to understanding the contributions mothers make to the phenomenon of reproductive health discussions between mothers and their adolescent daughters with diabetes. Qualitative description allows the researcher to describe a phenomenon in a way that is not highly abstract or interpretive, but is descriptive with low inference (Sandelowski, 2000b). Qualitative description was used for this study to elucidate the quantitative findings, rather than to develop theory. The mothers' interview responses are relevant to health care providers of adolescent girls with diabetes and for the future development of intervention studies that will include mothers. Due to the period of time (2 years) between mothers' completion of phase 1 of the study and their participation in the phase 2 interviews, mothers were asked if they would be willing to complete another set of 2 questionnaires after the interview, in order to examine for any differences from their 3-month follow-up responses to the time of their interviews. The questionnaires included the *Family Planning and Behavior* questionnaire and the *Initiating Discussion* questionnaire.

3.2 SAMPLE AND SETTING

3.2.1 Phase 1 – Quantitative Inquiry

Mothers were recruited for this study at the same time their daughters were recruited to participate in the RCT from the Pediatric Diabetes Clinic of Children's Hospital of Pittsburgh. Mothers were required to be English speaking and have an adolescent daughter with type 1 diabetes participate in the RCT. Mothers were to be living with their daughters, who could be natural, adoptive or step. Daughters were to be within the age range of 13 – 19 years, have no other chronic illness and could not be pregnant by self-report.

Sixty-two adolescents were recruited for the larger intervention study. However, due to a later submission of an amendment to the IRB for approval to include mothers for this study, only 44 mothers were recruited for phase 1 of this study. Three (7%) mothers dropped out of the study at 3 months follow-up. There was no significant difference in their demographic characteristics from those who completed the study. There were 19 (43%) mothers whose daughters' were in the IG group and 25 (57%) in the CG group. Mothers had a mean age of 45.3 years (SD = 5.3, range of 34 – 57.1). The majority of mothers were Caucasian (82%, n = 36), which was consistent with the prevalence of type 1 diabetes in Western Pennsylvania (Libman et al., 1998). The majority of mothers were college educated (73%, n = 32) and skilled workers (52%, n = 23). The only significant difference found between the treatment groups on any of the demographic characteristics of mothers was that there were 5 mothers in the control group who had diabetes (11% of total sample, 20% of control group). Two (40%) of these mothers reported using insulin and were diagnosed at 9 and 22 years of age, and 3 (60%) reported not using

insulin and were diagnosed after their first pregnancies. The demographic characteristics for mothers are summarized in Table 3.1.

Table 3.1 Demographic characteristics of mothers

Characteristic	Total sample* N = 44	Group	
		Intervention group* <i>n</i> = 19	Control group* <i>n</i> = 25
Age (years)	45.3 ± 5.3	46.5 ± 5.4	44.3 ± 5.2
Ethnicity			
African-American	4 (9)	1 (5)	3 (12)
Caucasian	36 (82)	17 (90)	19 (76)
Other / Native American	1 (2)	0 (0)	1 (4)
Missing	3 (7)	1 (5)	2 (8)
Marital status			
Never married	1 (2)	0 (0)	1 (4)
Married	38 (86)	17 (90)	21 (84)
Separated / divorced	5 (12)	2 (11)	3 (12)
Education			
≤ High school graduate	12 (27)	3 (16)	9 (36)
Attend some College	16 (36)		8 (32)
≥ College graduate	16 (36)	8 (42)	8 (32)
Employment			
Professional	6 (14)	5 (26)	1 (4)
Skilled	23 (52)	9 (47)	14 (56)
Unskilled	10 (23)	2 (11)	8 (32)
Unemployed	5 (11)	3 (16)	2 (8)
Family income			
≤\$5,999	1 (2)	0 (0)	1 (4)
\$6,000-11,900	1 (2)	1 (5)	0 (0)
>\$11,900-20,000	0 (0)	0 (0)	0 (0)
>\$20,000	41 (93)	18 (95)	23 (92)
Does not know income	1 (2)	0 (0)	1 (4)
Religion			
Protestant	28 (64)	15 (79)	13 (52)
Roman Catholic	15 (34)	4 (21)	11 (44)
None	1 (2)	0 (0)	1 (4)
Diabetes	5 (11)	0 (0)	5 (20)
Uses insulin and diagnosed before 1 st pregnancy	2 (5)	0 (0)	2 (8)
Doesn't use insulin	3 (7)	0 (0)	3 (12)
Gestational diabetes only	2 (5)	1 (5)	1 (4)

*Data are mean ± SD or n (%)

The daughters participating in the RCT had a mean age of 16.2 years (SD = 1.4, range of 13.7-18.9), with a mean age of diabetes onset of 8.7 years (SD = 4.3, range of 1-17). Twenty-five percent (n=11) of the adolescents were sexually active with a mean age of sexual debut of 15.2 years (SD = 1.4, range of 13-17). Almost half (45%, n=5) of those sexually active reported their parents knowing about their sexual activity. The mean for the adolescents' HbA1c levels was 8.8% (SD = 1.8, range of 6-13.9%) at baseline.

3.2.2 Phase 2 – Qualitative Inquiry

Criterion-related purposeful sampling was used to select a subset of 10 mothers from the total sample (N=44) for variation and complementarity, that is, to further elaborate on the results of the quantitative analyses (Miles & Huberman, 1994; Sandelowski, 2000a). Data from questionnaires administered in Phase 1 were used for criterion-related sampling (Sandelowski, 2000a). Participants were selected for variation on the following parameters: baseline knowledge and intention scores (low or high), daughters' group assignment (IG or CG), and daughters' age group (≤ 16 or ≥ 17 years) at the time of recruitment, and mothers' history of diabetes. Participants with scores below the median for knowledge and intention (knowledge = 60, intention = 13) were considered to have a low score; those with scores at or above the median score were considered to have a high score. The median was chosen as it represents the 50th percentile of a distribution of scores, the point where an equal number of scores will fall above and below the median score (Glass & Hopkins, 1996). Using this type of sampling technique was informationally representative (Sandelowski, 2000a) to the focus of this study.

Of the 10 mothers selected, 5 (50%) were from each group (IG and CG) with 6 (60%) mothers having daughters within the age range of 13-16 and low knowledge scores, and 7 (70%) had low intention scores. (Please refer to chapter 5, Tables 5.1 and 5.2 for the breakdown of mothers in each sampling parameter and sample demographics/characteristics.)

All 10 mothers had agreed to complete the third set of questionnaires after completion of the interviews. However, only 3 returned the consents and subsequent questionnaires. There were no significant differences on any of the demographic variables between the 3 interview participants who completed the third set of questionnaires and the 7 who did not.

3.2.3 Protection of Human Subjects

This study was approved by the University of Pittsburgh Institutional Review Board. Informed consents were obtained from mothers and adolescents ≥ 18 years of age. Parental consent and assent of the adolescent were obtained for adolescents < 18 years of age. Subject identification numbers were used to identify all data for this project. The principal investigator (PI) was responsible for examining all data for completeness and contacted subjects for any missing responses. All questionnaires were stored in a locked filing cabinet in the University of Pittsburgh's School of Nursing for confidentiality and protection of subject's identification. See Appendix A for IRB approval letter and Appendix B for consents.

3.3 MEASURES

3.3.1 Phase 1 – Quantitative Inquiry

Mothers and adolescents were assessed separately, at baseline and at 3-months post-intervention to coincide with the RCT. The pre-validated questionnaire called, *Family Planning Behavior and Diabetes Study Questionnaire* (Charron-Prochownik, Sereika et al., 2001; Wang, Charron-Prochownik, Sereika, Siminerio, & Kim, 2006), which was used with the adolescent girls in the RCT, was modified for mothers and used to measure demographic data, diabetes and reproductive health knowledge, the constructs of the HBM (i.e., susceptibility, severity, benefits, and barriers), and social support. For the HBM constructs, mothers' health beliefs reflected their perception of their daughters' health in relation to diabetes and reproductive health. The *Parent-Adolescent Communication scale (PAC)* (Barnes & Olson, 1985) was used to assess general communication, in which mothers reported their perception of general communication with their daughters and adolescents reported their perception of communication with their mothers. For the questionnaires, Teleform™ (version 6.0, Cardiff Software, Inc., Vista, CA), a Windows-based automated data entry/verification system, was used for form design, data entry, and data verification. The questionnaires used in this study are located in Appendix C.

3.3.1.1 Independent Variables

Demographic and clinical data: Demographic data were collected from the mother and adolescent at baseline, which included age, ethnicity, education level, marital status, household income, and religious affiliation. In addition, any history of diabetes or gestational diabetes was also collected from mothers. For adolescents, their age of diabetes onset, sexual activity, and age

of sexual debut was also collected. Nominally scaled categorical variables were marital status, religious affiliation, mother's history of diabetes or gestational diabetes and adolescent's sexually active status. Ordinally scaled variables were education level and household income. Ratio level variables were mothers' and adolescents' age in completed years.

General Communication: The PAC is a self-report instrument that measures both positive and negative aspects of communication, as well as content and process of the parent-adolescent interactions. It consists of a 20-item scale with a 5-point Likert-type response ranging from "strongly disagree" (scored as 1) to "strongly agree" (scored as 5). It contains two subscales, Open Family Communication (OFC) and Problems in Family Communication (PFC), each having 10 items that with a score range of 10 to 50. Internal consistency reliability was computed using Cronbach's alpha for the total scale and two subscales, OFC and PFC, which were .88, .87, and .78, respectively (Barnes & Olson, 1985). For the purpose of this study, only the OFC was used as this has found to be related to reproductive health communication between adolescents and their parents (Bettinger et al., 2004; Fisher, 1993). The measurement level of the scale score was highly ordinally scaled, but a composite score was used, which approximates interval scaling. Therefore, the OFC was treated as an intervally scaled score for analyses. Higher scores indicated more positive communication between mother and adolescent. See Appendix D for the letter giving permission to use the PAC.

Knowledge: Factual information about diabetes and reproductive health issues (pregnancy, birth control, and sexuality), and general family planning was measured by four separate scales. Summation scores of each scale represented knowledge of: 1) diabetes and pregnancy knowledge (12 items); 2) diabetes and birth control knowledge (4 items); 3) diabetes and sexuality knowledge (3 items); and 4) family planning knowledge (6 items). Knowledge

questions are dichotomous (true =1, false = 2). Each correct answer was given 1 point with a score range of 0-25 (0-100%). Summation scores of each scale was represented by percent correct (ratio data). Total summation of the 4 subscales was used for total knowledge, which was also represented by percent correct (ratio data). Higher scores indicated greater knowledge.

Items were originally formatted from a standard validated interview-schedule (Janz et al., 1995). Items were also derived or modified from several sources, "Pregnancy and Diabetes Assessment Form," (Magee-Womens Hospital, 1993) and the "Diabetes in Pregnancy Knowledge Screen" (Spirito, Ruggiero, Bond, Rotondo, & Coustan, 1990). Internal consistency reliability was computed using Cronbach's alpha coefficient, which was .71, and a test-retest reliability of $r = 0.76$. Still other items came from St. James's et al., (St. James et al., 1993) "Knowledge of Maternal Diabetes", which also has demonstrated predictive validity. Preliminary Cronbach's alpha coefficients were found for diabetes and pregnancy = .69; diabetes and contraception, and family planning were $< .50$, but modifications were made based on item-total statistics.

Attitudes: Attitudes were based on the Health Belief Model, the constructs were: *perceived susceptibility* (3 items, score range 3-15) to an unplanned pregnancy and pregnancy-related complications and *perceived benefits* (5 items, score range 5-25) of preventing an unplanned pregnancy and seeking preconception counseling (behavioral evaluation of effective family planning) were assessed with a 5-point Likert-type response ranging from 'Not at all' (scored as 1) to 'A lot' (scored as 5); *Perceived severity* (3 items, score range of 3-15) of those consequences was assessed with a 5-point Likert-type response ranging from 'Not serious at all' (scored as 1) to 'Very serious' (scored as 5); and, *Perceived barriers* (3 items, score range 2-15) to preventing an unplanned pregnancy and seeking preconception counseling (behavioral

evaluation of effective family planning) was assessed with 5-point Likert type scale with 2 questions using ‘Not at all difficult’ (scored as 1) to ‘Very difficult’ (scored as 5) and 1 item using ‘Does not apply’ (scored as 0) to ‘A big problem’ (scored as 5). Items were summed and higher scores represented stronger attitudes. The measurement level of the scale score was highly ordinally scaled, but a composite score was used, which approximates interval scaling. Therefore, the scales were treated as intervally scaled scores for analyses. The constructs of the HBM have Cronbach’s alpha coefficients of .73 for susceptibility, .77 for severity, .65 for benefits, and .72 for barriers (Charron-Prochownik, Wang, Sereika, Kim, & Janz, 2006).

Social support: Social support is the perceived availability of supportive behaviors (emotional, appraisal, informational, and instrumental) to be given to daughters for seeking preconception counseling and obtaining birth control. Eight items were based on a 5-point Likert-type response scale, ‘No support at all’ (scored as 1) to ‘A lot of support’ (scored as 5) with a score range of 8-40. The higher the mother’s score, the more social support the mother says she will provide to her daughter in seeking preconception counseling and obtaining birth control. The measurement level of the scale score was highly ordinally scaled, but a composite score was used, which approximates interval scaling. Therefore, social support was treated as an intervally scaled score for analyses. The original support scales demonstrated high internal consistency reliability (Cronbach’s alpha= .81) (Charron-Prochownik, 1991). More recent research showed even higher internal consistency based on Cronbach’s alpha of .92 (Charron-Prochownik, 2004).

3.3.1.2 Dependent Variables

Initiating Discussion: Intention to initiate discussion was measured using an adapted version of the RCT’s “*Initiating Discussion*” questionnaire. Mothers and adolescents self-reported on

intention to initiate discussion with the other regarding reproductive health issues. The measure contained 2 items with a 7-point Likert-type response scale ‘Unlikely’ (scored as 1) to ‘Likely’ (scored as 7) with a score range of 2-14. The items were summed and the higher scores indicated greater intention to initiate discussion. The measurement level of each item was highly ordinal, but was treated as an interval scale because the total score was used, not each individual item. Since the subscale total score had equal differences it was accepted as interval data. Internal consistency reliability has been reported to be .67 for intention (Charron-Prochownik, Wang et al., 2006).

Actual Discussion. Actual discussion was measured using the adapted version of the RCT’s “*Initiating Discussion*” questionnaire. Mothers self-reported on actual discussions with their daughters regarding reproductive health issues. The measure contained 4 items with a dichotomous choice of yes (1) or no (2). The no answers were rescored to be coded as 0. A total score was then tallied with a range of 0-4. The score was transformed into a dichotomous variable of no (0) or yes (1), indicating whether any discussion had not taken place or it had taken place. If a mother had a score of 0 this indicated no discussions had taken place. If she had a score range from 1-4 the score became a 1 this indicated a discussion had taken place. The variable was transformed to evaluate for behavior of actual discussion, not to examine content of discussions.

3.3.2 Phase 2 Qualitative Inquiry

An open-ended semi-structured telephone interview guide that began with a “grand tour” question (e.g., “I’d like for you to tell me about discussing reproductive health issues, such as monthly periods, sex, birth control or pregnancy with your daughter”) was used. Additional

questions probed the mother's perceptions of who initiated discussions, timing of discussions, barriers and facilitators to discussions, her comfort with initiation of discussion, and her perception of her daughter's comfort with discussions. There was no time limit to the interviews which generally lasted 20-30 minutes. The interview guide used in this study is located in Appendix E.

3.4 DATA COLLECTION AND PROCEDURE

3.4.1 Phase 1 – Quantitative Inquiry

The diabetes clinic nurse, a member of the research team, invited mothers to participate in this study at the same time they recruited the adolescent girls for the RCT. The nurse provided a full review of the study including the risks and benefits. During the initial clinic/study visit, after the consent was signed, mothers were assigned a study identification number that coincided with their daughters' and then were given the baseline questionnaires to complete. The 3-month visit for mothers was scheduled to coincide with their daughters' diabetes clinic appointment and the 3-month follow-up visit for the RCT. The mothers and daughters were each paid \$20 for their participation at each time point.

3.4.2 Phase 2 – Qualitative Inquiry

The interviews were conducted 2-3 years after completion of the quantitative inquiry portion of this study. Mothers were contacted by telephone to arrange a mutually convenient time for the

telephone interview and were instructed to allow 20-30 minutes for the interview. They were asked to provide a time that provided the most amount of privacy, free of interruptions and distractions. The principal investigator (MH) conducted interviews via the telephone using a semi-structured interview guide that began with a “grand tour” question (e.g., “I’d like for you to tell me about discussing reproductive health issues, such as monthly periods, sex, birth control or pregnancy with your daughter”). Additional questions probed the mother’s perceptions of who initiated discussions, timing of discussions, barriers and facilitators to discussions, her comfort with initiation of discussion, and her perception of her daughter’s comfort with discussions. There was no time limit to the interviews and they generally lasted 20-30 minutes. Interviews were digitally recorded, transferred to a secure laptop, transcribed verbatim, and reviewed by the PI for accuracy. Mothers were paid \$20 by mail for participation in the telephone interview.

3.5 DATA ANALYSIS

3.5.1 Phase 1 – Quantitative Inquiry Overview

SPSS for Windows v15.0 statistical software was used for all data analyses. All exploratory and descriptive analyses were conducted on the total sample and within each group (IG and CG) at each time point (baseline, 3-months). Inferential analyses were conducted on the total sample and within each group at each time point for the first 3 aims. For the 4th specific aim analyses were computed on the total sample and within group (IG and CG) over time. For the 5th specific aim, analyses were computed on the total sample and between groups (IG vs. CG) at each time point (baseline and 3-months).

3.5.1.1 Exploratory Data Analysis

Preliminary exploratory data analysis was conducted to appraise data accuracy, assess for missing values, detect outliers, and evaluate underlying assumptions (e.g., normality, linearity, homoscedasticity). More detailed exploratory analysis was conducted examining the relationships between each of the demographic, independent and dependent variables. All exploratory data analyses were accomplished separately for mothers and daughters as a total sample and within each group (IG and CG) at each time point (baseline and 3-months).

3.5.1.2 Appraisal of Data Accuracy

Data collection forms were examined immediately after collection for completion; participants were contacted for any incomplete data. Periodic proofreading of the database against raw data was conducted throughout the data entry process to insure the accuracy of data entry (Tabachnick & Fidell, 2001). Inconsistencies were examined with the generation of descriptive statistics and with the use of graphical representation of the variables. Minimum and maximum values, means and standard deviations were assessed to be sure they were plausible. Contingency checks were conducted to be sure that trigger and filtering questions were appropriate.

3.5.1.3 Treatment of Missing Data

Missing values were assessed for the degree and pattern for which they were missing (i.e., univariate, multivariate, bounded). All missing and extreme value data were appraised such that any values that were missing or were extremely high or low were validated with the original raw data. The missing data mechanism was characterized by both the data that were missing and the data observed as well as the dimensionality of the data. The best scenario for missing data was

for it to be missing randomly. If data were nonrandomly missing, the generalizability of the results would be affected (Tabachnick & Fidell, 2001). However, all missing data was determined to be missing completely at random. There were no subjects that had missing values greater than 20%. There were 3 subjects who had all data missing at 3-months due to attrition. These 3 cases were treated as missing. Imputation was not applied since the amount of missing data was insignificant.

In regards to mothers, two cases for mother's age (a modifying factor) were missing and treated as missing values. For general communication, 1 case was missing for the 3-month follow-up visit and was treated as missing. For the dependent variable of intention, one case was missing for the baseline assessment and 4 cases were missing at 3-month follow-up, these included the three mothers who dropped out at 3-months. For the dependent variable of actual discussion 4 cases were missing at 3-months, including the 3 mothers who dropped out. As for the daughters, for general communication, 1 case was missing at baseline and 5 were missing at 3-months. One of these 5 was a dropout and the other 4 were missed questionnaires. For intention, there were 2 missing cases at baseline and 6 cases missing at 3-months. Of these 6, one was a dropout, the others were missed questionnaires. These same 4 daughters, who did not complete the general communication questionnaire, did not complete the intention questions. These were all treated as missing cases using listwise deletion.

3.5.1.4 Outlier Assessment

Independent and dependent variables, as well as demographic data, were assessed for univariate and multivariate outliers with the use of descriptive, graphical and inferential statistics. For continuous variables, standardized scores with a value greater than the critical value of 3.29 ($p < .001$, two-tailed test) were considered to be outliers (Tabachnick & Fidell, 2001). This was

done on the total sample and by groups over time as well. Religion had one case reported as none that was a univariate outlier. Social support had 2 cases that had standardized Z-scores of -3.97 at baseline and 1 of -5.00 at 3-months. When groups were examined, there was 1 case in the control group that had a standardized score of -3.89 at 3-months.

Investigation for multivariate outliers was conducted computing Mahalanobis distance with the total sample and split by group. A critical value, $> \chi^2 (df = 8) = 26.13, p=.001$ was used for detection of multivariate outliers. There were no multivariate outliers found at baseline or 3-months for the total sample or when groups were examined.

3.5.1.5 Checking Underlying Assumptions

The data were examined for violation of the underlying assumptions of normality, linearity, and homoscedasticity. This was accomplished by analyzing the raw data (univariate) and residuals from regression analyses (multivariate). There was no violation of linearity. However, perceived benefits, perceived social support and mother's intention to initiate reproductive health discussion violated the assumption of univariate normality and homoscedasticity. Benefits and intention data were transformed, first reflecting the data and then applying logarithmic (base 10) transformation to improve their normal distributions. Social support was severely negatively skewed and data transformations using square root and logarithm were unsuccessful in normalizing this variable. Therefore, it was dichotomized into low scores ≤ 39 or high scores = 40. There were no violations of normality or homoscedasticity upon re-evaluation of these variables.

Multicollinearity was examined among predictor variables of perceived susceptibility, perceived severity, perceived benefits (transformed), perceived barriers, perceived social support

(transformed), and open communication at baseline and 3-months. No serious multicollinearity was seen at baseline or 3-months for the total sample or when groups were examined.

3.5.1.6 Descriptive Statistics

Appropriate descriptive statistics (i.e., means, medians, standard deviations, semi-quartile ranges for continuous-type data; frequency counts and percentages for categorical type data) were computed for mother and daughter demographic characteristics, mother's and daughter's general communication, mother's knowledge, mother's health beliefs/attitudes, mother's social support, mother's and daughter's intention to initiate to discussion of reproductive health issues, and mother's actual discussion of reproductive health issues at each assessment point (baseline and 3 months).

3.5.1.7 Data Analysis Procedures

General communication is the openness of general communication between the mother and her adolescent daughter with diabetes. Intention to initiate discussion about diabetes and reproductive health issues is the subject's (mother or adolescent) to speak with the other (adolescent or mother). Using correlational analysis may help us to understand if any relationship exists between these two variables (e.g., mothers who have more open communication have greater intention to speak with their daughters about diabetes and reproductive health issues).

Specific Aim #1 To examine bivariate associations between general communication and intention to initiate reproductive health discussion by subject type (mothers or adolescent girls with type 1 diabetes) within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 1 What is the association between general communication and intention to initiate reproductive health discussion for mothers and their adolescent girls with type 1 diabetes within each treatment group (IG, CG) at either time point (baseline or 3-months)?

Pearson's product moment correlation coefficient (r) was used to examine the relationship between general communication and intention to initiate reproductive health discussions for each subject type (mother and adolescent) in each group (IG and CG) at each time point (baseline, 3-months).

Specific Aim #2 To examine the agreement between mothers and daughters within dyads on general communication and intention to initiate reproductive health discussion within each treatment group (IG, CG) at each time point.

Question # 2a What is the agreement between mothers and daughters on general communication within each treatment group (IG, CG) at either time point (baseline, 3-months)?

Question # 2b What is the agreement between mothers and daughters on intention to initiate reproductive health discussion within each treatment group (IG, CG) at either time point (baseline, 3-months)?

Intra-class correlation coefficient was used to examine the agreement between mothers' and daughters' general communication, as well as mothers' and daughters' intention to initiate reproductive health discussion with the other. For both questions, #2a and #2b, IG mothers' scores were compared with IG adolescents' scores and CG mothers' scores were compared with CG adolescents' scores at each time point (baseline, 3-months).

Specific Aim #3 To examine bivariate associations between the dependent variables of intention to initiate reproductive health discussions and actual discussions of reproductive health issues with the independent variables of knowledge of diabetes and reproductive health, mother's

perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits of and barriers to her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 3a What are the any bivariate associations between the dependent variable of the intention to initiate reproductive health discussion and the independent variables of knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at either time point (baseline or 3-months)?

Question # 3b What are the bivariate associations between the dependent variable of actual reproductive health discussions and the independent variables of knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy with the total sample or within each treatment group (IG, CG) at either time point (baseline or 3-months)?

Pearson's product moment correlation coefficient was used to identify any associations between each of the independent variables with each of the dependent variables that were

continuous. Spearman's rho was used with the two dichotomous variables of social support and actual discussion.

Specific Aim #4 Compare differences over time (baseline to 3-months) of mothers within each treatment group (IG, CG) on knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support of daughter preventing an unplanned pregnancy, mother's intention to initiate reproductive health discussion with her daughter and, mother's actual discussion of reproductive health issues with her daughter.

Question # 4 What are the differences over time (baseline to 3-months) within mothers of adolescents in the IG or those within the CG on knowledge of diabetes and reproductive health, mothers' perception of daughters' susceptibility to pregnancy/pregnancy-related complications, mothers' perception of daughters' severity to pregnancy/pregnancy-related complications, mothers' perception of benefits to and barriers of their daughters preventing an unplanned pregnancy, mothers' social support of their daughters preventing an unplanned pregnancy, mothers' intention to initiate reproductive health discussion and, mothers' actual discussion of reproductive health issues?

Paired sample t-test was used to examine differences over time (baseline to 3-months) of mothers within each treatment group for the independent variables and dependent variables that were continuous. McNemar's test was used for the variables that were categorical.

Specific Aim #5 Compare treatment groups (IG vs. CG) on mothers' knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to

pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of the benefits and barriers of her daughter's prevention of an unplanned pregnancy, mother's social support, and intention to initiate reproductive health discussion at each time point (baseline, 3-months).

Question # 5 What are the differences between the treatment groups (IG vs. CG) for mothers' knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support, and intention to initiate reproductive health discussion at either time point (baseline or 3-months)?

Independent Samples t-test was used to examine differences between the two treatment groups (IG vs. CG) at each time point (baseline or 3-months) for each of the mothers' independent variables and dependent variables that were continuous. Fisher's exact test was used to examine the variables that were categorical.

In addition, change scores (baseline to 3-months) were computed by obtaining the difference between 3-month and baseline scores, then dividing this difference by the baseline score and multiplying by 100 to obtain a percent change score. Between-subject changes were further described using this percent change score. Percent means were compared between the two treatment groups using independent samples t-test.

3.5.1.8 Power Analysis

Post hoc power analysis was conducted using Pass (version 2007, NCSS, Kaysville, UT) for differences over time (baseline to 3-months) on intention to initiate reproductive health discussion. Power was estimated using between groups and the total sample. Change scores

were used to evaluate for differences between groups. With a mean difference between change scores of 0.25 and group standard deviations of 0.25 and 0.38 we were underpowered at 69% with 16 IG and 23 CG subjects and a two-sided alpha of 0.05. In order to achieve 81% power to detect a difference of 0.25 with an alpha of 0.05 we would need two group sample sizes of 27 each. On the other hand, looking at differences over time for the total sample we had a power of 82% with 39 subjects with a mean difference of 0.2 and a two-sided alpha of 0.05.

3.5.2 Phase 2 – Qualitative Inquiry

Specific Aim #6 Explore mothers’ perspectives (e.g., timing, who initiated, triggers, etc.) of initiating reproductive health discussions with their adolescent daughters with diabetes.

Question # 6 What are mothers’ perspectives about initiating reproductive health discussions with their adolescent daughters with diabetes?

Qualitative content analysis techniques were used to analyze the interview data (Miles & Huberman, 1994; Sandelowski, 2000b). “Qualitative content analysis is data-derived” (Sandelowski, 2000b, p. 338): that is, codes that are identified within the transcribed text are developed and defined. The unit of analysis was sentences or paragraphs. A qualitative database program, ATLAS.ti v5.2 was used to facilitate organization and maintenance of the data. Analyses began with dual review of the first two transcripts with the PI (MH) and an experienced qualitative researcher (MBH). Initial codes were labeled and defined by consensus agreement among coders. For each of the next two interviews, these investigators coded the data separately, and then reviewed each coded transcript together. The last 6 interviews were coded by the PI and then reviewed by the methodological expert. Each interview was reviewed, discussed and consensus was reached on all coded data during analytic meetings were conducted after each

interview. The code list and definitions were developed and refined with the coding of each interview. Comparisons were made within and across participant interviews during coding. Theoretical and methodological memoing (Miles & Huberman, 1994) techniques were also employed.

The following techniques were used to establish trustworthiness as described by Lincoln and Guba (Lincoln & Guba, 1985). Member checks were conducted by having one key informant and one certified diabetes educator review and comment on the overall adequacy of this report. In addition, an audit trail that includes the digitally recorded interviews, verbatim transcripts, coding template, data analysis notes, and analytic memos was developed to establish credibility. Transferability was addressed with the use of purposive sampling. Analysis by a second reviewer with expertise in qualitative analysis (MBH) enhanced rigor of the process and confirmability of findings.

4.0 RESULTS - QUANTITATIVE

The results of this research study were presented in the form of two manuscripts and a chapter of ‘other results’. The manuscript in section 4.1 presents the quantitative findings of the study and is titled, “Factors Associated with Initiating Discussion of Reproductive Health Issues between Mothers and their Adolescent Daughters with Type 1 Diabetes”. The manuscript that presents the qualitative findings is reported in Chapter 5 and is titled, “Mothers’ Perspectives about Reproductive Health of their Adolescent Daughters with Diabetes”. Other results from the specific aims not addressed in the two manuscripts are presented in Chapter 6.

4.1 QUANTITATIVE MANUSCRIPT

4.1.1 Abstract

Objectives: To: 1) describe and examine relationships of variables associated with mothers’ intention to initiate discussion and actual discussion of reproductive health (RH) issues; 2) compare differences of these variables over time; and, 3) identify predictors of RH discussions.

Research Design & Methods: A repeated-measures (baseline, 3-month) design was used as part of a larger preconception counseling RCT with adolescent girls with diabetes. Mothers in this study did not receive an intervention, but were identified according to daughters’ RCT

randomization assignment. Forty-four mothers participated; mean age of 45.3 years (SD=5.3, range 34-57.1) and 82% (n=36) were Caucasian.

Results: Overall, mothers reported high levels of general communication with their daughters. In regards to RH, mothers lacked knowledge, had strong beliefs/attitudes and high perceived social support. Mothers reported moderate levels of intention to speak with their daughters about RH issues; 55% reported having actual discussions. Intention was significantly associated ($r=.579$, $p<.05$) with general communication. There was a significant ($p<.05$) time effect for knowledge about diabetes and RH and perceived barriers to their daughters preventing an unplanned pregnancy, both increasing. There was a significant ($p<.05$) group-by-time effect for intention to initiate discussion with education ($p=.025$), general communication. ($p=.0002$) and severity ($p=.036$) in the model. For actual discussion there was a significant ($p<.05$) time effect with susceptibility ($p=.0164$) and social support ($p=.0407$) as covariates in the model.

Conclusions: Mothers with greater perceived susceptibility and social support were more likely to be talking with their daughters about RH issues. However, mothers lacked knowledge. Mothers could benefit from an intervention that provides information about diabetes and RH and guidance on how to improve their communication skills, to enhance their effectiveness when speaking with their daughters about diabetes and RH.

4.2 INTRODUCTION

Pregnancy during adolescence is considered to be high risk (Porter, 1988); type 1 diabetes increases those risks exponentially for maternal and fetal complications (Coustan, 1995; Rosenstock et al., 1988). To prevent maternal and fetal complications (e.g., birth defects) a

woman with diabetes must have tightly regulated blood glucoses prior to conception and throughout the pregnancy (Kitzmilller et al., 1996). The American Diabetes Association (ADA) recommends that all women with diabetes of childbearing age be counseled about the potential fetal and maternal complications associated with unplanned pregnancies through preconception counseling (American Diabetes Association, 2007). Many of these problems are potentially preventable by practicing effective reproductive health behaviors and instituting preconception counseling. It is of the utmost importance that adolescent women learn about how diabetes can affect their reproductive health and a pregnancy.

Parents can be influential figures in the life of the adolescent (Lefkowitz et al., 1998). They can be accessible and willing sources of information, which can be a significant factor in the knowledge, attitude and sexual behavior of the adolescent (Lefkowitz et al., 2000). Adolescent girls with type 1 diabetes are at risk for unplanned pregnancies and complications related to an unplanned pregnancy (Charron-Prochownik, Sereika et al., 2001). They need to have timely and accurate information. Although mothers of adolescent girls with diabetes can be a prime source of information, mothers' knowledge about diabetes and reproductive health is not known. It is also unknown as to whether or not mothers intend to discuss or actually have discussions with their daughters with diabetes about these important issues.

The purposes of this study were to: 1) describe the variables of mother's general communication, knowledge of diabetes and reproductive health (e.g., pregnancy, birth control and sexuality), beliefs/attitudes of diabetes and reproductive health, perceived social support for her daughter preventing an unplanned pregnancy, mother's intention to initiate reproductive health discussions and her report of actual discussions of reproductive health issues with her daughter at baseline and 3-months; 2) examine the associations between the independent

variables of general communication, knowledge and beliefs/attitudes of diabetes and reproductive health, and the dependent variables of intention to initiate discussions and actual discussion of reproductive health issues at baseline and 3-months; 3) compare within group and between group differences of the independent and dependent variables over time (baseline to 3-months); and, 4) identify any of the independent variables that may be associated with predicting mothers' intention to initiate reproductive health discussions and their actual discussions of reproductive health issues with their adolescent daughters.

4.3 RESEARCH DESIGN AND METHODS

This sub-study of mothers utilized a correlational and repeated-measures (baseline and 3-month follow-up) design. This study was part of a larger intervention trial where adolescent girls with type 1 diabetes between the ages of 13 to 19 years of age were recruited to participate in a randomized-controlled clinical trial (RCT). The RCT examined the effects of a newly developed CD-ROM preconception counseling educational program entitled “Reproductive Health Awareness for Teens with Diabetes (*READY-Girls*)” (Charron-Prochownik, Sereika, Hannan et al., 2006). In the RCT adolescent girls were randomly assigned to an intervention group (IG) or standard care control group (CG). However, although mothers did not receive an intervention as a part of this study they were identified as IG or CG based on their daughters' randomization in the larger RCT.

The underlying conceptual framework for selection of variables was the Health Belief Model (HBM). The HBM postulates that an individual is more likely to engage in a preventive health behavior to avoid a health problem/complication if she (1) feels susceptible to a health

problem or complication (e.g., a mother's perception of her daughter's susceptibility to an unplanned pregnancy and pregnancy-related complications), (2) perceives that the complication(s) would be serious (e.g., a mother perceives the complications of her daughter having an unplanned pregnancy to be serious), (3) considers the recommended behavior(s) to be beneficial in maintaining health (e.g., a mother's perception of the benefits to her daughter preventing an unplanned pregnancy and seeking preconception counseling), and (4) believes that the benefits of following the preventive health behavior recommendations outweigh the barriers (e.g., cost and inconvenience) to performing the behavior(s) (e.g., a mother's perception of the barriers to her daughter preventing an unplanned pregnancy and seeking preconception counseling) (Rosenstock, 1974; Strecher & Rosenstock, 1997). However, overt action (e.g., discussion of reproductive health issues) may not occur unless there is an instigating event, or cue to action that sets the course of action in motion (Rosenstock, 1974).

4.3.1 Sample

Mothers were recruited for this study at the same time their daughters were recruited to participate in the larger RCT from the Pediatric Diabetes Clinic of a large university-based tertiary center in Western Pennsylvania. To be eligible to participate, mothers were required to be English speaking and have an adolescent daughter participating in the larger RCT. Mothers were to be living with their daughters the majority of time, who could be natural, adoptive or step. Daughters were to be within the age range of 13 – 19 years and could not be pregnant by self report.

Institutional Review Board approval was obtained from the University of Pittsburgh. Informed consent was obtained from mothers and teens ≥ 18 years of age. Parental consent and

adolescent assent were obtained for teens < 18 years of age. Subject identification numbers were used to identify data for this project.

Forty-four mothers were recruited for this study (73% of 60 adolescent girls who participated in RCT). Mothers' recruitment started 3 months after recruitment of adolescent girls for the RCT as it was an amendment to the IRB. There were 19 (43%) mothers whose daughters' were in the IG group and 25 (57%) in the CG group. Mothers had a mean age of 45.3 years (SD = 5.3, range of 34 – 57.1). The majority of mothers were Caucasian (82%, n = 36), which was consistent with the prevalence of type 1 diabetes in Western Pennsylvania (Libman et al., 1998). The majority of mothers were college educated (73%, n = 32) and skilled workers (52%, n = 23). The only significant difference found between the assigned groups on any of the demographic characteristics of mothers was that there were 5 mothers with daughters in the control group who had diabetes (11% of total sample, 20% of control group). Two (40%) of these mothers reported using insulin and were diagnosed at 9 and 22 years of age, and 3 (60%) mothers reported not using insulin and were diagnosed after their first pregnancy. Three (7%) mothers dropped out of the study at 3 months follow-up. There was no significant difference in their demographic characteristics from those who completed the study. See Table 4.1 for mother's demographic data.

Table 4.1 Demographic characteristics of mothers (N=44)

Age (years)	45.3 \pm 5.3
Ethnicity	
African-American	4 (10)
Caucasian	36 (82)
Other / Native American	1 (2.5)
Missing	3 (7)
Marital status	
Never married	1 (2)
Married	38 (86)
Separated / divorced	5 (12)
Education	
High school grad or less	12 (27)
Attend some College	16 (36)
College grad or more	16 (36)
Employment	
Professional	6 (14)
Skilled	23 (52)
Unskilled	10 (23)
Unemployed	5 (11)
Religion	
Protestant	28 (64)
Roman Catholic	15 (34)
None	1 (2)
Mothers with Diabetes	
Pregestational diabetes using insulin	2 (5)
Post-gestational diabetes not using insulin	3 (7)
Gestational diabetes only	2 (5)

Data are means \pm SD and *n* (%).

The 44 daughters participating in the RCT had a mean age of 16.2 years (SD = 1.4, range of 13.7-18.9), with a mean age of diabetes onset of 8.7 years (SD = 4.3, range of 1-17), and a mean duration of diabetes of 7.2 years (SD = 4.5, range of 1-17). Twenty-five percent (n=11) of the adolescents were sexually active with a mean age of sexual debut of 15.2 years (SD = 1.4, range of 13-17). Almost half (45%, n=5) of those sexually active reported their parents knowing about their sexual activity. The mean for the adolescents' HbA1c levels was 8.8% (SD = 1.8, range of 6-13.9%) at baseline.

4.3.2 Measurement

Mothers were assessed at baseline and 3-months to coincide with the larger RCT. The larger study's pre-validated questionnaire called, *Family Planning Behavior and Diabetes Study Questionnaire* (Charron-Prochownik, Sereika et al., 2001; Wang et al., 2006), was modified for mothers and used to measure demographic data, diabetes and reproductive health knowledge, the constructs of the HBM (i.e., susceptibility, severity, benefits, and barriers), and social support. For the HBM constructs, mothers' health beliefs reflected their perception of their daughters' health in relation to diabetes and reproductive health. The *Parent-Adolescent Communication scale (PAC)* (Barnes & Olson, 1985) was used to assess general communication, in which mothers reported their perception of general communication with their daughters.

Demographic and clinical data: Demographic and clinical data collected included: age, ethnicity, marital status, education level, employment status, religious affiliation, and any history of diabetes or gestational diabetes. In addition, specifically for adolescents the following data were obtained from the larger intervention study: age, age of diabetes onset, sexual activity, age

of sexual debut, if parents know about sexual activity, and hemoglobin A1c, using the A1C At Home™ Sample Collection Kit.

Independent Variables

General Communication: The PAC is a self-report instrument that measures both positive and negative aspects of communication, as well as content and process of the parent-adolescent interactions. It contains two subscales, Open Family Communication (OFC) and Problems in Family Communication (PFC), each having 10 items, for a total of 20-items. For the purpose of this study, the OFC subscale was used as this has found to be related to reproductive health communication between adolescents and their parents (Bettinger et al., 2004; Fisher, 1993). The OFC consists of 10-items with 5-point Likert-type responses ranging from “strongly disagree” (scored as 1) to “strongly agree” (scored as 5) with a score range of 10 to 50. Internal consistency reliability was computed using Cronbach’s alpha for the OFC, which was .87 (Barnes & Olson, 1985). The measurement level of the scale score was highly ordinal scaled, but a composite score was used, which approximates interval scaling. Therefore, the OFC was treated as an intervally scaled score for analyses. Higher scores indicated more positive communication between the mother and her daughter.

Knowledge: Factual information about diabetes and reproductive health issues (pregnancy, birth control, and sexuality), and general family planning was measured by four separate scales (Janz et al., 1995; Magee-Womens Hospital, 1993; Spirito et al., 1990; St. James et al., 1993). Summation scores of each scale represent knowledge of diabetes and pregnancy (12 items), diabetes and birth control (4 items), diabetes and sexuality (3 items), and general family planning (6 items). Knowledge questions were dichotomous items (true =1, false = 2). Each correct answer was given 1 point with a score range of 0-25. Total summation of the 4

subscales was used for total knowledge, which is represented by percent correct (0-100%). Higher scores indicated greater knowledge. Predictive validity has been previously demonstrated (Charron-Prochownik, Sereika et al., 2001).

Attitudes: Mothers' beliefs/attitudes about their daughters are based on the HBM and the constructs were measured using a 5-point Likert-type response as follows: *perceived susceptibility* (3 items, score range 3-15) of daughter to an unplanned pregnancy and pregnancy-related complications; *perceived severity* (3 items, score range of 3-15) of those complications; *perceived benefits* (5 items, score range 5-25) of daughter preventing an unplanned pregnancy and seeking preconception counseling; and, *perceived barriers* (3 items, score range 2-15; one item used 'Does not apply' scored as 0) of daughter preventing an unplanned pregnancy and seeking preconception counseling. Items were summed and higher scores represented stronger beliefs/attitudes. The measurement level of the scale score was highly ordinally scaled, but a composite score was used, which approximates interval scaling. Therefore, the attitude scored scales were treated as intervally scaled scores for analyses. Cronbach's alpha coefficients have been reported to be .73 for susceptibility, .77 for severity, .65 for benefits, and .72 for barriers (Charron-Prochownik, Wang et al., 2006; Wang et al., 2006).

Social support: Social support is the perceived availability of supportive behaviors (emotional, appraisal, informational, and instrumental) to be given to daughters for preventing an unplanned pregnancy and seeking preconception counseling. Eight items are based on a 5-point Likert-type response scale, 'No support at all' (scored as 1) to 'A lot of support' (scored as 5) with a score range of 8-40. The higher the mother's score, the more social support the mother perceives she will provide to her daughter in preventing an unplanned pregnancy and in seeking preconception counseling. The measurement level of the scale score was highly ordinally scaled,

but a composite score was used, which approximates interval scaling. Cronbach's alpha coefficient was reported as .92 (Charron-Prochownik, 2004). Due to a ceiling effect this variable was dichotomized into low scores ≤ 39 (0) or high scores = 40 (1).

Dependent Variables

Initiating Discussion: Intention to initiate reproductive health discussion was measured using an adapted version of the larger study's "*Initiating Discussion*" questionnaire. Mothers self-reported on intention to initiate discussion with their daughters regarding reproductive health issues. The measure contained 2 items with a 7-point Likert-type response scale with a score range of 2-14. The items were summed and the higher scores indicated greater intention to initiate discussion. The measurement level of the scale score was highly ordinal scaled, but a composite score was used, which approximates interval scaling. Therefore, the intention scaled score was treated as an intervally scaled score for analyses. Internal consistency reliability has been reported as .67 for intention (Charron-Prochownik, Wang et al., 2006).

Actual Discussion: Actual discussion was measured using the adapted version of the larger study's "*Initiating Discussion*" questionnaire. Mothers self-reported on actual discussion with their daughters regarding reproductive health issues. This is a 4-item measure with a dichotomous choice of no (0) or yes (1) ("Have you ever started a discussion with or asked questions of your daughter regarding reproductive health, such as: 1. diabetes and pregnancy; 2. diabetes and sexuality; 3. diabetes and birth control; and, 4. diabetes and preconception counseling"). A total score was tallied with a range of 0-4. The score was then transformed into a dichotomous variable of no (0) or yes (1). If a mother had a score of 0, which indicated no discussion had taken place, the score stayed a 0. If she had a score range from 1-4, which indicated some discussion had taken place, the score became a 1. The variable was transformed

to evaluate for behavior of actual reproductive health discussion, not to examine content of the discussion.

4.3.3 Procedure

The diabetes clinic nurse, a member of the research team, invited mothers to participate in this study at the same time they recruited the adolescent girls for the larger intervention study. During the initial clinic/study visit, after the consent was signed, mothers were assigned a study number that coincided with their daughters' and then were given self-administered paper/pencil baseline questionnaires. After completion the questionnaires were given back to the nurse and were subsequently collected by another research team member. The 3-month visit was then scheduled to coincide with the daughter's diabetes clinic appointment and larger RCT. The mothers were reimbursed \$20 for their time at each visit, baseline and 3-months.

4.3.4 Data Management and Statistical Analysis

Teleform™ (version 6.0, Cardiff Software, Inc., Vista, CA), a Windows-based automated data entry/verification system, was used for form design, data entry, and data verification for all paper/pencil questionnaires. SPSS for Windows v15.0 and SAS v9.1.3 statistical software were used for data analyses. All exploratory analyses were conducted with the total sample (N=44) and within each group (IG, CG) at each time point (baseline, 3-months). Frequencies, percentages, means and standard deviations were used for variable description.

The primary analysis methods used included bivariate correlations, repeated measures and linear mixed modeling. Bivariate associations were examined using Pearson's product

moment correlation coefficient for two continuous variables that did not violate the assumptions of parametric correlational analysis (e.g., normality, linearity and homoscedasticity). Spearman's rank correlation coefficient was used with two ordinal variables. Paired sample t-test was used to examine within group differences over time for the continuous variables of communication, knowledge, susceptibility, severity, benefits, barriers and intention. McNemar's test was used to examine within group differences over time for the ordinal variables of social support and actual discussion. Independent samples t-test was used to examine between group differences on the continuous variables at each time point. Due to the small sample size and cell sizes, Fisher's exact test was used to examine between group differences for the ordinal variables at each time point. Linear mixed modeling was used to predict intention to initiate discussion and actual discussion of reproductive health issues over time between groups, while controlling for covariates.

4.4 RESULTS

4.4.1 Descriptive

Overall, mothers in this study reported having high open family communication with their daughters at both times points. Mothers' total knowledge was low (mean=60%, SD=19) at baseline and remained low (mean=70%, SD=20) at 3-months. When each of the 4 subscales of knowledge were examined separately it was found that mothers scored the lowest on diabetes and pregnancy, followed by diabetes and contraception, and then diabetes and sexuality. General family planning knowledge had the highest scores. These findings were consistent at baseline

and 3-months. However, the 3 subscales of knowledge regarding diabetes and reproductive health scores increased from baseline to 3-months, where knowledge of general family planning stayed the same.

It was also found that mothers perceived their daughters to be moderately susceptible to unplanned pregnancies and pregnancy-related complications at both time points and had high perceived severity of these complications. Most mothers perceived their daughters would benefit from preventing an unplanned pregnancy and felt at baseline there were few barriers. However, at 3-months, although the benefit scores did not change, their barrier scores increased. Mothers reported very high perceived social support in helping their daughters prevent an unplanned pregnancy and seek preconception counseling at both time points. However, mothers reported only moderate intentions to speak with their daughters about reproductive health issues and reported even lower scores of actual discussion of these issues. Actual discussion did increase at 3-months from 55% to 66%. There were no significant between-group differences at either time point on any of the variables.

4.4.2 Associations between the independent and outcome variables

Mothers' age was significantly ($p < .05$) associated with intention to initiate reproductive health discussions at baseline in the negative direction; younger mothers had greater intentions to speak with their daughters. Mothers' education was significantly associated with intention at 3-months; mothers with a higher education level were more likely to have greater intentions. Significant associations ($p < .05$) between the independent variables and outcome variables were also found. Greater intention to initiate reproductive health discussions was significantly ($p < .05$) associated with greater general communication at both time points, with greater perceived

severity at baseline and with both greater benefits and lower barriers at 3-months. Actual discussion of reproductive health issues was significantly ($p<.05$) associated with greater susceptibility and greater social support at baseline. There were no significant associations for actual discussion at 3-months. Intention and actual discussion were not significantly associated at either time point. Group assignment was not significantly associated with either intention or actual discussion at either time point. See Tables 4.2 and 4.3.

Table 4.2 Association between independent variables and intention to initiate discussion at each time point

	Baseline (N=43)	3-months (N=40)
Communication & Intention	.579**	.389*
Knowledge & Intention	.062	.228
Susceptibility & Intention	.125	.076
Severity & Intention	.368*	.090
Benefits & Intention	.014	.526**
Barriers & Intention	-.091	-.331*
Social support & Intention	.220	.279
Mother's age & Intention	-.327*	.090
Education & Intention	.078	.333*
Religion & Intention	-.014	.115
HbA1c & Intention	.170	-.111
Group & Intention	-.013	.182

Data are Pearson product moment correlations coefficients.

** $p \leq .01$, * $p \leq .05$ (2-tailed).

Education: 0 = High school, 1 = Attend some college, 3 = college grad.

Religion: 0 = Catholic, 1 = Protestant.

Group: 0 = control group, 1 = intervention group.

Intention and barriers were transformed using reflect and logarithmic (base 10). Social support was transformed into low (<39) or high (=40) scores.

Table 4.3 Association between independent variables and actual discussion at each**time point**

	Baseline (N=44)	3-months (N=41)
Communication & Actual discussion	.105	.016
Knowledge & Actual discussion	.103	.304
Susceptibility & Actual discussion	.317*	.025
Severity & Actual discussion	.084	.048
Benefits & Actual discussion	.026	-.060
Barriers & Actual discussion	.071	.086
Social support & Actual discussion†	.316*	.139
Mother's age & Actual discussion	.017	.243
Education & Actual discussion†	-.015	.229
Religion & Actual discussion†	-.178	-.021
HbA1c & Actual discussion	.231	.286
Intention & Actual discussion	.211	-.089
Group & Actual discussion†	.059	.075

Data are Pearson correlation coefficients, except as noted.

† Data are Spearman rho.

** $p \leq .01$, * $p \leq .05$ (2-tailed).

Actual discussion: 0 = no, 1 = yes.

Education: 0 = High school, 1 = Attend some college, 3 = college grad.

Religion: 0 = Catholic, 1 = Protestant.

Group: 0 = control group; 1 = intervention group.

Intention and barriers were transformed using reflect and logarithmic (base 10). Social support was transformed into low (<39) or high (=40) scores.

4.4.3 Differences between baseline and 3-months scores

There was a significant ($p < .05$) time effect for mothers' knowledge and barriers between baseline and 3-months irrespective of their daughters' group assignment. Both knowledge and barriers increased from baseline to 3-months. Table 4.5 presents the variable scores and t-test values.

Table 4.4 Mothers' scores on all variables at each time point

Variables (Possible Score Range)	Mothers N=44		<i>t</i> -test baseline and 3-month	Effect size‡
	Baseline	3-month	t-value	Cohen's d
Communication (10-50)	39.4 ± 6.5	39.1 ± 6.5	.300	.05
Knowledge (0-100%)	60.1 ± 18.9	69.9 ± 19.9	-3.413**	.51
Susceptibility (3-15)	9.1 ± 3.1	9.4 ± 3	-1.492	.098
Severity (3-15)	12.6 ± 2.4	12.8 ± 2.7	-.973	.078
Benefits (5-25)	.301 ± .377	.301 ± .349	.119	.184
Barriers (2-15)	5.9 ± 2.4	8.7 ± 3.5	-8.733**	.93
Social support† (% high)	75%	68%	0.41	0.71 (OR)
Intention (2-14)	.301 ± .372	.477 ± .367	-1.248	0.16
Actual discussion† (% Yes)	55%	66%	0.40*	3 (OR)

Data are mean ± SD, unless otherwise indicated.

** $p \leq .01$, * $p \leq .05$ (2-tailed).

† McNemar's test.

‡ Cohen's d, except where noted.

Intention and barriers were transformed using reflect and logarithmic (base 10).

Social support was transformed into low (<39) or high (=40) scores.

OR – Odds ratio.

4.4.4 Predicting intention to initiate and actual discussion of reproductive health issues

When using linear mixed modeling to predict intention, there was a significant ($p=.035$) group-by-time effect when no covariates were included in the unadjusted model, where the intervention group had a slight increase over time and the control group had a significant ($p<.05$) decrease over time. In an adjusted model, where covariates were omitted in a backward fashion based on p -values $> .20$, the group-by-time effect remained significant ($p=.049$). The covariates that remained were education ($p=.025$), general communication ($p=.0002$) and severity ($p=.036$). The covariates that were removed were knowledge, susceptibility, benefits, barriers, social support, mother's age, and religion.

For the behavior of engaging in actual discussion, there was only a significant ($p=.0135$) time effect when no covariates were included in the model, where both groups showed increases over time. The addition of covariates one at a time identified susceptibility ($p=.0164$), social support ($p=.0407$), and total knowledge ($p=.0324$) as significant. The remaining covariates (general communication, severity, benefits, barriers, mother's age, education, religion) had p -values $>.20$. The time effect remained significant when susceptibility and social support were added to the model, but became marginally significant when knowledge was added. When these three covariates were simultaneously added to the model, each was significant (p -values around $.04$) and the time effect was marginally significant ($p=.0985$).

4.5 CONCLUSIONS

Not surprisingly, only half of the mothers in this study reported having had an actual discussion with their daughters about reproductive health issues at baseline with a slight, non-significant, increase at 3-months. The results of predictive modeling for actual discussion showed that mothers who perceived their daughters as being susceptible to an unplanned pregnancy, perceived themselves as providing social support, and had greater reproductive health knowledge were more likely to actually talk with their daughters about diabetes and reproductive health issues. Interestingly, the predictive model for a mother's intention to initiate reproductive health discussion showed that mothers who reported having greater open communication with their daughters, perceived more severe complications if their daughters had an unplanned pregnancy, and had some college education had greater intention to speak with their daughters about diabetes and reproductive health issues. In this study, a mother's intention to initiate discussion was not significantly associated with her actual discussion and both predictive models had different predictors. Differences in these models could be due to daughters' age and/or mothers' age.

In general, mothers in this sample had greater open general communication with their daughters. As expected, mothers lacked diabetes-related reproductive health knowledge, which is similar to previous findings from the larger RCT of daughters who lack this information as well (Charron-Prochownik, Sereika, Hannan et al., 2006). However, mothers had strong beliefs about diabetes and their daughters' reproductive health. They also had high perceived social support in helping their daughters prevent an unplanned pregnancy.

At both time points (baseline, 3-months), mothers indicated that they perceived their daughters to be only moderately susceptible to an unplanned pregnancy, but had high perceived

severity of pregnancy-related complications. Surprisingly, mothers perceived strong benefits to their daughters preventing an unplanned pregnancy and seeking preconception counseling. Unexpectedly, mothers' perceived barriers to their daughters' preventing an unplanned pregnancy and seeking preconception counseling increased from baseline to 3-months. Therefore, although mothers could see the benefit of their daughter preventing an unplanned pregnancy and seeking preconception counseling they did not feel that their daughters would be able to do so adequately.

There was an unexpected group-by-time interaction effect for mothers' intention to initiate reproductive health discussions with her daughter. It was the mothers whose daughters were in the CG group who had a significant decrease in their intentions from baseline to 3-months, which may be an indirect effect of their daughter participating in the larger RCT. However, as expected, when controlling for covariates and group assignment, mothers with higher education, higher general communication and higher perceived social support were more likely to intend to speak with their daughters about reproductive health issues. This is consistent with findings reported in the literature on the general population, whereby higher general communication was significantly associated with maternal communication about sex (Hutchinson & Montgomery, 2007).

Several independent variables in this study were constructs derived from the HBM. Relationships between the independent and dependent variables were found based on the assumptions of the HBM. In the bivariate analysis, a mother's intention to speak with her daughter about reproductive health issues was significantly associated with greater severity, greater benefits and lower barriers. However, only severity was a significant predictor in the multivariate analysis. Mothers' actual discussion of reproductive health issues was significantly

associated with greater susceptibility, which was confirmed with multivariate analysis. These findings were in the hypothesized direction of the HBM, which is consistent with other studies (Brock & Beazley, 1995; Elliott et al., 2001; Soliday & Hoeksel, 2000) that used the HBM to examine parental health beliefs/attitudes associated with preventive health behavior in regards to their children and adolescents.

It is important for mothers to not only intend to speak with their daughters about reproductive health issues, but to actually do so with the correct information. Parent-child sexual communication has been reported to be one of the most critical processes to have a positive impact on adolescent sexual behavior (Hutchinson, 2002, 2007). However, the mothers in this study lacked knowledge about these issues. Mothers' overall knowledge was low, specifically their knowledge regarding diabetes and pregnancy, birth control and sexuality, which parallels the adolescents' knowledge in the larger CT study (Charron-Prochownik, Sereika, Hannan et al., 2006) and in a previous study of 80 adolescents with diabetes. (Charron-Prochownik, Sereika, Falsetti et al., 2006). Although mothers' knowledge increased from baseline to 3-months, it may have been due to an indirect effect of being in this study. On the other hand, it may also indicate that these mothers were stimulated to seek more knowledge about these very important reproductive health issues.

4.5.1 Limitations

There were several limitations of this study. The small sample size makes it difficult to generalize to the larger population. However, a repeated-measures design was used to increase the power of the findings. There may have been an indirect effect on the mothers whose daughters were in the intervention group. However, group assignment was controlled for and no

significant differences were found between mothers whose daughters were in the intervention group with those mothers with daughters in the control group. The last limitation of this study to mention is that of the dependent variable of actual discussion, which was a dichotomous variable. However, intention is a strong predictor of behavior, and was also measured.

4.5.2 Implications

4.5.2.1 Practice

This study is unique in that it raises awareness of the importance of maternal involvement in reproductive health discussions with adolescent daughters with diabetes. It is imperative that mothers, as well as health care providers be able to provide the proper information about reproductive health to adolescent women with diabetes to help them make well-informed reproductive health decisions. Mothers can provide valuable support to their daughters with diabetes in regards to the issues surrounding diabetes and reproductive health. Diabetes nurse educators need to include mothers when discussing these very important issues with adolescents. Diabetes nurse educators can assist mothers in their discussions with their daughters by making sure that mothers have the correct information. Mothers can be taught how to capitalize on ‘everyday triggers’ to initiate or resume conversations with their daughters. Nurse educators should recognize that despite available information and media references to sexual activity in popular culture, discussions between mothers and adolescent daughters are still difficult.

4.5.2.2 Research

The findings in this study indicate that an intervention targeting mothers’ knowledge, comfort and communication skills regarding diabetes and reproductive health and communication with

their daughters about these issues is needed. The findings of this study provide a good basis for developing an education program specifically designed for mothers of adolescent girls with diabetes. However, further research is needed to evaluate actual discussion of reproductive health issues between mothers and their adolescent daughters with diabetes. Perhaps in selecting predictor variables a larger composite model including subjective norm from the Theory of Reasoned Action could be included. Future research could also examine dyadic responses as well as the influence of race, early pubertal development and religion or spiritual influence on a mother's intention or actual behavior of discussing reproductive health issues with her daughter. Future research with a larger sample size should include adolescent girls with type 2 diabetes. It should also examine the relationship between general knowledge of diabetes, adolescents' duration of diabetes, metabolic control and self-management of diabetes regimen with the 2 outcome variables of intention to initiate discussion and actual discussion of reproductive health issues between mothers and their adolescent daughters with diabetes.

5.0 RESULTS - QUALITATIVE

5.1 QUALITATIVE MANUSCRIPT

5.1.1 Abstract

Objectives: The purpose of this study was to explore mothers' perspectives about reproductive health (RH) discussions with their adolescent daughters with diabetes.

Research Design & Methods: This study of mothers used a sequential explanatory mixed method design with 2 phases. Phase 2, the focus of this report, was a qualitative descriptive study using open-ended semi-structured telephone interviews. Ten mothers from a larger study sample were selected by criterion-related purposeful sampling. Qualitative content analysis techniques were used to analyze the interview transcripts.

Results: The following 5 themes regarding mothers' perspectives about RH discussions with their adolescent daughters with diabetes were identified: 1) maternal awareness; 2) maternal knowledge; 3) triggers for initiating RH discussions; 4) maternal fears/concerns; and, 5) maternal comfort level with RH discussions. Some mothers were aware of their daughters' sexual activity and were aware that their daughters should preplan a pregnancy. They knew that an unplanned pregnancy may have detrimental effects on their daughters' health and feared that their daughters would have an unplanned pregnancy. A major trigger for mothers to initiate RH discussions was

when a daughter had a steady boyfriend. Mothers' fears and concerns were focused around their daughters having an unplanned pregnancy. Overall, mothers were not comfortable with reproductive health conversations.

Conclusions: Mothers fear unplanned pregnancies for their diabetic daughters and want to discuss RH issues, but are uncomfortable doing so. Diabetes educators could be instrumental in educating and providing communication skills to mothers about diabetes and RH to help their adolescent daughters.

5.2 INTRODUCTION

Adolescence is a time when sexual risk-taking behaviors emerge (Feldman & Elliott, 1997; Wiener & Cohen, 1997). It has been reported that 43% of high school white females have been sexually active (Grunbaum et al., 2004). Almost half had an onset of sexual debut by the tenth grade. Of these, only 57% reported condom use and 27% used birth control during their last sexual intercourse. Similar patterns of sexual activity have been reported in adolescents with type 1 diabetes (Charron-Prochownik et al., 2002; Falsetti et al., 2003). In a multi-site phone survey of 87 adolescent girls with diabetes with a mean age of 17.86 years (SD=1.26, range 16-22) it was found that 43% had been sexually active (Falsetti et al., 2003). These adolescents with diabetes had their sexual debut at a mean age of 15.8 years (SD=1.2, range 14-18). Seventy-three percent reported use of a condom at each sexual encounter. However, only 30% reported the use of combination methods for birth control (i.e., condom with another method). In another report of 47 adolescent girls with diabetes with a mean age of 17.4 years (range 16-19) 32% reported being sexually active (Charron-Prochownik et al., 2002). In summary, from these

studies, adolescents with diabetes have similar sexual risk-taking behaviors as adolescents in the general population.

Risk-taking sexual behaviors may result in negative consequences, such as an unplanned pregnancy and complications (Burns et al., 1996). Approximately 400,000 American teens in the general population become pregnant each year (Abma et al., 2004; Hamilton et al., 2005), with approximately 80% being unplanned (Henshaw, 1998). Pregnancy rates for teens with diabetes are consistent with those of the general population. In the previously reported multi-site phone survey (Falsetti et al., 2003), 11% of the adolescent girls with diabetes had reported having at least one unplanned pregnancy. Pregnancy during adolescence is considered to be high risk (Porter, 1988), and diabetes presents added risks for maternal and fetal complications.

According to the American Diabetes Association (2007), all women with diabetes of child-bearing age, starting at puberty, must receive preconception counseling and be educated about the risks of an unplanned pregnancy so that they may be empowered to be in control of their own reproductive health. It has been reported that adolescent girls with diabetes have limited awareness of how diabetes can affect their reproductive health, and of the risks of unplanned pregnancies to maternal and fetal complications (Charron-Prochownik, Becker et al., 2001; Charron-Prochownik, Sereika et al., 2001). However, mothers can be key figures in dissemination of this very important reproductive health information to their adolescent daughters. Fortunately, parental involvement, such as mother-daughter sexual communication has shown to decrease the risk of negative developmental outcomes and prevent high-risk behaviors, such as, unprotected sex, in adolescents (Anderson et al., 1999; Resnick et al., 1997; Whitaker & Miller, 2000).

Although many studies have investigated reproductive health communication between mothers and daughters in the general population no studies have examined reproductive health communication between a mother and her daughter with diabetes. Moreover, no studies have examined what mothers think about discussing these very important issues with their daughters with diabetes. Therefore, the purpose of this study was to explore mothers' perspectives about initiating reproductive health discussions with their adolescent daughters with diabetes.

5.3 RESEARCH DESIGN AND METHODS

This qualitative descriptive study used semi-structured telephone interviews to explore mothers' perspective of reproductive health discussions with their adolescent daughters with diabetes. As the second phase in a sequential explanatory mixed method design (Creswell & Plano Clark, 2007), this study's sample (n=10) was purposively selected from the primary quantitative correlational and repeated measures study (n=44).

The sequential explanatory mixed method design is a two-phase model, where quantitative data is collected in the first phase and qualitative data is collected in the second phase (Creswell & Plano Clark, 2007). The qualitative phase, the interviews in this study, is designed so that it is linked to the quantitative results of the first phase. However, in this report we are focusing only on the interview data.

This study of mothers was nested within a larger randomized, controlled clinical trial (RCT) that examined the effects of a newly developed CD-ROM preconception counseling educational program entitled "Reproductive Health Awareness for Teens with Diabetes (RHATD)" (Charron-Prochownik, Sereika, Hannan et al., 2006). Adolescent girls with type 1

diabetes between the ages of 13 to 19 years of age participated in the RCT while their mothers participated in the current study. See Figure 5.1.

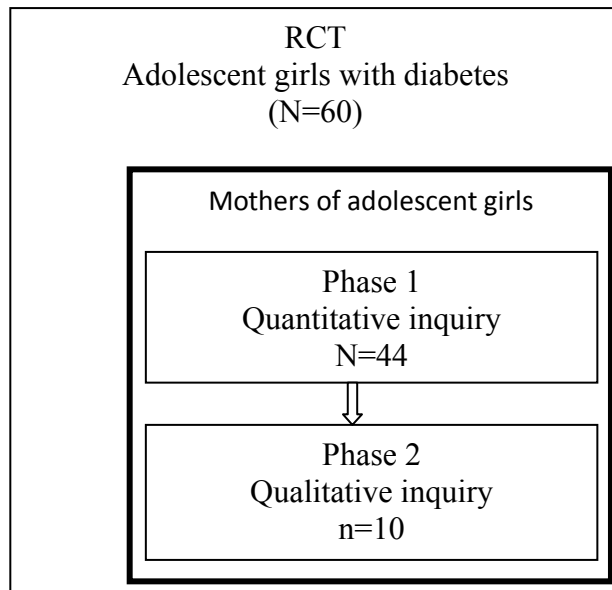


Figure 5.1 Sequential explanatory mixed method design

5.3.1 Sample

Mothers were recruited for the current study when their daughters' were recruited to participate in the RCT of preconception counseling education intervention. Mothers did not receive an intervention, however, they were labeled as intervention group (IG) or standard care control group (CG) based on their daughters' randomization in the larger RCT. Mothers were required to be English speaking and living with their daughters, who could be natural, adoptive or step. We used criterion-related purposeful sampling to select a subset of 10 mothers from the total sample (n=44) (Sandelowski, 2000a). Participants were selected for variation on the following

parameters: baseline knowledge (modified Family Planning Behavior and Diabetes Study Questionnaire) and intention scores (modified Initiating Discussion questionnaire), daughters' group assignment (IG or CG), and daughters' age group (≤ 16 or ≥ 17 years) at the time of recruitment. Data from questionnaires administered in Phase 1 were used for criterion-related sampling (Sandelowski, 2000a). Table 5.1 presents the breakdown of sampling parameters. Table 5.2 presents a sampling matrix.

Table 5.1 Sampling parameters (n=10)

Daughter's group assignment	
Intervention	5 (50)
Control	5 (50)
Daughter's age group	
13-16 years	6 (60)
17-20 years	4 (40)
Mother's knowledge	
Low $\leq 60\%$ correct	6 (60)
High $> 60\%$ correct	4 (40)
Mother's intention to initiate discussion	
Low ≤ 13	7 (70)
High > 13	3 (30)
Data <i>n</i> (%).	

Table 5.2 Sampling matrix

Intervention group						Control group				
	Daughter's age group 13-16 years		Daughter's age group 17-19 years			Daughter's age group 13-16 years		Daughter's age group 17-19 years		
	Maternal history of diabetes		Maternal history of diabetes			Maternal history of diabetes		Maternal history of diabetes		
	Yes	No	Yes	No		Yes	No	Yes	No	Total
Low knowledge / Low intention		1					1	1	1	4
Low knowledge / High intention		1		1						2
High knowledge / Low intention	1	1							1	3
High knowledge / High intention							1			1
Total	1	3	0	1		0	2	1	2	10

The following 2 paragraphs describe the measures used for sample selection. The *Family Planning Behavior and Diabetes Study Questionnaire* (Charron-Prochownik, Sereika et al., 2001; Wang et al., 2006), which was used with the adolescent girls in the RCT, was modified for mothers in this study. This questionnaire measured mothers' demographic characteristics, and mothers' reproductive health knowledge. Four subscales measured knowledge of diabetes and pregnancy, diabetes and birth control, diabetes and sexuality, and general family planning. Summation of these 4 subscales comprised total knowledge, which is represented by percent correct (0-100%). Baseline scores of knowledge were dichotomized into low and high for sampling purposes. The median score of 60 was used as the cut point. Knowledge scores below 60 were considered to be low and those above 60 were considered to be high. The median score was chosen as it represents the 50th percentile of a distribution of scores, the point where an equal number of scores will fall above and below the median score (Glass & Hopkins, 1996).

Intention to initiate reproductive health discussion was measured using an adapted version of the larger study's "*Initiating Discussion*" questionnaire (Charron-Prochownik, Wang et al., 2006). Mothers self-reported their intention to initiate discussion with their daughters regarding reproductive health issues. The measure contained 2 items with a 7-point Likert-type response scale with a score range of 2-14. The items were summed and the higher scores indicated greater intention to initiate discussion. Baseline scores of intention were dichotomized into low and high for sampling purposes. The median score of 13 was used as the cut point. Intention scores below 13 were considered to be low and those above 13 were considered to be high. The median score was chosen as it represents the 50th percentile of a distribution of scores, the point where an equal number of scores will fall above and below the median score (Glass & Hopkins, 1996).

This study was approved by the University of Pittsburgh Institutional Review Board. Informed consent was obtained from mothers. To maintain confidentiality, transcripts were identified only by the subject identification number assigned at the beginning of the study. Mothers were compensated \$20 for their time during the interview.

5.3.2 Data Collection

The principal investigator (PI) conducted interviews via the telephone using a semi-structured interview guide that began with a “grand tour” question (e.g., “I’d like for you to tell me about discussing reproductive health issues, such as monthly periods, sex, birth control or pregnancy with your daughter”). Additional questions probed the mother’s perceptions of who initiated discussions, timing of discussions, barriers and facilitators to discussions, her comfort with initiation of discussion, and her perception of her daughter’s comfort with discussions. There was no time limit to the interviews which generally lasted 20-30 minutes. Interviews were digitally recorded, transferred to a secure laptop, transcribed verbatim, and reviewed for accuracy. The interviews were conducted over a 1-year period of time, which began 2 years after mothers’ completion of phase 1, the quantitative portion of this study.

5.3.3 Data Management and Statistical Analysis

Qualitative content analysis techniques were used to analyze the interview data (Miles & Huberman, 1994; Sandelowski, 2000b). The unit of analysis was sentences or paragraphs. A qualitative database program, ATLAS.ti v5.2 was used to facilitate organization and maintenance of the data. Analyses began with dual review of the first two transcripts with the PI (MH) and an

experienced qualitative researcher (MBH). Initial codes were labeled and defined by consensus agreement among coders. For each of the next two interviews, these investigators coded the data separately, and then reviewed each coded transcript together. The last 6 interviews were coded by the PI and then reviewed by the methodological expert. Each interview was reviewed, discussed and consensus was reached on all coded data during analytic meetings. The code list and definitions were developed and refined with the coding of each interview. Comparisons were made within and across participant interviews during coding. Theoretical and methodological memoing (Miles & Huberman, 1994) techniques were also employed.

The following techniques were used to establish trustworthiness as described by Lincoln and Guba (1985). Member checks were conducted by having two certified diabetes educators review and comment on the overall adequacy of this report. In addition, an audit trail that includes the digitally recorded interviews, verbatim transcripts, coding template, data analysis notes, and analytic memos was developed to establish credibility. Transferability was addressed with the use of purposive sampling and a thorough description of the context in which the interviews were carried out. Analysis by a second reviewer with expertise in qualitative analysis (MBH) enhanced rigor of the process and confirmability of findings.

5.4 RESULTS

Ten mothers participated in interviews. Demographic characteristics of the mothers are presented in Table 5.3. We identified the following five themes describing mothers' perspectives of speaking with their adolescent daughters with diabetes about reproductive health issues: 1) maternal awareness; 2) maternal knowledge; 3) triggers for initiating reproductive

health discussions; 4) maternal fears/concerns; and, 5) maternal comfort level with reproductive health discussions.

Table 5.3 Demographic characteristics of mothers (n=10)

Age (years)	46.2 \pm 3.2
Ethnicity	
African-American	1 (10)
Caucasian	7 (70)
Missing	2 (20)
Marital status	
Married	9 (90)
Separated / divorced	1 (10)
Education	
High school grad	3 (30)
Attend some college	1 (10)
College grad	6 (60)
Employment	
Professional	3 (30)
Skilled	4 (40)
Unskilled	2 (20)
Unemployed	1 (10)
Religion	
Protestant	4 (40)
Roman Catholic	6 (60)
Mothers with Diabetes (n=2)	
Pregestational diabetes using insulin	0 (0)
Post-gestational diabetes not using insulin	1 (10)
Gestational diabetes only	1 (10)

Data are means \pm SD and *n* (%).

5.4.1 Maternal Awareness

Maternal awareness refers to a mother's awareness of her daughter's sexual behavior and/or health risk in regards to diabetes and reproductive health, such as experiencing an unplanned pregnancy. A recurrent pattern of awareness involved a daughter's sexual activity or the possibility of her becoming sexually active. "She was growing up and I knew it was going to happen sooner or later." "I don't want to act like I'm stupid and that this girl is never going to have sex." "I don't believe she is sexually active, though you are never 100% sure."

Mothers were also aware of the risks of unplanned pregnancies in women with diabetes and verbalized support for the use of birth control by their daughters. "I think it is appropriate to tell people in this situation birth control is available and you've got to be using it." "Since this study (larger RCT) she has been put on birth control because she was open enough with me to make me aware she was sexually active." However, some mothers verbalized displeasure with their daughter's decision to be sexually active. "She's very open and honest with me so I can appreciate that, but you don't like it." "I was very disappointed it (sexual activity) did come." Even if mothers were not pleased with the decisions of their daughters to be sexually active, they understood the need for protection. "I made her aware that even though she is on the pill she still needs to wear condoms because you still need to be cautious." "I didn't want to support it or promote that she have sex by putting her on the pill, but I didn't want to be a stupid parent and act like just because I tell her don't do that (have sex) she won't do it."

5.4.2 Maternal Knowledge

Maternal knowledge refers to a mother's knowledge of diabetes and reproductive health. Although specific complications were not mentioned, mothers seemed to have some general knowledge about the effects of diabetes on an unplanned pregnancy and that a pregnancy should be planned. "I don't approve of her getting, having children right away because of the effects of diabetes and pregnancy." "They (referring to the RCT intervention) told her that she had to get her sugar regulated, make sure it's always in check months in advance and make sure her A_{1C} level is steady months in advance." "There's example after example, of people we know who have had successful pregnancies because they were careful, they took care of themselves, they did the right thing in getting ready for it." One mother mentioned abortion as an option to preserve her daughter's health in the event of an unplanned pregnancy, "if it came to her health or terminating a pregnancy, I would have to say terminate the pregnancy as a recommendation, and I don't want to ever have to do that."

5.4.3 Triggers to Initiating Reproductive Health Discussions

Triggers for initiating reproductive health discussions are those instances that prompt mothers to talk with their daughters about these important issues. All 10 of the mothers used one or more types of triggers as prompts to begin talking with their daughters about reproductive health. Some mothers initiated discussion when their daughters were younger, others when they were older.

One mother reported using her daughter's questioning about why her adopted brother looked different as a starting point for talking about sex with her daughter, who was 3 years of

age at the time of the discussion. Other mothers reported using school or formal sex education classes as a trigger to begin reproductive health discussions. “We attended a basic class together when she was probably in 5th or 6th grade...and that opened up the opportunity for us to just give her some basic information.”

They do have...sex education at school...I think the first year they do that is...the 6th grade...they discuss general body function of the reproductive organs, menstrual periods and things like that with the girls and that was always a big help to be a start for conversations at home.

Television programs were also used as triggers to begin discussions. One mother reported, “if there was something on TV...that generally would be one that would trigger conversations.”

We always watched television with them...so anytime something on television...one of those sitcoms or something that had innuendos we would always discuss, we could always say well do you have any thoughts on that?

Mother participation in phase 1 of this study and the daughters’ participation in the RCT triggered discussions between mothers and daughters. One mother reported “right after she took it (RCT questionnaires) we talked more about the questions that were on it...the questions sure sparked conversations.” Another mother reported using the one-on-one time in the car after participating in the study to talk with her daughter. “I think basically a lot of our conversations were on the way home...after she had answered questions or I had answered questions.” Some mothers used ‘alone time,’ whether it was a long walk or a long car ride, or an evening out to dinner as a trigger to talk with their daughters about their reproductive health concerns.

Mothers reported using different triggers for older daughters. The most frequently reported impetus for mothers to initiate discussions about preventing a pregnancy was a ‘steady boyfriend’. A steady boyfriend in their daughters’ lives triggered mothers to talk with their

daughters about the risks that are involved with an unplanned pregnancy. One mother talked with her daughter and boyfriend together, “I actually sat down with both of them and so that he was totally aware of how the consequences of an unplanned pregnancy would be for her.” “We’ve talked a lot more about it since then (the RCT) because she’s had her first kind of boyfriend, sexual experience situation.” “Any time she’s had a boyfriend or anything like that we talk about those things.” Other mothers predicted that when a steady boyfriend comes on the scene or their daughters go to college they will talk with them at that time about the importance of preventing an unplanned pregnancy.

If she was graduating and/or there was someone significant on the scene, then I think that would be the time when I would do that. But right now her being on the pill I think it’s really sufficient.

I feel like we need to have a conversation before she goes off to college about what...how she is going to handle this...would she go to the college clinic for birth control or would she just not get herself into situations where she might you know, might be tempted.

5.4.4 Maternal Fears/Concerns

Mothers have many fears and concerns for a daughter with diabetes.

I think with diabetes, it’s something a mother never forgets..... her diabetes has been shall I say a cross, that not only that I bear, but probably every parent of a child with diabetes carries the same cross, it’s something that never leaves you and something you have a fear about because even when your child gets a certain age you still have a fear that they are doing the right thing.

Maternal fears/concerns encompassed general health, diabetes associated complications and reproductive ability as well as unplanned pregnancies. Some of the teens are now attending college and mothers voiced concerns about college life. “I think I worry more about actually the drinking and maintaining control and diabetes.” Others verbalized concerns about their daughters smoking and about the ill effects of smoking with diabetes.

However, the majority of fears/concerns verbalized were those associated with reproductive health issues, which was the focus of the study. One mother's fear was that of the unknown, whether her daughter would be able to have children. She asked the doctor about childbearing when the diagnosis of diabetes was made, "even though she was only 10 years old, ...I asked the doctor I said if [sic] she was going to be able to have a baby?".

As the girls have grown older mothers have more fears and concerns about their daughters experiencing an unplanned pregnancy, as these mothers seem to know that women with diabetes should plan their pregnancies. Fears and concerns about unplanned pregnancies were expressed by 8 of the 10 mothers. "I'm still ongoing always concerned and always telling her that she needs to be very careful because even with contraceptives they don't always work." "Right now we're worried because she can't be on the pill and we're kind of grappling with what that might mean." "I still worry that even though she's still on the pill and using condoms that there could always still be that chance that she could get pregnant."

5.4.5 Maternal Comfort Level with Reproductive Health Discussions

Mothers were asked to rate their comfort level in talking with their daughters about reproductive health issues on a scale from 1 (extremely uncomfortable) to 10 (extremely comfortable). This question was used not only to obtain information on the mother's level of comfort, but also to stimulate conversation about comfort in talking with their daughters about reproductive health issues. Three mothers reported levels of 5-6, indicating some discomfort in talking with their daughters. "I'm just not that comfortable with it myself discussing sexuality." While another mother said, "Well I wouldn't say I was extremely comfortable, it's kind of like weird talking to

your daughter like that.” “Maybe a lot of mothers are like me that don’t really like to talk about that stuff to their daughters.”

Four mothers reported a moderate comfort level of 7-8. One mother reported that being in the study “did help to make it not be like an awkward thing. I feel it made her aware it’s okay to be open with this with your mother”. Three mothers reported being extremely comfortable, levels of 9-10, with discussing these sensitive issues with their daughters. Nevertheless, one of these mothers admitted “It’s not an easy subject to discuss.”

5.5 CONCLUSIONS

This study is the first to explore mothers’ perspectives about reproductive health issues of their adolescent girls with diabetes and their communication practices regarding these issues. From the 10 interviews conducted with mothers of adolescent girls with diabetes, the following themes were identified: maternal awareness, maternal knowledge, triggers for initiating reproductive health discussion, maternal fears/concerns, and maternal comfort level with reproductive health discussions. Overall, these mothers had initiated some discussion with their daughters about reproductive health issues. Most of these mothers claimed to have been aware of their daughters’ sexual behavior or aware that they were at an age when they may become sexually active. Mothers were also aware that their daughters should plan a pregnancy and that preventing an unplanned pregnancy is very important for their daughters’ health. This coincides with the recommendations from the American Diabetes Association (2007) that women with diabetes need to plan their pregnancies.

There were many triggers that prompted mothers to talk with their daughters about reproductive health issues. In early adolescence, sex education classes or something seen on television prompted a discussion. In later adolescence, a steady boyfriend was consistently reported as a trigger for mothers to begin discussing issues of reproductive health. Specifically, mothers began to talk about birth control and the importance of preventing an unplanned pregnancy. They felt their daughters were susceptible to unplanned pregnancies. This is similar to findings of other studies conducted in the general population where it has been reported that mothers talked more with their adolescents about sex when they had greater perceived risks of their adolescents being exposed to the AIDS virus (Miller & Whitaker, 2001; Romo, Lefkowitz, Sigman, & Au, 2001).

Mother, naturally, have many fears and concerns for the overall health and welfare of their children. During the interviews, mothers did express fears and concerns for their daughters' health. Most of these fears and concerns were associated with their daughters having an unplanned pregnancy. Mothers recognized that a higher risk for detrimental health effects is associated with an unplanned pregnancy in their daughters with diabetes. They reported that it was, however, sometimes difficult to discuss these issues with their daughters.

A broad literature search was conducted and unsuccessful for finding any studies that had examined, from a mother's perspective, reproductive health communication between mothers and their adolescent daughters with or without diabetes. The majority of studies examine whether sexual communication has taken place and whether there was agreement between parents and their adolescents as to what was discussed. No studies were found that reported on what triggers prompt mothers to discuss sexual information with their daughters. However, one study examined videotaped conversations between a mother and her daughter about AIDS

(Lefkowitz et al., 1998). It was reported in this study of 21 dyads that the content of the AIDS conversations were focused around preventive measures and AIDS education and mothers were dominant in these conversations. In a follow-up study where mothers were trained in communication skills (Lefkowitz et al., 2000) mothers reported moderate comfort levels in discussing sexual information and AIDS with their daughters. These findings of moderate comfort levels are similar to the findings in our study, except our study did not have an intervention.

5.5.1 Limitations

Conducting the interviews via the telephone was a limitation due to the inability to capture the nonverbal language of the participant. However, to minimize this effect, the interviews were digitally recorded and tone deflections of the mothers were noted as memos in the analyses. Another limitation was that the sample was from a small convenience sample embedded within a larger RCT study. However, criterion-related purposive sampling was used to enhance transferability of the findings. The sampling provided variability on several key characteristics to assure a sample of mothers with a range of experiences. The sample was likely better educated or attuned to reproductive health knowledge as a result of study participation. However, the interviews provided good insight into mothers' awareness and knowledge of diabetes and reproductive health as well as what prompted mothers to speak with their daughters about these issues.

A 2 year time delay between participation in phase 1 of the mothers' study and the interviews may have limited mothers' recall. To minimize this potential threat to credibility, mothers were asked to think about conversations with their daughters at the age they were during

study participation. Although it was difficult to determine if the RCT intervention or study participation (surveys and topic alone) had an effect on mothers' discussions with their daughters, the results provide a basis for future studies in the area of diabetes and mother-daughter discussions about reproductive health issues. Moreover, these results provide insight into the potential positive effects of mothers participating in educational interventions on this topic.

5.5.2 Implications

This study is unique in that it raises awareness of the importance of maternal involvement in reproductive health discussions with adolescent daughters with diabetes. Diabetes nurse educators need to include mothers when discussing these very important issues with adolescents. Diabetes nurse educators can assist mothers in their discussions with their daughters by making sure that mothers have accurate information and effective communication skills. Mothers can be taught how to capitalize on 'everyday triggers' to initiate or resume conversations with their daughters. Nurse educators should recognize that despite available information and media references to sexual activity in popular culture, discussions between mothers and adolescent daughters are still difficult.

Future studies need to evaluate actual reproductive health discussions between mothers and their adolescent daughters with diabetes. Intervention studies should include prospective description and evaluation of intervention effects on mother-daughter reproductive health discussions. The use of videotape to capture actual reproductive health conversations between mothers and their daughters with diabetes may provide further examination of the quality of these conversations. These studies could provide valuable insight into the effects of maternal

discussions regarding diabetes and reproductive health on the daughters' reproductive health behaviors, specifically those steps taken to prevent an unplanned pregnancy.

6.0 OTHER RESULTS

6.1 SPECIFIC AIMS

6.1.1 Specific aim #1

To examine bivariate associations between general communication and intention to initiate reproductive health discussion by subject type (mothers or adolescent girls with type 1 diabetes) within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 1 What is the association between general communication and intention to initiate reproductive health discussion for mothers and their adolescent girls with type 1 diabetes within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Significant associations ($p < .05$) were found between intention to initiate reproductive health discussions and general communication for both mothers and daughters at each time point. When groups were examined all had moderate associations with a correlation coefficient of $> .300$; however, all were not statistically significant. See Table 6.1 for presentation of findings.

Table 6.1 Association between general communication and intention to initiate discussion

	Total Sample		Intervention group		Control group	
	Baseline	3-month	Baseline	3-month	Baseline	3-month
Mothers	.559**	.479**	.466*	.312	.658**	.408*
Daughters	.371*	.492**	.306	.562*	.424*	.410

Data are Pearson correlation coefficients.

** $p \leq .01$, * $p \leq .05$, (2-tailed).

Intention was transformed using reflect and logarithmic (base 10).

6.1.2 Specific aim #2

To examine the agreement between mothers and daughters within dyads on general communication and intention to initiate reproductive health discussion within each treatment group (IG, CG) at each time point.

Question # 2a What is the agreement between mothers and daughters on general communication within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Question # 2b What is the agreement between mothers and daughters on intention to initiate reproductive health discussion within each treatment group (IG, CG) at each time point (baseline, 3-months)?

Agreement between mothers' and daughters' general communication was significant ($p < .05$) at the 3-month follow up for the total sample. However, when the groups were examined this agreement was significant ($p < .05$) for the intervention group at baseline and the control group at 3-months. No significant agreement was found between mothers' and

daughters' intention to initiate reproductive health discussion. These results are presented in Table 6.2.

Table 6.2 Agreement between dyads' general communication and intention to initiate discussion

	Total sample		Intervention group		Control group	
	Baseline	3-month	Baseline	3-month	Baseline	3-month
Communication	.155	.321*	.375*	.288	.080	.364*
Intention	.197	.243	.102	.235	.257	.232

Data are Mother-daughter Intraclass correlations.

* $p \leq .05$, (2-tailed).

Intention was transformed using reflect and logarithmic (base 10).

6.1.3 Specific aim #3

To examine bivariate associations between the dependent variables of intention to initiate reproductive health discussions and actual discussions of reproductive health issues with the independent variables of knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits of and barriers to her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at each time point (baseline, 3-months).

Question # 3a What are the bivariate associations between the dependent variable of the intention to initiate reproductive health discussion and the independent variables of knowledge of

diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy within each treatment group (IG, CG) at either time point (baseline or 3-months)?

Associations between the independent variables and dependent variable of intention to initiate discussion were examined by group. Benefits and barriers were significantly ($p < .05$) associated with intention to initiate discussion at 3-months for the control group. See Table 6.3.

Table 6.3 Associations between independent variables and intention to initiate discussion

	Intervention group n=19		Control group n=25	
	Baseline	3-months	Baseline	3-months
Knowledge & Intention	-.223	.015	.208	.389
Susceptibility & Intention	.177	.311	.096	.024
Severity & Intention	.348	.197	.396	.042
Benefits & Intention	-.402	.347	.275	.591**
Barriers & Intention	-.265	.152	.034	-.438*
Social support & Intention	.205	.150	.250	.338

Data are Pearson correlations coefficients.

** $p \leq .01$, * $p \leq .05$ (2-tailed).

Intention and barriers were transformed using reflect and logarithmic (base 10).

Social support was dichotomized into low (<39) or high ($=40$) score.

Question # 3b What are the bivariate associations between the dependent variable of actual reproductive health discussions and the independent variables of knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, and mother's social support of daughter preventing an unplanned pregnancy with the total sample or within each treatment group (IG, CG) at either time point (baseline or 3-months)?

When the groups were examined the intervention group had 2 significant ($p < .05$) associations: intention and actual discussion at baseline; and, knowledge and actual discussion at 3-months. The control group had one significant ($p < .05$) association at baseline between social support and actual discussion. See Table 6.4 for presentation of data.

Table 6.4 Relationship between independent variables and actual discussion

	Intervention group n=19		Control group n=25	
	Baseline	3-months	Baseline	3-months
Knowledge & Actual discussion	-.078	.502*	.214	.201
Susceptibility & Actual discussion	.418	.232	.282	-.042
Severity & Actual discussion	.000	.222	.122	-.040
Benefits & Actual discussion	-.415	-.192	.278	-.026
Barriers & Actual discussion	.076	.075	.081	.094
Social support & Actual discussion†	.217	-.333	.397*	.379
Intention & Actual discussion	.454*	-.399	.030	.082

Data are Pearson correlation coefficients, except as noted.

† - Spearman's rho correlation coefficient.

** $p \leq .01$, * $p \leq .05$ (2-tailed).

Barriers was transformed using reflect and logarithmic (base 10).

Social support was dichotomized into low (<39) or high (=40) score.

Social support: 0 = Lower social support, 1 = Higher social support.

Actual discussion: 0 = no, 1 = yes.

6.1.4 Specific aim #4

Compare differences over time (baseline to 3-months) of mothers within each treatment group (IG or CG) on knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and

barriers of her daughter preventing an unplanned pregnancy, mother's social support of daughter preventing an unplanned pregnancy, mother's intention to initiate reproductive health discussion with her daughter and, mother's actual discussion of reproductive health issues with her daughter.

Question # 4 What are the differences over time (baseline to 3-months) within mothers of adolescents in the IG or those within the CG on knowledge of diabetes and reproductive health, mothers' perception of daughters' susceptibility to pregnancy/pregnancy-related complications, mothers' perception of daughters' severity to pregnancy/pregnancy-related complications, mothers' perception of benefits to and barriers of their daughters preventing an unplanned pregnancy, mothers' social support of their daughters preventing an unplanned pregnancy, mothers' intention to initiate reproductive health discussion with her daughter and, mothers' actual discussion of reproductive health issues with her daughter?

Knowledge is significantly ($p < .05$) different within the control group from baseline to 3-months. Barriers also has a significant ($p < .05$) change within both groups from baseline to 3-months. See Table 6.5.

Table 6.5 Within group differences over time

Variables (Score Range)	Intervention group n=19		t-test	Control group n=25		t-test
	Baseline	3-month		Baseline	3-month	
Knowledge (0-100%)	57.7 ± 14.7	67.8 ± 19.9	1.86	63.4 ± 21.5	71.2 ± 19.7	2.86**
Susceptibility (3-15)	8.5 ± 2.7	8.7 ± 2.4	1.40	9.5 ± 3.4	9.8 ± 3.4	0.79
Severity (3-15)	13.0 ± 2.1	12.7 ± 2.5	0.10	12.2 ± 2.6	12.8 ± 2.8	1.11
Benefits (5-25)	.380 ± .325	.284 ± .277	-0.11	.414 ± .418	.410 ± .386	-0.06
Barriers (2-15)	5.6 ± 2.4	8.6 ± 3	7.25**	6.1 ± 2.5	8.8 ± 3.8	5.77**
Social support (% high)	74%	75%	0.2†	76%	64%	0.57†
Intention (2-14)	.367 ± .371	.358 ± .357	-1.27	.357 ± .381	.493 ± .370	2.20*
Actual discussion (% Yes)	58%	63%	2.0†	52%	68%	2.0†

Data are means ± SD, except as noted.

† McNemar's test.

**p≤.01, *p≤.05.

Intention and barriers were transformed using reflect and logarithmic (base 10).

Social support was dichotomized into low (<39) or high (=40) score.

6.1.5 Specific aim #5

Compare treatment groups (IG vs. CG) on mothers' knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support, and intention to initiate reproductive health discussion at each time point (baseline and 3-months).

Question # 5 Is there a difference between the treatment groups (IG vs. CG) for mothers' knowledge of diabetes and reproductive health, mother's perception of daughter's susceptibility to pregnancy/pregnancy-related complications, mother's perception of daughter's severity to pregnancy/pregnancy-related complications, mother's perception of benefits and barriers of her daughter preventing an unplanned pregnancy, mother's social support, and intention to initiate reproductive health discussion at either time point (baseline or 3-months)?

There were no significant differences between the groups at either time point on any of the independent or dependent variables. There was no significant difference between the groups on their percent change scores. See Tables 6.6 and 6.7.

Table 6.6 Between group differences at each time point

Variables (Score Range)	Intervention group n=19		Control group n=25		<i>t</i> -test between groups	
	Baseline	3-month	Baseline	3-month	Baseline	3-month
Knowledge (0-100%)	57.7 ± 14.7	67.8 ± 19.9	63.4 ± 21.5	71.2 ± 19.7	0.985	0.542
Susceptibility (3-15)	8.5 ± 2.7	8.7 ± 2.4	9.5 ± 3.4	9.8 ± 3.4	1.007	1.145
Severity (3-15)	13.0 ± 2.1	12.7 ± 2.5	12.2 ± 2.6	12.8 ± 2.8	-1.039	0.176
Benefits (5-25)	.380 ± .325	.284 ± .277	.414 ± .418	.410 ± .386	0.296	1.222
Barriers (2-15)	5.6 ± 2.4	8.6 ± 3	6.1 ± 2.5	8.8 ± 3.8	0.733	0.120
Social support (% high)	74%	75%	76%	64%	NS†	NS†
Intention (2-14)	.367 ± .371	.358 ± .357	.357 ± .381	.493 ± .370	-0.085	1.140
Actual discussion (% Yes)	58%	63%	52%	68%	NS†	NS†

Data are mean ± SD, except as noted.

† Fisher's exact test.

**p≤.01, *p≤.05.

Table 6.7 Percent change scores

	Intervention group n=19	Control group n=25	<i>t</i> -test between groups
Knowledge	13 ± 27 (-33.3 – 57.1)	18.58 ± 33.8 (-21.7 – 142.9)	0.554
Susceptibility	12.67 ± 30 (-33.3 – 80)	7.56 ± 28.9 (-62.5 – 83.3)	-0.545
Severity	1.97 ± 23.2 (-27.3 – 66.7)	7.46 ± 25.9 (-44.4 – 66.7)	0.688
Benefits	.17 ± 7.9 (-12.5 – 13.6)	3.72 ± 20.2 (-20.8 – 61.5)	0.668
Barriers	71.2 ± 46.4 (11.1 – 166.7)	48.28 ± 40 (-16.7 – 166.7)	-1.655
Social Support	0 ± 1.6 (-2.63 – 2.56)	-1.67 ± 9.11 (-25 – 25)	-0.897
Intention	13.3 ± 39.3 (-40 – 100)	-2.96 ± 32 (-57.1 – 100)	-1.423

Data are mean + SD, (% change range).

**p≤.01, *p≤.05.

7.0 SUMMARY AND CONCLUSIONS

7.1 OVERALL SUMMARY OF THE RESULTS

The main purpose of this research was to examine reproductive health communication between mothers and their adolescent daughters with diabetes. The ADA recommends that all women with diabetes of childbearing potential be counseled about the potential fetal and maternal complications associated with unplanned pregnancies through preconception counseling (American Diabetes Association, 2007). It is of the utmost importance that adolescent girls receive timely and accurate information regarding the effects of diabetes on their reproductive health in order to make well-informed choices. This research is significant because this was the first known attempt to have examined this phenomenon of mother-daughter reproductive health communication in the diabetes population, both quantitatively and qualitatively.

The major variables of interest in phase 1, the quantitative portion of this study, were mothers' and daughters' general communication and their intention to speak to each other about reproductive issues, and mothers' knowledge and beliefs/attitudes about diabetes and reproductive health, mothers' perceived social support available to their daughters for preventing an unplanned pregnancy, and mothers' actual discussion about reproductive health issues with their daughters. Mothers' thoughts and experiences in talking with their daughters about these issues were explored in phase 2, the qualitative portion of this study.

Overall, mothers in this study had higher general communication, low knowledge about reproductive health, specifically knowledge in regards to diabetes and pregnancy, birth control and sexuality, and stronger reproductive health beliefs/attitudes. They also had high perceived social support in helping their daughters prevent an unplanned pregnancy. Mothers had moderate intentions to speak with their daughters about reproductive health issues, but only half of them had reported having any actual discussions with their daughters.

Mothers' knowledge about diabetes and reproductive health parallels the adolescents' baseline knowledge in the larger RCT (Charron-Prochownik, Sereika, Hannan et al., 2006) and in a previous study of 80 adolescents with diabetes (Charron-Prochownik, Sereika, Falsetti et al., 2006). Regardless of their daughters' group assignment in the larger RCT, mothers' knowledge about diabetes and reproductive health increased from baseline to 3-months, perhaps due to an indirect effect of participating in the study. On the other hand, it may also indicate that these mothers were stimulated to seek more knowledge about these very important reproductive health issues. Mothers intended to speak with their daughters about reproductive health issues with more than half of the mothers reported having had actual discussions with their daughters on this topic.

In regards to their beliefs/attitudes, mothers indicated that they perceived their daughters to be moderately susceptible to an unplanned pregnancy and had high perceived severity of pregnancy-related complications. Mothers also had strong perceived benefits of their daughters preventing an unplanned pregnancy and seeking preconception counseling, but at the 3-month follow-up they had an increase of perceived barriers to their daughters' performance of these actions. Therefore, although mothers could see the benefit of their daughter preventing an

unplanned pregnancy and seeking preconception counseling at the 3-month follow-up visit some did not feel that their daughters would be able to do so adequately.

Significant positive correlations were identified for both mothers and daughters between their intention to speak with the other about reproductive health issues and their general communication. Mothers and daughters who reported greater intentions to initiate reproductive health discussions with the other also reported higher general communication. This is consistent with the literature of the general population (Kotva & Schneider, 1990), where mothers' and daughters' general communication was reported as being significantly related to intention to initiate reproductive health discussions.

Mothers reported moderate intentions to initiate reproductive health discussions with their daughters. Furthermore, mothers who perceived greater benefits of their daughters preventing an unplanned pregnancy had greater intentions to speak with their daughters about reproductive health issues. There was an unexpected group-by-time interaction effect for mothers' intention to initiate reproductive health discussions with her daughter. It was the mothers whose daughters were in the CG group who had lower intentions at 3-months to speak with their daughters about these issues, which may be an indirect of their daughter being in the larger RCT. However, when controlling for covariates and group assignment, mothers with higher education, higher general communication and higher perceived social support were more likely to intend to speak with their daughters about these very important issues.

Several independent variables in this study were constructs derived from the HBM. Relationships between the independent and dependent variables were found based on the assumptions of the HBM. In the bivariate analysis, a mother's intention to speak with her daughter about reproductive health issues was significantly associated with greater severity,

greater benefits and lower barriers. However, only severity was a significant predictor in the multivariate analysis. Mothers' actual discussion of reproductive health issues was significantly associated with greater susceptibility, which was confirmed with multivariate analysis. These findings were in the hypothesized direction of the HBM, which is consistent with other studies (Brock & Beazley, 1995; Elliott et al., 2001; Soliday & Hoeksel, 2000) that used the HBM to examine parental health beliefs/attitudes associated with preventive health behavior in regards to their child.

Mother's actual discussion of reproductive health issues with her daughter had a significant time effect, whereby, mothers reported an increase from baseline to 3-months. Mothers engaging in actual discussion were predicted by perceived susceptibility, perceived social support, and diabetes and reproductive health knowledge. Mothers who had high perceived susceptibility of their daughters having an unplanned pregnancy and pregnancy complications, high perceived social support of helping their daughters prevent an unplanned pregnancy and greater knowledge about diabetes and reproductive health were more likely to be talking with their daughters about these important issues. These findings for actual discussion were also confirmed during the qualitative study (phase 2). In the interviews mothers talked about their awareness of their daughters' sexual activity or the possibility of her becoming sexually active. Those mothers who suspected or knew of their daughter's sexual activity felt their daughters were susceptible to unplanned pregnancies and were concerned enough to discuss birth control with their daughters. This is similar to findings of other studies conducted in the general population where it has been reported that mothers talked more with their adolescents about sex when they had greater perceived risks of their adolescents being exposed to the AIDS virus (Miller & Whitaker, 2001; Romo et al., 2001). However, mothers need to be talking with

their daughters before they become sexually active and are at risk for sexually transmitted diseases or unplanned pregnancies.

The qualitative study (phase 2), explored mothers' perspectives about reproductive health discussions with their daughters. From the 10 interviews conducted with mothers of adolescent girls with diabetes, the following themes were identified: maternal awareness, maternal knowledge, triggers for initiating reproductive health discussions, maternal fears/concerns, and maternal comfort level with reproductive health discussions. The qualitative phase of this study confirmed quantitative findings, such as to some extent these mothers were discussing some reproductive health issues with their daughters. Although mothers were aware of reproductive health issues, they lacked accurate knowledge and had low scores on the phase 1 knowledge test.

In phase 1, only 55-66% of mothers reported having had actual discussions with their daughters. In phase 2, during the interviews, mothers reported their comfort level to be only moderate. One mother reported, "It's not an easy subject to discuss." Similarly, a study where mothers were trained in communication skills (Lefkowitz et al., 2000), mothers reported moderate comfort levels in discussing sexual information and AIDS with their daughters.

Although they were not always pleased, mothers in this study were aware of their daughters' sexual activity, or at least aware that they may become sexually active. They knew that their daughters should plan a pregnancy and that preventing an unplanned pregnancy is very important for their daughters' health.

New knowledge that emerged from the qualitative study included triggers that prompt mothers to talk with their daughters about reproductive health issues. The triggers reported by mothers for initiating these discussions ranged from sexual innuendos seen on television to a daughters' report to her mother that she had been or will become sexually active. An adolescent

having a steady boyfriend was consistently reported as a trigger for mothers to begin discussing issues of reproductive health. Specifically, mothers began to talk about birth control and the importance of preventing an unplanned pregnancy. Participation in the larger RCT was also a trigger for mothers and daughters to discuss reproductive health issues. Although many studies have examined mother-daughter sexual communication in the general population, no studies could be found that examined what triggers those conversations. Future studies could further examine what triggers mothers to begin talking with their daughters.

During the interviews, mothers expressed fears and concerns for their daughters' health. Most were associated with their daughters having an unplanned pregnancy and the complications that could occur due to their diabetes. Mothers recognized that a higher risk for detrimental health effects is associated with an unplanned pregnancy in their daughters with diabetes. They reported that it was sometimes difficult to discuss these issues with their daughters. The fears and concerns expressed during the interviews were confirmed quantitatively. Mothers' attitude scale scores indicated that they perceived their daughters to be moderately susceptible to an unplanned pregnancy and had high perceived severity of pregnancy-related complications. Mothers had strong perceived benefits of their daughters preventing an unplanned pregnancy and seeking preconception counseling, but they also had strong perceived barriers to their daughters' performance of these actions. Although mothers could see the benefit of their daughter preventing an unplanned pregnancy and seeking preconception counseling they did not feel that their daughters would be able to do so adequately because of their age and/or immaturity. One mother reported, "I still worry that even though she's on the pill and using condoms that there could always be that chance that she could get pregnant." These findings are important as no

other studies have been conducted with mothers of adolescent daughters with diabetes that have examined the mothers' fears and concerns for her daughter's reproductive health.

As expected, there were no patterns seen for differences on any of the variables between the mothers who had daughters in the intervention group and those mothers with daughters in the control group. Since mothers did not receive an intervention, most likely, any differences seen between the groups would be due to an indirect effect.

7.2 LIMITATIONS

This study had several limitations. First, the quantitative study (phase 1) used a small convenience sample embedded within a larger intervention study, which makes it difficult to generalize to the larger population. The larger intervention study recruited 60 adolescent girls with diabetes and because this current sub-study started approximately 6 months later, only 44 mothers were recruited. Second, as a sub-study of a larger intervention study, there may also have been an indirect effect on the mothers whose daughters were in the intervention group. Group assignment was controlled and no significant differences were found between mothers whose daughters were in the intervention group with those mothers with daughters in the control group. Third, a more comprehensive measure of behavior would have been preferable. In this study, intention to initiate reproductive health discussion was measured; actual behavior is the standard measure. In the quantitative phase of the study, actual behavior was measured, but it was a dichotomous variable, yes = a mother has talked with her daughter, no = she has not talked with her daughter. It would be a stronger study if a more in-depth examination of actual

discussion was examined (e.g., content). Nonetheless, the qualitative interview data from phase 2 supported the actual discussions reported by mothers in phase 1.

There were several limitations to the qualitative inquiry, phase 2, of this study as well. First, the time delay of 2 years between participation in phase 1 of the mothers' study and the interviews may have limited mothers' recall. To minimize this potential threat to credibility, mothers were asked to think about conversations they had with their daughters during the time of study participation. Second, conducting the interviews via the telephone was a limitation due to the inability of capturing any nonverbal language of the participant. However, to minimize this effect, the interviews were digitally recorded and tone deflections of the mothers were noted as memos in the analyses. Third, the sample size was small. However, criterion-related purposive sampling was used to enhance transferability of the findings. The sampling provided variability on several key characteristics to assure a sample of mothers with a range of experiences. The sample was likely better educated or attuned to reproductive health knowledge as a result of study participation. However, the interviews provided good insight into mothers' awareness and knowledge of diabetes and reproductive health as well as what prompted mothers to speak with their daughters about these issues.

One other limitation to the qualitative study was that there was no opportunity to explore the thoughts and experiences of the two mothers who had type 1 diabetes. Their phone numbers had been changed. Lastly, we did not have data to distinguish between natural, adoptive or step mothers, which could potentially affect discussion or reproductive health issues.

Although it was difficult to determine if the RCT intervention or study participation (surveys and topic alone) had an effect on mothers' discussions with their daughters, the results provide a basis for future studies in the area of diabetes and mother-daughter discussions about

reproductive health issues. Moreover, these results provide insight into the potential positive effects of participating in educational interventions and/or research on this topic.

7.3 IMPLICATIONS

7.3.1 Practice

This study is unique in that it raises awareness of the importance of maternal involvement in reproductive health discussions with adolescent daughters with diabetes. Diabetes nurse educators need to include mothers when discussing these very important issues with adolescents. Diabetes nurse educators can assist mothers in their discussions with their daughters by making sure that mothers have the correct information. Mothers can be taught how to capitalize on ‘everyday triggers’ to initiate or resume conversations with their daughters. Nurse educators should recognize that despite available information and media references to sexual activity in popular culture, discussions between mothers and adolescent daughters are still difficult.

7.3.2 Research

The information obtained from this study can help guide future studies that need to evaluate reproductive health discussions that actually take place between mothers and their adolescent daughters with diabetes. However, in order to further assist mothers with their sexual communication with their daughters, it would be beneficial to further examine mothers’ comfort and what would make this process ‘easier’ for them. This information could be used to develop

intervention studies that should include prospective description and evaluation of intervention effects on mother-daughter reproductive health discussions and maternal support. The intervention should target both mothers and adolescents, raising their awareness of PC, providing them with adequate information, reproductive health communication skills, and decision-making skills for adolescents. The intervention should be tailored to help increase mothers' comfort level with these discussions and decrease the barriers to communication. In the general population it has been shown that mother-daughter communication about reproductive health issues has a positive effect on an adolescent's sexual behavior (Anderson et al., 1999; Resnick et al., 1997). These types of studies need to be conducted within the diabetes population. These studies could provide valuable insight into the effects of maternal discussions regarding diabetes and reproductive health on the daughters' reproductive health behaviors, specifically those steps taken to prevent an unplanned pregnancy.

Perhaps in selecting predictor variables in future research a larger composite model including subjective norm from the Theory of Reasoned Action could be included. Future research could also examine dyadic responses as well as the influence of race, early pubertal development and religion or spiritual influence on a mother's intention or actual behavior of discussing reproductive health issues with her daughter. Future research with a larger sample size should include adolescent girls with type 2 diabetes. It should also examine the relationship between general knowledge of diabetes, adolescents' duration of diabetes, metabolic control and self-management of diabetes regimen with the 2 outcome variables of intention to initiate discussion and actual discussion of reproductive health issues between mothers and their adolescent daughters with diabetes.

In conclusion, we know that adolescent women with diabetes are at risk for unplanned pregnancies and that mothers can be influential resources for their daughters in regards to their diabetes and reproductive health. As health care providers we must provide mothers with the necessary skills and information needed to communicate with their daughters and provide the appropriate support about reproductive health issues.

APPENDIX A

IRB AMENDMENT REQUEST AND APPROVAL



University of Pittsburgh

School of Nursing

Reproductive Health Awareness for Teens with Diabetes

Department of Health Promotion
and Development
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Pittsburgh, Pennsylvania 15261
412-624-6953, Fax: 412-624-8521
E-mail: dcpro@pitt.edu

Denise Charron-Prochownik,
Ph.D., R.N., C.P.N.P.
Assistant Professor
School of Nursing and
Graduate School of Public Health,

July 21, 2003

Ev Vogeley, MD, JD
Chairman, Human Rights Committee
Children's Hospital of Pittsburgh
3705 Fifth Ave
Pittsburgh, PA 15213

RE: "Reproductive Health Program for Teen Girls with Diabetes: An Intervention Study
(Outcomes and Cost-Effectiveness Evaluation) (02-079)

Dear Dr. Vogeley:

Enclosed you will find an amendment application for the above-mentioned study. As per our conversation with Lynda Cocco, this application is being submitted for expedited review. We would like to conduct a sub-study with this protocol. The sub-study is looking at factors that may be associated with reproductive health discussions between teen girls with diabetes and their mothers. The changes that have been made are highlighted in yellow in the protocol. These include adding 2 questionnaires for the teens to complete; one for general communication and one for reproductive health discussions between the teens and mothers. Mothers are also to be recruited to complete parallel questionnaires; they will not participate in the intervention.

The consent documents have been revised to include the communication information to be collected from the teens. The changes have been highlighted in the consents as well. A consent has been constructed for the mothers.

I have also enclosed the following: Parent-Adolescent Scale, teen's and mother's version; Initiating Discussion questionnaire-mother's version, teen's version will be worded for teen; and, the mother's parallel questionnaire from larger study.

If you have any questions please call Meg Ferons at 412-692-8774 or 412-624-9554. I will be back in town on August 4, 2003.

Sincerely,

Denise Charron-Prochownik, PhD
Assistant Professor
School of Nursing

September 2, 2003

Denise Charron-Prochownik, Ph.D., RN
School of Nursing
440 Victoria Building
Pittsburgh, PA 15261

RE: 02-079: Reproductive Health Program for Teen Girls with Diabetes: An Intervention Study (Outcomes and Cost-Effectiveness Evaluation)

Dear Dr. Charron-Prochownik:

At its regularly scheduled meeting on August 7, 2003, the Human Rights Committee reviewed the amendment to the above-mentioned study and it was approved with contingencies. As of this date, we have received your satisfactory response to those contingencies. You may consider this letter as final approval to continue your study as amended.

Under our Federalwide Assurance (FWA-600) with DHHS, annual review and approval of all ongoing research projects is necessary. CHP has instituted an eleven-month cycle for renewals to ensure that there are no periods of lapse. Therefore, by January 2004 you should submit your renewal for consideration at a(n) February 2004 meeting.

If there are any serious adverse events which occur related to this study, they should be reported in a timely manner to the HRC. Any changes in the protocol or the consent document must receive approval from the HRC prior to their implementation.

Sincerely,



Ev Vogeley, M.D., J.D.
Chairman
Human Rights Committee

APPENDIX B

CONSENTS



University of Pittsburgh

School of Nursing

Reproductive Health Awareness for Teens with Diabetes

Department of Health Promotion
and Development
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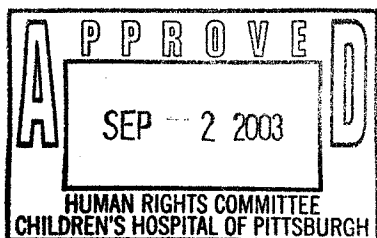
Denise Charron-Prochownik,
Ph.D., R.N., C.P.N.P.
Assistant Professor
School of Nursing and
Graduate School of Public Health

CONSENT (MOTHER) TO BE A SUBJECT IN A CLINICAL STUDY AND AUTHORIZATION TO PERMIT THE USE AND DISCLOSURE OF IDENTIFIABLE MEDICAL INFORMATION (PROTECTED HEALTH INFORMATION) FOR RESEARCH PURPOSES

HRC Protocol Number: 02-079

TITLE: Reproductive Health Program for Teen Girls with Diabetes (RHATD): An
Intervention Study (Outcome and Cost-effectiveness Evaluation)

INVESTIGATORS: Dr. Denise Charron-Prochownik, Assistant Professor
Department of Health Promotion and Development
School of Nursing
University of Pittsburgh
(412)-692-5325



EXPIRES FEB 28 2004

Dr. Dorothy J. Becker, Professor
Professor of Pediatrics
Director, Division of Endocrinology, Metabolism, & Diabetes Mellitus
Children's Hospital of Pittsburgh
(412)-692-5179

Margaret Ferons, RN, MSN, CPNP
Doctoral Student
School of Nursing
University of Pittsburgh
(412)-692-5325

SPONSOR: AMERICAN DIABETES ASSOCIATION

DESCRIPTION:

Dr. Denise Charron-Prochownik and her associates invite you to participate in a study that is being conducted in conjunction with the intervention study your daughter has agreed to participate in. This sub-study will explore reproductive health discussions between the teen girls with diabetes and their mothers.

Reproductive health awareness means understanding your own body, its normal changes, and to know what's healthy for you. For teens with diabetes, this includes how

Initials and Date: _____

diabetes may affect sexuality and pregnancy, and how preconception (pre-pregnancy) counseling can help. The educational program was developed to help young women with diabetes to learn how to talk to their health care team and to make decisions that can have positive effects on their reproductive health. However, it is felt that mothers can also be key figures in providing reproductive health information to their teen daughters. The information to be obtained for the sub-study will provide the foundation for intervention studies, like this larger study, to improve mother-daughter communication.

If you agree to participate in this sub-study, you will be asked to complete a total of six questionnaires, three at the initial visit and three in three months. It will take approximately 15 minutes for you to complete these questionnaires. The questionnaires contain questions related to demographics, general communication with your daughter and reproductive health communication as well. There are knowledge questions about diabetes and reproductive health, attitudes and beliefs about these issues and questions about support you provide to your daughter. The time points coincide with when your daughter will complete questionnaires for the larger study. This sub-study will also include an audio-taped phone interview with approximately 10 mothers to explore their perspective of reproductive health discussions they have with their teen daughters with diabetes.

BENEFITS AND RISKS

There are no direct benefits to you if you take part in this sub-study. There is the potential to benefit a significant number of people (your daughter and her baby). There may be some emotional risks to discussing issues regarding the risks of pregnancy with diabetes. Because the questionnaires are self-administered and the phone interview will be no longer than 15 minutes, such risks should be minimal.

NEW INFORMATION

If any new helpful information comes to our attention, that information will be made available to you. Or, if any information is learned that might affect your willingness to continue participation in this research, you will be informed.

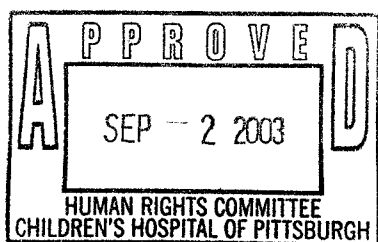
COSTS AND PAYMENTS:

You will not have to pay any costs in order to participate in this study. All laboratory, physician, or hospital costs not related to the research will be charged to you just as though you were not part of the study. You will receive \$20.00 for each completed session for a possible total of \$ 60.00.

RIGHT TO REFUSE OR WITHDRAW:

Your OK to use and disclose your medical information for the purpose of this research study is completely up to you. However, if you do not provide your OK, you will not be allowed to participate in this study.

Your daughter's doctor may be an investigator in this research study, and as an investigator, is interested both in her medical care and in the conduct of this research.



Before entering this study or at any time during the research, you may discuss her care with another doctor who is in no way associated with this research project. You are not under any obligation to participate in any research study offered by her doctor. You have the right to withdraw from participation in this study at any time without penalty. This will have no effect on your daughter's care; she will receive the same excellent care from the doctors and nurses.

Of course, if you withdraw your OK for the use of your health information, you may no longer participate in this research study. To the extent that researchers have already used your health information in data analysis and/or scientific publication, this information cannot be withdrawn (although any publication of information will be such that your information will not be identifiable). If you decide to withdraw your OK, you should notify the researcher in writing along with the date of your decision. Your decision to withdraw your OK for the use of your private health information for this research study will have no effect on your current or future medical care at Children's Hospital of Pittsburgh, a UPMC Health System Hospital or affiliated health provider or the University of Pittsburgh.

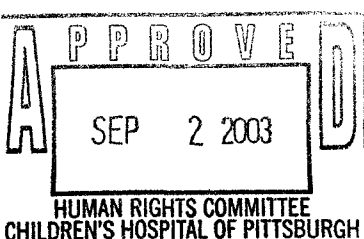
PRIVACY AND CONFIDENTIALITY:

Under the Health Insurance Portability and Accountability Act (HIPAA), your private health care information cannot be used for the research purposes of this study without your OK. You will be informed of the specific uses and disclosures of your medical information for the purpose of this research study and who will have access to your health information.

In general, research records are kept confidential. Paper records are stored in locked cabinets and computerized records are password protected. There are, however, some disclosures of your research-related medical information that may occur.

In addition to the investigators listed on the first page of this authorization form and their research staff, the following persons may have access to your identifiable private health information related to your participation in this research study (Some of the investigators may not be at Children's Hospital of Pittsburgh or may still see your information if they go somewhere else):

- Authorized representatives of the Human Rights Committee. The Human Rights Committee is responsible for assuring the ethical conduct of research at Children's Hospital of Pittsburgh. The Human Rights Committee sometimes asks for names and addresses and telephone numbers of research subjects. By agreeing to participate in this study, you also agree that representatives of the Human Rights Committee can contact you. Of course, you don't have to answer the committee's questions if you don't want to.
- Authorized representatives of the Children's Hospital of Pittsburgh General Clinical Research Center (GCRC), where the study will take place.
- Authorized representatives from the Children's Hospital of Pittsburgh Office of Corporate Compliance for the purpose of monitoring the appropriate conduct of this research study.



- Authorized representatives of the sponsor of this study, American Diabetes Association, may review and/or obtain your identifiable medical information for the purpose of monitoring the accuracy and completeness of the research data and for performing required scientific analyses of the research data. While the American Diabetes Association has provided its assurance that it will not release your identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.
- Authorized representatives of the Office for Human Research Protections (OHRP) may review and/or obtain your identifiable health information for the purpose of ensuring that the research is being conducted according to the Department of Health and Human Services Guidelines. While the OHRP has provided its assurance that it will not release your identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.

In unusual cases, the investigators may be required to release your research information in response to a court order. Research investigators may be required under Pennsylvania law to report any suspicion of child abuse to child protection services. If the investigators learn that you or someone with whom you are involved is in serious danger of potential severe harm, they may need to warn those who are in danger and contact other agencies to ensure safety. The investigators will be permitted to use your identifiable health information until the completion of this.

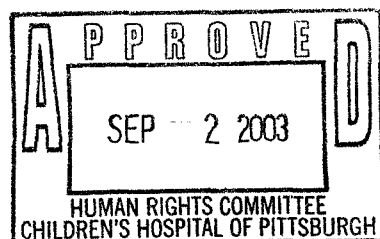
FUTURE USE OF DATA:

You may choose how your private health information will be used in future studies by initialing one of the options below:

_____ My health information from this study may be used without restriction for future research at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates. I need not be contacted to give additional permission or authorization for such future use. *Initials and date:* _____

_____ My health information from this study may be used for additional research purposes at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates only if I specifically give OK for such use. I may be contacted by telephone, fax, e-mail, or regular mail for the purposes of obtaining my OK for additional research. *Initials and date:* _____

_____ My health information from this study may be used only for the purposes of this study. I do not want to be contacted about future studies.
Initials and date: _____



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___ I agree to be contacted by Children's Hospital of Pittsburgh or UPMC Health System and its affiliates for follow-up studies or information, which may be needed as a result of this study. *Initials and date:* _____

COMPENSATION FOR ILLNESS OR INJURY:

There is the possibility with any medical treatment or research that you may suffer some physical illness or injury. In the unlikely event of an injury or illness resulting from this research, no monetary compensation will be made, but any immediate emergency treatment that may be necessary will be provided without charge. You may contact the investigator to obtain information about treatment if it is needed.

VOLUNTARY CONSENT AND AUTHORIZATION:

I have read this form or it has been read to me. All of my current questions have been answered. I will be given a copy of this form for future reference. I understand that throughout my participation in this research, I am encouraged to ask any additional questions I may have about the research and use of my identifiable private health information. Dr. Denise Charron-Prochownik 412-624-6953 or 412-692-5325 (24hr) will be available for questions about this research, my rights, and any possible research-related injury. I may also call the Patient Representative (412-692-5489) or the Human Rights Committee (412-692-5247) concerning questions about my rights as a research subject. Any questions I have about the research use of my health care information will be answered by the Human Protections Coordinator at Children's Hospital of Pittsburgh (412-692-8289), by the Children's Hospital of Pittsburgh Privacy Board (412-692-5247) or by the Children's Hospital of Pittsburgh Corporate Compliance and Privacy Officer (412-692-7842.) By signing this form, I agree to participate in this research and agree to allow the disclosure of my medical information for the purposes described above.

Printed Name of Subject (Research Subject): _____

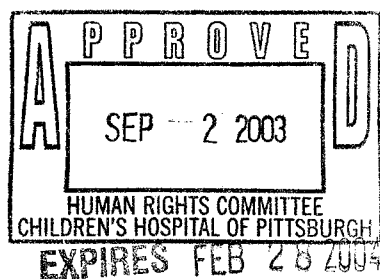
Date: _____ Signature of Subject: _____

Certification of Person Explaining the Research

I have explained the nature and the purpose of this research and the disclosure of the medical information to the subject listed above. She has had the opportunity to ask questions. Based on this conversation, I believe that she understands what this research project involves.

Signature of person explaining the research: _____

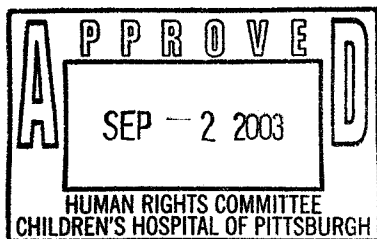
Printed name of person explaining the research: _____



Investigator's Certification

I certify that this subject was not begun on any research component of this protocol until after this consent form was signed.

Date: _____ Investigator's signature: _____



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University of Pittsburgh

School of Nursing

Reproductive Health Awareness for Teens with Diabetes

Department of Health Promotion
and Development
440 Victoria Building
Pittsburgh, Pennsylvania 15261
412-624-6953, Fax: 412-624-8521
E-mail: dcpro@pitt.edu

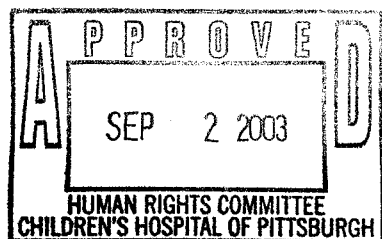
Denise Charron-Prochownik,
Ph.D., R.N., C.P.N.P.
Assistant Professor
School of Nursing and
Graduate School of Public Health

CONSENT TO BE A SUBJECT IN A CLINICAL STUDY AND AUTHORIZATION TO PERMIT THE USE AND DISCLOSURE OF IDENTIFIABLE MEDICAL INFORMATION (PROTECTED HEALTH INFORMATION) FOR RESEARCH PURPOSES

HRC Protocol Number: 02-079

TITLE: Reproductive Health Program for Teen Girls with Diabetes (RHATD): An Intervention Study (Outcome and Cost-effectiveness Evaluation)

INVESTIGATORS: Dr. Denise Charron-Prochownik, Assistant Professor
Department of Health Promotion and Development
School of Nursing
University of Pittsburgh
(412)-692-5325



EXPIRES FEB 28 2004

Dr. Dorothy J. Becker, Professor
Professor of Pediatrics
Director, Division of Endocrinology, Metabolism, & Diabetes Mellitus
Children's Hospital of Pittsburgh
(412)-692-5179

Margaret Ferons, RN, MSN, CPNP
Doctoral Student
School of Nursing
University of Pittsburgh
(412)-692-5325

SPONSOR: AMERICAN DIABETES ASSOCIATION

DESCRIPTION:

Dr. Denise Charron-Prochownik and her associates invite you to participate in a study to evaluate the outcomes and cost-effectiveness of a reproductive health awareness educational program (RHATD), in the form of a CD-ROM and book, specifically designed for teenage women with diabetes. This also includes the evaluation of a face-to-face counseling session with a diabetes clinic nurse and use of a website for

Initials and Date: _____

communication. A sub-study is also being conducted that will explore initiating reproductive health discussions between the teen girls and their mothers.

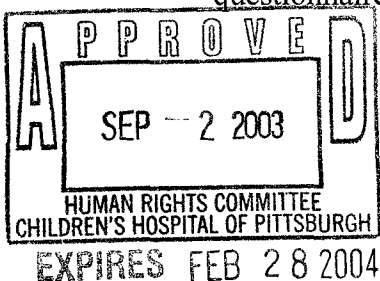
Reproductive health awareness means understanding your own body, its normal changes, and to know what's healthy for you. For teens with diabetes, this includes how diabetes may affect sexuality and pregnancy, and how preconception (pre-pregnancy) counseling can help. This educational program will also help you to learn how to talk to your health care team and to make decisions that can have positive effects on your reproductive health.

In addition to educational programs, like the one in this study, it is felt that mothers can also be key figures in providing reproductive health information to their teen daughters. This study contains a small, sub-study that will examine reproductive health communication among teen girls with diabetes and their mothers. We hope this information will help us to develop other intervention studies that will improve this mother-daughter communication. You will be asked to complete 2 short additional questionnaires for the sub-study. These questionnaires ask about your general communication with your mother and about reproductive health communication. Your mother will also be asked to complete questionnaires. She will not be participating in the intervention study. If you choose not to have your mother participate in the sub-study, you may still participate in the intervention study.

Your participation in the study includes being randomly (picked by chance) assigned to one of the following groups:

1. RHATD Educational Program Group: At your clinic visit the project nurse will set up a laptop computer with a CD-ROM reproductive health awareness program that will take approximately 30 minutes to complete. At the next 3- month clinic visit, you will view the second part of the CD-ROM (30 minutes to complete). At the following clinic visit, (six months after the first CD-ROM viewing), the project nurse will hand you a short book about reproductive health awareness to read at a clinic visit. In addition, at the 3-month and 6-month visit, you will receive information and have the opportunity to ask questions and set goals related to reproductive health awareness with a project nurse. Half of teens participating in the CD group will be further randomized (picked by chance) to receive access to a web site that allows you to communicate with other teen girls with diabetes and a health care provider about reproductive health related topics.
2. Standard Usual Care Control Group: At your clinic visit, the project nurse will hand you a brochure of general preconception counseling care for all women with or without diabetes. In 9 months, at a regularly scheduled clinic visit, the project nurse will set up a laptop computer with the CD-ROM RHATD program, for you to view prior to your clinic appointment.

All participants (in both groups) will continue to receive routine care provided to all patients in the diabetes clinics. If you are chosen to participate in the RHATD educational group, you are asked to complete eleven questionnaires (includes sub-study questionnaires), three at the initial clinic visit, three in three months and six months, and



two in nine months. If you are chosen to participate in the standard care group, you are asked to complete nine questionnaires (includes sub-study questionnaires), three at the initial visit, and two in three months, six months, and nine months. All questionnaires will be given to you to fill out and return at the clinic visits. The questionnaires will take approximately 30 minutes to complete. We ask questions about your age, with whom you live with, how long you have had diabetes, what you may already know about diabetes and reproductive health and what your attitudes or beliefs are about these issues. At each clinic visit (baseline, 3, 6, and 9 months), you will be required to perform a routine blood sugar finger test to check your blood glucose and to obtain a glycosylated hemoglobin blood sample (HbA1c). The project nurse will help you obtain the finger stick blood samples with the HbA1c kit.

BENEFITS AND RISKS

The benefits of taking part in this study are that you will increase your awareness of how diabetes effects pregnancy/reproductive health/preconception counseling. This information could help you make healthy reproductive choices and therefore lead to healthier future pregnancies and healthy babies. Should these educational interventions be successful in promoting improved reproductive health, there is the potential to benefit a significant number of people (you and your baby). There may be some emotional risks to discussing sexual information and the issues regarding the risks of pregnancy with diabetes. Because the questionnaires are self-administered, such risks should be minimal. Additionally, while there may be some minor discomfort associated with the finger stick necessary for the HbA1c test, this finger stick is part of a routine diabetes treatment plan for home blood glucose monitoring.

NEW INFORMATION

If any new helpful information comes to our attention, that information will be made available to you. Or, if any information is learned that might affect your willingness to continue participation in this research, you will be informed.

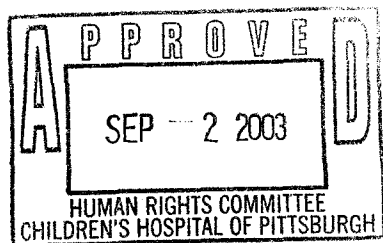
COSTS AND PAYMENTS:

You will not have to pay any costs in order to participate in this study. All laboratory, physician, or hospital costs not related to the research will be charged to you just as though you were not part of the study. You will receive \$20.00 for each completed session for a total of \$ 80.00.

RIGHT TO REFUSE OR WITHDRAW:

Your OK to use and disclose your medical information for the purpose of this research study is completely up to you. However, if you do not provide your OK, you will not be allowed to participate in this study.

Your doctor may be an investigator in this research study, and as an investigator, is interested both in your medical care and in the conduct of this research. Before entering this study or at any time during the research, you may discuss your care with another doctor who is in no way associated with this research project. You are not under



any obligation to participate in any research study offered by your doctor. You have the right to withdraw from participation in this study at any time without penalty. This will have no effect on your care; you will receive the same excellent care from the doctors and nurses.

Of course, if you withdraw your OK for the use of your health information, you may no longer participate in this research study. To the extent that researchers have already used your health information in data analysis and/or scientific publication, this information cannot be withdrawn (although any publication of information will be such that your information will not be identifiable). If you decide to withdraw your OK, you should notify the researcher in writing along with the date of your decision. Your decision to withdraw your OK for the use of your private health information for this research study will have no effect on your current or future medical care at Children's Hospital of Pittsburgh, a UPMC Health System Hospital or affiliated health provider or the University of Pittsburgh.

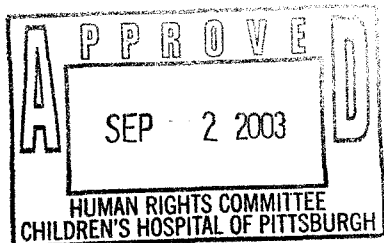
PRIVACY AND CONFIDENTIALITY:

Under the Health Insurance Portability and Accountability Act (HIPAA), your private health care information cannot be used for the research purposes of this study without your OK. You will be informed of the specific uses and disclosures of your medical information for the purpose of this research study and who will have access to your health information.

In general, research records are kept confidential. Paper records are stored in locked cabinets and computerized records are password protected. There are, however, some disclosures of your research-related medical information that may occur.

In addition to the investigators listed on the first page of this authorization form and their research staff, the following persons may have access to your identifiable private health information related to your participation in this research study (Some of the investigators may not be at Children's Hospital of Pittsburgh or may still see your information if they go somewhere else):

- Authorized representatives of the Human Rights Committee. The Human Rights Committee is responsible for assuring the ethical conduct of research at Children's Hospital of Pittsburgh. The Human Rights Committee sometimes asks for names and addresses and telephone numbers of research subjects. By agreeing to participate in this study, you also agree that representatives of the Human Rights Committee can contact you. Of course, you don't have to answer the committee's questions if you don't want to.
- Authorized representatives of the Children's Hospital of Pittsburgh General Clinical Research Center (GCRC), where the study will take place.
- Authorized representatives from the Children's Hospital of Pittsburgh Office of Corporate Compliance for the purpose of monitoring the appropriate conduct of this research study.
- Authorized representatives of the sponsor of this study, American Diabetes Association, may review and/or obtain your identifiable medical information for the



purpose of monitoring the accuracy and completeness of the research data and for performing required scientific analyses of the research data. While the American Diabetes Association has provided its assurance that it will not release your identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.

- Authorized representatives of the Office for Human Research Protections (OHRP) may review and/or obtain your identifiable health information for the purpose of ensuring that the research is being conducted according to the Department of Health and Human Services Guidelines. While the OHRP has provided its assurance that it will not release your identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.

In unusual cases, the investigators may be required to release your research information in response to a court order. Research investigators may be required under Pennsylvania law to report any suspicion of child abuse to child protection services. If the investigators learn that you or someone with whom you are involved is in serious danger of potential severe harm, they may need to warn those who are in danger and contact other agencies to ensure safety. The investigators will be permitted to use your identifiable health information until the completion of this.

FUTURE USE OF DATA:

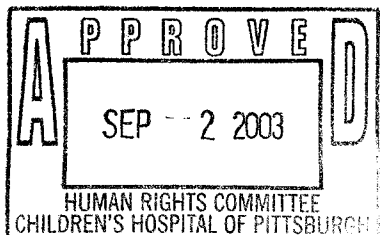
You may choose how your private health information will be used in future studies by initialing one of the options below:

_____ My health information from this study may be used without restriction for future research at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates. I need not be contacted to give additional permission or authorization for such future use. *Initials and date:* _____

_____ My health information from this study may be used for additional research purposes at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates only if I specifically give OK for such use. I may be contacted by telephone, fax, e-mail, or regular mail for the purposes of obtaining my OK for additional research. *Initials and date:* _____

_____ My health information from this study may be used only for the purposes of this study. I do not want to be contacted about future studies. *Initials and date:* _____

_____ I agree to be contacted by Children's Hospital of Pittsburgh or UPMC Health System and its affiliates for follow-up studies or information, which may be needed as a result of this study. *Initials and date:* _____



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COMPENSATION FOR ILLNESS OR INJURY:

There is the possibility with any medical treatment or research that you may suffer some physical illness or injury. In the unlikely event of an injury or illness resulting from this research, no monetary compensation will be made, but any immediate emergency treatment that may be necessary will be provided without charge. You may contact the investigator to obtain information about treatment if it is needed.

VOLUNTARY CONSENT AND AUTHORIZATION:

I have read this form or it has been read to me. All of my current questions have been answered. I will be given a copy of this form for future reference. I understand that throughout my participation in this research, I am encouraged to ask any additional questions I may have about the research and use of my identifiable private health information. Dr. Denise Charron-Prochownik 412-624-6953 or 412-692-5325 (24hr) will be available for questions about this research, my rights, and any possible research-related injury. I may also call the Patient Representative (412-692-5489) or the Human Rights Committee (412-692-5247) concerning questions about my rights as a research subject. Any questions I have about the research use of my health care information will be answered by the Human Protections Coordinator at Children's Hospital of Pittsburgh (412-692-8289), by the Children's Hospital of Pittsburgh Privacy Board (412-692-5247) or by the Children's Hospital of Pittsburgh Corporate Compliance and Privacy Officer (412-692-7842.) By signing this form, I agree to participate in this research and agree to allow the disclosure of my medical information for the purposes described above.

Printed Name of Subject (Research Subject): _____

Date: _____ Signature of Subject: _____

Certification of Person Explaining the Research

I have explained the nature and the purpose of this research and the disclosure of the medical information to the subject listed above. She has had the opportunity to ask questions. Based on this conversation, I believe that she understands what this research project involves.

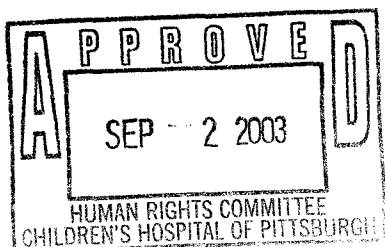
Signature of person explaining the research: _____

Printed name of person explaining the research: _____

Investigator's Certification

I certify that this subject was not begun on any research component of this protocol until after this consent form was signed.

Date: _____ Investigator's signature: _____





University of Pittsburgh

School of Nursing

Reproductive Health Awareness for Teens with Diabetes

Department of Health Promotion
and Development
440 Victoria Building
Pittsburgh, Pennsylvania 15261
412-624-6953, Fax: 412-624-8521
E-mail: dcpro@pitt.edu

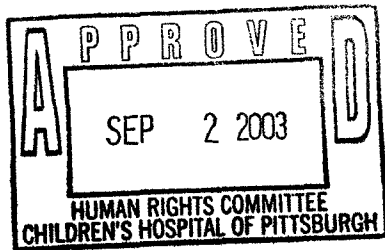
Denise Charron-Prochownik,
Ph.D., R.N., C.P.N.P.
Assistant Professor
School of Nursing and
Graduate School of Public Health

CONSENT FOR A CHILD TO BE A SUBJECT IN A CLINICAL STUDY AND AUTHORIZATION TO PERMIT THE USE AND DISCLOSURE OF IDENTIFIABLE MEDICAL INFORMATION (PROTECTED HEALTH INFORMATION) FOR RESEARCH PURPOSES

HRC Protocol Number: 02-079

TITLE: Reproductive Health Program for Teen Girls with Diabetes (RHATD): An
Intervention Study (Outcome and Cost-effectiveness Evaluation)

INVESTIGATORS: Dr. Denise Charron-Prochownik, Assistant Professor
Department of Health Promotion and Development
School of Nursing
University of Pittsburgh
(412)-692-5325



EXPIRES FEB 28 2004

Dr. Dorothy J. Becker, Professor
Professor of Pediatrics
Director, Division of Endocrinology, Metabolism, & Diabetes Mellitus
Children's Hospital of Pittsburgh
(412)-692-5179

Margaret Feron, RN, MSN, CPNP
Doctoral Student
School of Nursing
University of Pittsburgh
(412)-692-5325

SPONSOR: AMERICAN DIABETES ASSOCIATION

DESCRIPTION:

Dr. Denise Charron-Prochownik and her associates invite your child to participate in a study to evaluate the outcomes and cost-effectiveness of a reproductive health awareness educational program (RHATD), in the form of a CD-ROM and book, specifically designed for teenage women with diabetes. This also includes the evaluation of a face-to-face counseling session with a diabetes clinic nurse and use of a website for communication. A sub-study is also being conducted that will explore initiating reproductive health discussions between the teen girls and their mothers.

Initials and Date: _____

Reproductive health awareness means understanding your child's own body, its normal changes, and to know what's healthy for your child. For teens with diabetes, this includes how diabetes may affect sexuality and pregnancy, and how preconception (pre-pregnancy) counseling can help. This educational program will also help your child to learn how to talk to her health care team and to make decisions that can have positive effects on her reproductive health.

In addition to educational programs, like the one in this study, it is felt that mothers can also be key figures in providing reproductive health information to their teen daughters. This study contains a small, sub-study that will examine reproductive health communication among teen girls with diabetes and their mothers. We hope this information will help us to develop other intervention studies that will improve this mother-daughter communication. You daughter will be asked to complete 2 short additional questionnaires for the sub-study. These questionnaires ask about her general communication with you and about reproductive health communication. You (her mother) will also be asked to participate in the sub-study and complete questionnaires only. You will not be participating in the intervention study.

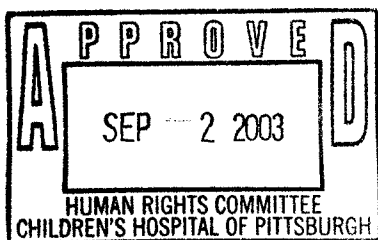
If your child does not want you (her mother) to participate in the sub-study, she may still participate in the larger study.

Your child's participation in the study includes being randomly (picked by chance) assigned to one of the following groups:

1. RHATD Educational Program Group: At your child's clinic visit the project nurse will set up a laptop computer with a CD-ROM reproductive health awareness program that will take approximately 30 minutes to complete. At the next 3- month clinic visit, your child will view the second part of the CD-ROM (30 minutes to complete). At the following clinic visit, (six months after the first CD-ROM viewing), the project nurse will hand your child a short book about reproductive health awareness to read at a clinic visit. In addition, at the 3-month and 6-month visit, your child will receive information and have the opportunity to ask questions and set goals related to reproductive health awareness with a project nurse. Half of teens participating in the CD group will be further randomized (picked by chance) to receive access to a web site that allows your child to communicate with other teen girls with diabetes and a health care provider about reproductive health related topics.

2. Standard Usual Care Control Group: At her clinic visit, the project nurse will hand your child a brochure of general preconception counseling care for all women with or without diabetes. In 9 months, at a regularly scheduled clinic visit, the project nurse will set up a laptop computer with the CD-ROM RHATD program, for your child to view prior to your clinic appointment.

All participants (in both groups) will continue to receive routine care provided to all patients in the diabetes clinics. If your child is chosen to participate in the RHATD educational group, she is asked to complete eleven questionnaires (includes sub-study questionnaires), three at the initial clinic visit, three in three months and six months, and two in nine months. If your child is chosen to participate in the standard care group, she



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Initials and Date: _____

is asked to complete nine questionnaires (includes sub-study questionnaires), three at the initial visit, and two in three months, six months, and nine months. All questionnaires will be given to your child to fill out and return at the clinic visits. The questionnaires will take approximately 30 minutes to complete. We ask questions your daughter's age, with whom she lives with, how long she has had diabetes, what she may already know about diabetes and reproductive health and what her attitudes or beliefs are about these issues. At each clinic visit (baseline, 3, 6, and 9 months), your child will be required to perform a routine blood sugar finger test to check her blood glucose and to obtain a glycosylated hemoglobin blood sample (HbA1c). The project nurse will help your child obtain the finger stick blood samples with the HbA1c kit.

BENEFITS AND RISKS:

The benefits of taking part in this study are that your child will increase her own awareness of how diabetes affects pregnancy and reproductive health and about preconception counseling. This information could help your child make healthy reproductive choices and therefore lead to healthier future pregnancies and healthy babies. Should these educational interventions be successful in promoting improved reproductive health, there is the potential to benefit a significant number of people (your child and her baby). There may be some emotional risks to discussing sexual information and the issues regarding the risks of pregnancy with diabetes. Because the questionnaires are self-administered, such risks should be minimal. Additionally, while there may be some minor discomfort associated with the finger stick necessary for the HbA1c test, this finger stick is part of a routine diabetes treatment plan for home blood glucose monitoring.

NEW INFORMATION:

If any new helpful information comes to our attention, that information will be made available to your child. Or, if any information is learned that might affect your willingness to have your child continue participation in this research, you will be informed.

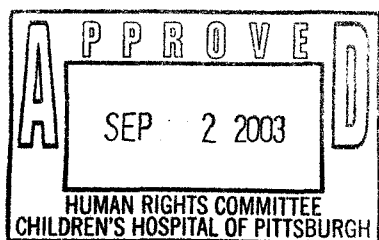
COSTS AND PAYMENTS:

You and your child will not have to pay any costs in order to participate in this study. All laboratory, physician, or hospital costs not related to the research will be charged to your child just as though she were not part of the study. Your child will receive \$20.00 for each completed session for a total of \$ 80.00.

RIGHT TO REFUSE OR WITHDRAW:

Your OK to use and disclose your child's medical information for the purpose of this research study is completely up to you. However, if you do not provide your OK, your child will not be allowed to participate in this study.

Your doctor may be an investigator in this research study, and as an investigator, is interested both in your medical care and in the conduct of this research. Before entering this study or at any time during the research, you may discuss your care with



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Initials and Date: _____

another doctor who is in no way associated with this research project. You are not under any obligation to participate in any research study offered by your doctor. This will have no effect on the care of your child; she will receive the same excellent care from the doctors and nurses.

Of course, if you withdraw your OK for the use of your child's health information, your child may no longer participate in this research study. To the extent that researchers have already used your child's health information in data analysis and/or scientific publication, this information cannot be withdrawn (although any publication of information will be such that your child's information will not be identifiable). If you decide to withdraw your OK, you should notify the researcher in writing along with the date of your decision. Your decision to withdraw your OK for the use of your child's private health information for this research study will have no effect on your or your child's current or future medical care at Children's Hospital of Pittsburgh, a UPMC Health System Hospital or affiliated health provider or the University of Pittsburgh.

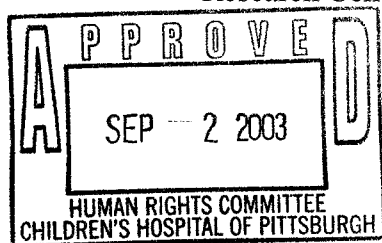
PRIVACY AND CONFIDENTIALITY:

Under the Health Insurance Portability and Accountability Act (HIPAA), your child's private health care information cannot be used for the research purposes of this study without your OK. You will be informed of the specific uses and disclosures of your child's medical information for the purpose of this research study and who will have access to your child's health information. If your child can consent because of a certain status they have obtained (i.e. have graduated from high school, married, is or has been pregnant), then you as the parent in such circumstances do not have the right to consent to the uses and disclosures of such information, nor will you be informed of such access, uses and disclosures. Only your child has the right under these circumstances to authorize such access, use and disclosures.

In general, research records are kept confidential. Paper records are stored in locked cabinets and computerized records are password protected. There are, however, some disclosures of your child's research-related medical information that may occur.

In addition to the investigators listed on the first page of this authorization form and their research staff, the following persons may have access to your child's identifiable private health information related to your child's participation in this research study (Some of the investigators may not be at Children's Hospital of Pittsburgh or may still see your information if they go somewhere else):

- Authorized representatives of the Human Rights Committee. The Human Rights Committee is responsible for assuring the ethical conduct of research at Children's Hospital of Pittsburgh. The Human Rights Committee sometimes asks for names and addresses and telephone numbers of research subjects. By agreeing to have your child participate in this study, you also agree that representatives of the Human Rights Committee can contact you. Of course, you don't have to answer the committee's questions if you don't want to.
- Authorized representatives of the Children's Hospital of Pittsburgh General Clinical Research Center (GCRC), where the study will take place.



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Initials and Date: _____

- Authorized representatives from the Children's Hospital of Pittsburgh Office of Corporate Compliance for the purpose of monitoring the appropriate conduct of this research study.
- Authorized representatives of the sponsor of this study, American Diabetes Association, may review and/or obtain your child's identifiable medical information for the purpose of monitoring the accuracy and completeness of the research data and for performing required scientific analyses of the research data. While the American Diabetes Association has provided its assurance that it will not release your child's identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.
- Authorized representatives of the Office for Human Research Protections (OHRP) may review and/or obtain your child's identifiable health information for the purpose of ensuring that the research is being conducted according to the Department of Health and Human Services Guidelines. While the OHRP has provided its assurance that it will not release your child's identifiable medical information to anyone else, the Children's Hospital of Pittsburgh cannot guarantee this.

In unusual cases, the investigators may be required to release your child's research information in response to a court order. Research investigators may be required under Pennsylvania law to report any suspicion of child abuse to child protection services. If the investigators learn that you or someone with whom you are involved is in serious danger of potential severe harm, they may need to warn those who are in danger and contact other agencies to ensure safety.

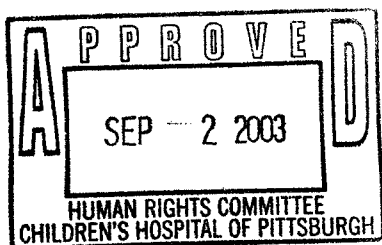
The investigators will be permitted to use your child's identifiable health information until the study is completed. When your child reaches age 18, your permission is no longer valid. For the continued use of your child's health information, she would need to provide permission.

FUTURE USE OF DATA:

You may choose how your child's private health information will be used in future studies by initialing one of the options below:

_____ My child's health information from this study may be used without restriction for future research at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates. I need not be contacted to give additional permission or authorization for such future use. *Initials and date:* _____

_____ My child's health information from this study may be used for additional research purposes at Children's Hospital of Pittsburgh, UPMC Health Systems Hospitals and affiliates only if I specifically give OK for such use. I may be contacted by telephone, fax, e-mail, or regular mail for the purposes of obtaining my OK for additional research. *Initials and date:* _____



EXPIRES FEB 28 2004

____ My child's health information from this study may be used only for the purposes of this study. I do not want to be contacted about future studies.

Initials and date: _____

____ I agree to be contacted by Children's Hospital of Pittsburgh or UPMC Health System and its affiliates for follow-up studies or information which may be needed as a result of this study. Initials and date: _____

Once your child reaches age 18 years, your permission is no longer valid and she would need to provide permission for future use.

COMPENSATION FOR ILLNESS OR INJURY:

There is the possibility with any medical treatment or research that your child may suffer some physical illness or injury. In the unlikely event of an injury or illness resulting from this research, no monetary compensation will be made, but any immediate emergency treatment that may be necessary will be provided without charge. You may contact the investigator to obtain information about treatment if it is needed.

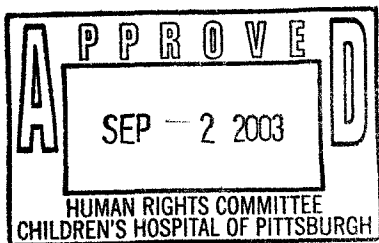
VOLUNTARY CONSENT AND AUTHORIZATION:

I have read this form or it has been read to me. All of my current questions have been answered. I will be given a copy of this form for future reference. I understand that throughout my child's participation in this research, I am encouraged to ask any additional questions I may have about the research and use of my child's identifiable private health information. Dr. Denise Charron-Prochownik 412-624-6953 or 412-692-5325 (24hr) will be available for questions about this research, my child's rights, and any possible research-related injury. I may also call the Patient Representative (412-692-5489) or the Human Rights Committee (412-692-5247) concerning questions about my child's rights as a research subject. Any questions I have about the research use of my child's health care information will be answered by the Human Protections Coordinator at Children's Hospital of Pittsburgh (412-692-8289), by the Children's Hospital of Pittsburgh Privacy Board (412-692-5247) or by the Children's Hospital of Pittsburgh Corporate Compliance and Privacy Officer (412-692-7842.) By signing this form, I agree to permit my child to participate in this research and agree to allow the disclosure of my child's medical information for the purposes described above.

Printed Name of Child (Research Subject): _____

Date: _____ Signature(s) of Parents or
Legally Authorized Guardian(s): _____

Printed names of Parents or Legally Authorized Guardian(s): _____



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Certification of Person Explaining the Research

I have explained the nature and the purpose of this research and the disclosure of the child's medical information to the parent(s) or legally authorized guardian(s). He/she/they have had the opportunity to ask questions. Based on this conversation, I believe that he/she/they understand what this research project involves.

Signature of person explaining the research: _____

Printed name of person explaining the research: _____

Assent

I have explained the research to the child-subject in words and pictures that she understands. I believe that she understands the research and has assented to participation.

Signature of person explaining the research: _____

Printed name of person explaining research: _____

(For children who are developmentally able to sign name:)

This research has been explained to me, and I agree to participate.

Signature of child-subject: _____

Printed name of child-subject: _____

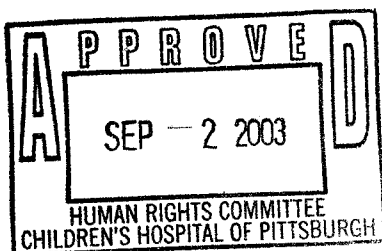
I believe that my child understands what this research involves and that he/she has given assent for his/her participation.

Signature of parent: _____

Investigator's Certification

I certify that this subject was not begun on any research component of this protocol until after this consent form was signed.

Date: _____ Investigator's signature: _____



EXPIRES FEB 28 2004

APPENDIX C

QUESTIONNAIRES

Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Questionnaire for Mothers

Pre-Test

Center for Research in Chronic Disorders

ID Number:

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Administration Date:

--	--

(month)

--	--

(day)

--	--	--	--

(year)

Research Assistant:

--	--

(FOR STAFF USE ONLY)

Open Ended Questions

Please read the following questions and write your answer in the space below.

1. What do you know about diabetes and pregnancy?
2. Where did you get this information?
3. What do you know about diabetes and birth control?
4. What do you know about preconception counseling and care?
5. If your daughter needed preconception counseling and care, where would she get it?
6. If your daughter needed information about diabetes and pregnancy, where would she get it?

(For Office Use Only)

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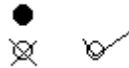
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Please use the following example to answer all questions:

Shade circles like this:
Not like this:



Demographics

Please answer the following questions.

7. When were you born:

		/			/				
(month)			(day)			(year)			

8. What is your ethnic background?

- ☐ 1 Asian-American
- ☐ 2 African-American
- ☐ 3 Caucasian
- ☐ 4 Hispanic
- ☐ 5 Native American
- ☐ 6 Other

9. What is your current occupation? _____

(For Office Use Only)

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10. What is the highest grade that you completed in school?

- ☐ 1 Grade 8 or less
- ☐ 2 Grade 9 -12, did not graduate
- ☐ 3 High school graduate
- ☐ 4 Some college/university/trade school
- ☐ 5 College graduate
- ☐ 6 Some graduate school
- ☐ 7 Graduate school completed

11. What is your marital status?

- ☐ 1 Never married
- ☐ 2 Married
- ☐ 3 Separated
- ☐ 4 Divorced
- ☐ 5 Widowed

12. Considering all sources of income and all salaries, what was your total family gross income over the last 12 months, before taxes?

- ☐ 1 \$5,999 or less
- ☐ 2 \$6,000 - \$11,999
- ☐ 3 \$12,000 - \$20,000
- ☐ 4 More than \$20,000

¹
☐ do not know



Religiosity

13. What is your religion?

- ☐ 1 Protestant
- ☐ 2 Roman Catholic
- ☐ 3 Jewish
- ☐ 4 Other; specify ----> _____
- ☐ 5 None

14. About how often do you usually attend religious services?

- ☐ 1 Never
- ☐ 2 Once a year
- ☐ 3 Less than once a month, but more than once a year
- ☐ 4 Once a month or more, but less than once a week
- ☐ 5 Once a week or more

Awareness of Diabetes and Pregnancy/Cues

Next are some questions about diabetes, pregnancy, and birth control.

15. Do you have diabetes?

- ☐ 1 Yes ---->
 - ☐ 2 No
- a. Do you use insulin?

 - ☐ 1 Yes
 - ☐ 2 No

b. Age in years when diagnosed:

c. Did you have diabetes before your first pregnancy?

 - ☐ 1 Yes
 - ☐ 2 No

16. Have you ever had gestational diabetes (diabetes only during pregnancy)?

- ☐ 1 Yes
- ☐ 2 No

17. Did you ever seek preconception counseling?

- ☐ 1 Yes
- ☐ 2 No

18. Has a health care professional (doctor, nurse, etc.) ever told you that your daughter should get special medical care and advice BEFORE she becomes pregnant or plans for a pregnancy? This is called "preconception counseling and care."

- ☐ 1 Yes
- ☐ 2 No

19. Has anyone else told you that your daughter should get preconception counseling and care (special medical care and advice) BEFORE she becomes pregnant or plans for a pregnancy?

- ☐ 1 Yes
- ☐ 2 No

20. Has a health care professional (doctor, nurse, etc.) told you that your daughter should use some type of birth control when preventing a pregnancy?

- ☐ 1 Yes
- ☐ 2 No

21. Has anyone else told you that your daughter should use some type of birth control when preventing a pregnancy?

- ☐ 1 Yes
- ☐ 2 No

22. Women with diabetes can have healthy pregnancies, but has anyone ever told you that your daughter should not have biological (her own) children?

- ☐ 1 Yes
- ☐ 2 No



Attitudes & Beliefs Toward Birth Control/Preconception Counseling and Care

The next questions focus on your attitudes regarding diabetes and pregnancy.

Susceptibility

23. How much do you worry that your daughter could become pregnant?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

24. How much do you worry that your daughter could develop health problems during pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

25. How much do you worry that your daughter's baby could develop health problems during her pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

Severity

26. If your daughter had an unplanned pregnancy, do you think that this problem would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all

27. If your daughter developed health problems during pregnancy, do you think that those problems would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all

28. If your daughter's baby developed health problems during pregnancy, do you think that the problems would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all



Benefits

29. Would using birth control prevent an unplanned pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

30. Would having blood sugar levels in the normal range before becoming pregnant improve your daughter's chances of having a healthy baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

31. Would getting preconception counseling and care (special medical care and advice) when planning a pregnancy improve your daughter's chances of having a healthy baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

32. Would getting preconception counseling and care (special medical care and advice) improve your daughter's chances of having a healthy pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

33. Would getting preconception counseling and care (special medical care and advice) help prevent your daughter from having a miscarriage or losing the baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all



Barriers

34. How much of a problem would it be for your daughter to use birth control on a regular basis?

- ☐ 5 A big problem
- ☐ 4 A moderate problem
- ☐ 3 Somewhat of a problem
- ☐ 2 A little problem
- ☐ 1 No problem at all
- ☐ 0 Does not apply

35. How difficult would it be for your daughter to seek preconception counseling and care (special medical care and advice) when planning a pregnancy?

- ☐ 5 Very difficult
- ☐ 4 Moderately difficult
- ☐ 3 Somewhat difficult
- ☐ 2 A little difficult
- ☐ 1 Not at all difficult

36. How difficult would it be, in general, for your daughter to follow the preconception counseling and care advice given by a health professional (e.g., keeping blood sugar levels in normal range, taking more insulin injections, etc.)?

- ☐ 5 Very difficult
- ☐ 4 Moderately difficult
- ☐ 3 Somewhat difficult
- ☐ 2 A little difficult
- ☐ 1 Not at all difficult

Social Support

37. How much support (help) would you give to your daughter if she needed help with getting or using birth control?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

38. How much support (help) would you give to your daughter if she needed someone to listen to her about using birth control?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

39. How much support (help) would you give to your daughter if she needed information about birth control and diabetes?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

40. How much support (help) would you give to your daughter if she needed help with getting preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all



Social Support (continued)

41. How much support (help) would you give to your daughter if she needed someone to listen to her about needing preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

42. How much support (help) would you give to your daughter if she needed information about preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

43. How much support (help) would you give to your daughter if she needed information about pregnancy and diabetes?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

44. How much support (help) would you give to your daughter if she needed someone to give her feedback, encouragement, and reassurance about her decisions regarding the use of birth control and getting preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all



Diabetes and Pregnancy Knowledge - Rating

45. How would you rate your understanding of how diabetes and pregnancy affect one another?

- ☐ 4 Excellent
☐ 3 Very good
☐ 2 Fair
☐ 1 Poor

Next, please read the following statements and mark if they are "True" or "False." If you are unsure of an answer, please leave the question blank.

Diabetes and Pregnancy Knowledge

	True 1	False 2
46. Women with diabetes can have a healthy baby.	<input type="radio"/>	<input type="radio"/>
47. During pregnancy, the level of blood sugar in the unborn baby will be similar to the mother's sugar.	<input type="radio"/>	<input type="radio"/>
48. High blood sugar levels early in pregnancy increase the risk of problems for the mother but not the baby.	<input type="radio"/>	<input type="radio"/>
49. Women with diabetes who want to become pregnant should use some form of birth control until their blood sugar levels are in the normal range.	<input type="radio"/>	<input type="radio"/>
50. The normal range for blood sugar during pregnancy is 100-200 mg/dl.	<input type="radio"/>	<input type="radio"/>
51. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could be born with low blood sugar (hypoglycemia).	<input type="radio"/>	<input type="radio"/>
52. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could be a large baby making delivery more difficult.	<input type="radio"/>	<input type="radio"/>
53. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could have breathing problems after birth.	<input type="radio"/>	<input type="radio"/>
54. Women with diabetes who have poorly controlled blood sugar levels at conception (moment they get pregnant) have an increased risk of having a baby with birth defects.	<input type="radio"/>	<input type="radio"/>
55. Women with diabetes who have poorly controlled blood sugar before pregnancy have an increased risk of miscarriages.	<input type="radio"/>	<input type="radio"/>
56. The best time for a woman with diabetes to see a physician for a pregnancy is right after she misses her first period.	<input type="radio"/>	<input type="radio"/>
57. For women with diabetes, the best known treatment to prevent problems to the baby is getting under good metabolic control after a positive pregnancy test.	<input type="radio"/>	<input type="radio"/>



Diabetes and Birth Control Knowledge

	True 1	False 2
58. Women with diabetes have very limited (few) choices of birth control.	<input type="radio"/>	<input type="radio"/>
59. All birth control methods are less effective in women with diabetes than in women without diabetes.	<input type="radio"/>	<input type="radio"/>
60. Women with diabetes have an increased risk for some side effects of birth control methods.	<input type="radio"/>	<input type="radio"/>
61. Women with diabetes cannot use any type of birth control pills.	<input type="radio"/>	<input type="radio"/>

Diabetes & Sexuality Knowledge

	True 1	False 2
62. Sex is like exercise and can cause low blood sugar reactions.	<input type="radio"/>	<input type="radio"/>
63. High blood sugar levels can cause irregular menstrual periods.	<input type="radio"/>	<input type="radio"/>
64. Women with diabetes do not have an increased risk of vaginal infections.	<input type="radio"/>	<input type="radio"/>

Family Planning Knowledge

	True 1	False 2
65. Once a girl has begun having periods, she could become pregnant.	<input type="radio"/>	<input type="radio"/>
66. A girl/woman can become pregnant during her period.	<input type="radio"/>	<input type="radio"/>
67. A girl/woman can become pregnant the first time she has sexual intercourse.	<input type="radio"/>	<input type="radio"/>
68. A condom is another method of birth control.	<input type="radio"/>	<input type="radio"/>
69. To prevent pregnancy, birth control must be used each time a girl/woman has sex.	<input type="radio"/>	<input type="radio"/>
70. A girl/woman is most likely to become pregnant if she has sex about two weeks after her period begins its cycle.	<input type="radio"/>	<input type="radio"/>



Salient Beliefs*/Personal Goals/Sexuality Attitudes

On a scale from 1 to 5, where "Strongly disagree" is number 1 and "Strongly agree" is number 5, please choose the number that best describes how much you agree or disagree with the statement.

	Strongly disagree			Strongly agree	
	1	2	3	4	5
71. I want (wanted) my daughter to continue her education or training.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72. I want (wanted) my daughter to have a career.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73. I want (wanted) my daughter to be married.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74. I want (wanted) my daughter to have a child of her own (biological).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75. I feel (felt) adopting a child would be better for my daughter than going through a pregnancy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76. I would rather my daughter had her "tubes tied" rather than go through a pregnancy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77. *My daughter's using birth control is immoral. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78. Sexual intercourse before marriage is wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79. I worry a lot about my daughter getting pregnant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80. If my daughter does not use birth control, her chances of becoming pregnant are high.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
81. *My daughter's use of birth control takes away the worry of her becoming pregnant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82. I'm afraid of my daughter using birth control. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. It is good for my daughter to use birth control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84. I would not want my daughter to consider having an abortion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
85. *My daughter's seeking of preconception counseling and care is a hassle. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
86. *My daughter's seeking of preconception counseling and care will improve her chances of having a healthy baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
87. *My daughter's seeking of preconception counseling and care will help her to have normal blood sugars (tight control).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. I would feel comfortable about my daughter asking a professional for birth control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Preconception Counseling and Care

89. Before filling out this questionnaire, did you know that special medical advice and/or care called "preconception counseling and care" existed for women with diabetes who are planning a pregnancy?

- ☐ 1 Yes ----> How did you find out about preconception counseling and care (e.g., health professional, media, read about it, know someone who had it)?
- ☐ 2 No

(For Office Use Only)

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90. Did you ever ask about preconception counseling and care for your daughter or did the doctors/nurses tell you about it?

- ☐ 1 Sought information
- ☐ 2 Told about information

91. Has your daughter ever received preconception counseling and care (e.g., told about risks of pregnancy)?

- ☐ 1 Yes ----> From whom did your daughter get this preconception counseling and care?
- ☐ 2 No

(For Office Use Only)

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Thank You !

ITEMS WERE SELECTED, PATTERNED, OR ADAPTED FROM: Diabetes Knowledge Test IDDM (MRDTC), Pregnancy and Diabetes Assessment Form (Magee), Diabetes in Pregnancy Knowledge Screen (Spirito, et al), Knowledge of Maternal Diabetes (St. James, et al), Pregnancy & Diabetes Attitude Scale (Janz, et al), Health Belief Model Scale (Given, et al), Diabetes Care Profile (MDRTC), National Survey of Family Growth (Fontbonne, et al), Handbook of Adolescent Sexuality & Pregnancy (CARD), Self-Esteem (Rosenberg)



Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Questionnaire for Mothers

Post-Test

Center for Research in Chronic Disorders

ID Number:

--	--	--	--	--	--	--	--	--	--

Administration Date:

--	--

(month)

--	--

(day)

--	--	--	--

(year)

Research Assistant:

--	--

(FOR STAFF USE ONLY)

Open Ended Questions

Please read the following questions and write your answer in the space below.

1. What do you know about diabetes and pregnancy?

2. Where did you get this information?

3. What do you know about diabetes and birth control?

4. What do you know about preconception counseling and care?

5. If your daughter needed preconception counseling and care, where would she get it?

6. If your daughter needed information about diabetes and pregnancy, where would she get it?

(For Office Use Only)

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Please use the following example to answer all questions:

Shade circles like this:



Not like this:



Awareness of Diabetes and Pregnancy/Cues

Next are some questions about diabetes, pregnancy, and birth control.

7. Has a health care professional (doctor, nurse, etc.) ever told you that your daughter should get special medical care and advice BEFORE she becomes pregnant or plans for a pregnancy? This is called "preconception counseling and care."
- ☐ 1 Yes
☐ 2 No
8. Has anyone else told you that your daughter should get preconception counseling and care (special medical care and advice) BEFORE she becomes pregnant or plans for a pregnancy?
- ☐ 1 Yes
☐ 2 No
9. Has a health care professional (doctor, nurse, etc.) told you that your daughter should use some type of birth control when preventing a pregnancy?
- ☐ 1 Yes
☐ 2 No
10. Has anyone else told you that your daughter should use some type of birth control when preventing a pregnancy?
- ☐ 1 Yes
☐ 2 No
11. Women with diabetes can have healthy pregnancies, but has anyone ever told you that your daughter should not have biological (her own) children?
- ☐ 1 Yes
☐ 2 No



Attitudes & Beliefs Toward Birth Control/Preconception Counseling and Care

The next questions focus on your attitudes regarding diabetes and pregnancy.

Susceptibility

12. How much do you worry that your daughter could become pregnant?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

13. How much do you worry that your daughter could develop health problems during pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

14. How much do you worry that your daughter's baby could develop health problems during her pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

Severity

15. If your daughter had an unplanned pregnancy, do you think that this problem would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all

16. If your daughter developed health problems during pregnancy, do you think that those problems would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all

17. If your daughter's baby developed health problems during pregnancy, do you think that the problems would be:

- ☐ 5 Very serious
- ☐ 4 Moderately serious
- ☐ 3 Somewhat serious
- ☐ 2 A little serious
- ☐ 1 Not serious at all

Benefits

18. Would using birth control prevent an unplanned pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

19. Would having blood sugar levels in the normal range before becoming pregnant improve your daughter's chances of having a healthy baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

20. Would getting preconception counseling and care (special medical care and advice) when planning a pregnancy improve your daughter's chances of having a healthy baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

21. Would getting preconception counseling and care (special medical care and advice) improve your daughter's chances of having a healthy pregnancy?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all

22. Would getting preconception counseling and care (special medical care and advice) help prevent your daughter from having a miscarriage or losing the baby?

- ☐ 5 A lot
- ☐ 4 A moderate amount
- ☐ 3 Somewhat
- ☐ 2 A little
- ☐ 1 Not at all



Barriers

23. How much of a problem would it be for your daughter to use birth control on a regular basis?

- ☐ 5 A big problem
- ☐ 4 A moderate problem
- ☐ 3 Somewhat of a problem
- ☐ 2 A little problem
- ☐ 1 No problem at all
- ☐ 0 Does not apply

24. How difficult would it be for your daughter to seek preconception counseling and care (special medical care and advice) when planning a pregnancy?

- ☐ 5 Very difficult
- ☐ 4 Moderately difficult
- ☐ 3 Somewhat difficult
- ☐ 2 A little difficult
- ☐ 1 Not at all difficult

25. How difficult would it be, in general, for your daughter to follow the preconception counseling and care advice given by a health professional (e.g., keeping blood sugar levels in normal range, taking more insulin injections, etc.)?

- ☐ 5 Very difficult
- ☐ 4 Moderately difficult
- ☐ 3 Somewhat difficult
- ☐ 2 A little difficult
- ☐ 1 Not at all difficult



Social Support

26. How much support (help) would you give to your daughter if she needed help with getting or using birth control?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

27. How much support (help) would you give to your daughter if she needed someone to listen to her about using birth control?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

28. How much support (help) would you give to your daughter if she needed information about birth control and diabetes?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

29. How much support (help) would you give to your daughter if she needed help with getting preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all



Social Support (continued)

30. How much support (help) would you give to your daughter if she needed someone to listen to her about needing preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

31. How much support (help) would you give to your daughter if she needed information about preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

32. How much support (help) would you give to your daughter if she needed information about pregnancy and diabetes?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

33. How much support (help) would you give to your daughter if she needed someone to give her feedback, encouragement, and reassurance about her decisions regarding the use of birth control and getting preconception counseling and care?

- ☐ 5 A lot of support
- ☐ 4 A moderate amount of support
- ☐ 3 Some support
- ☐ 2 A little support
- ☐ 1 No support at all

Diabetes and Pregnancy Knowledge - Rating

34. How would you rate your understanding of how diabetes and pregnancy affect one another?

- ☐ 4 Excellent
☐ 3 Very good
☐ 2 Fair
☐ 1 Poor

Next, please read the following statements and mark if they are "True" or "False." If you are unsure of an answer, please leave the question blank.

Diabetes and Pregnancy Knowledge

	True	False
	1	2
35. Women with diabetes can have a healthy baby.	<input type="radio"/>	<input type="radio"/>
36. During pregnancy, the level of blood sugar in the unborn baby will be similar to the mother's sugar.	<input type="radio"/>	<input type="radio"/>
37. High blood sugar levels early in pregnancy increase the risk of problems for the mother but not the baby.	<input type="radio"/>	<input type="radio"/>
38. Women with diabetes who want to become pregnant should use some form of birth control until their blood sugar levels are in the normal range.	<input type="radio"/>	<input type="radio"/>
39. The normal range for blood sugar during pregnancy is 100-200 mg/dl.	<input type="radio"/>	<input type="radio"/>
40. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could be born with low blood sugar (hypoglycemia).	<input type="radio"/>	<input type="radio"/>
41. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could be a large baby making delivery more difficult.	<input type="radio"/>	<input type="radio"/>
42. If women with diabetes have problems controlling their blood sugar during pregnancy, their baby could have breathing problems after birth.	<input type="radio"/>	<input type="radio"/>
43. Women with diabetes who have poorly controlled blood sugar levels at conception (moment they get pregnant) have an increased risk of having a baby with birth defects.	<input type="radio"/>	<input type="radio"/>
44. Women with diabetes who have poorly controlled blood sugar before pregnancy have an increased risk of miscarriages.	<input type="radio"/>	<input type="radio"/>
45. The best time for a woman with diabetes to see a physician for a pregnancy is right after she misses her first period.	<input type="radio"/>	<input type="radio"/>
46. For women with diabetes, the best known treatment to prevent problems to the baby is getting under good metabolic control after a positive pregnancy test.	<input type="radio"/>	<input type="radio"/>



Diabetes and Birth Control Knowledge

	True	False
	1	2
47. Women with diabetes have very limited (few) choices of birth control.	<input type="radio"/>	<input type="radio"/>
48. All birth control methods are less effective in women with diabetes than in women without diabetes.	<input type="radio"/>	<input type="radio"/>
49. Women with diabetes have an increased risk for some side effects of birth control methods.	<input type="radio"/>	<input type="radio"/>
50. Women with diabetes cannot use any type of birth control pills.	<input type="radio"/>	<input type="radio"/>

Diabetes & Sexuality Knowledge

	True	False
	1	2
51. Sex is like exercise and can cause low blood sugar reactions.	<input type="radio"/>	<input type="radio"/>
52. High blood sugar levels can cause irregular menstrual periods.	<input type="radio"/>	<input type="radio"/>
53. Women with diabetes do not have an increased risk of vaginal infections.	<input type="radio"/>	<input type="radio"/>

Family Planning Knowledge

	True	False
	1	2
54. Once a girl has begun having periods, she could become pregnant.	<input type="radio"/>	<input type="radio"/>
55. A girl/woman can become pregnant during her period.	<input type="radio"/>	<input type="radio"/>
56. A girl/woman can become pregnant the first time she has sexual intercourse.	<input type="radio"/>	<input type="radio"/>
57. A condom is another method of birth control.	<input type="radio"/>	<input type="radio"/>
58. To prevent pregnancy, birth control must be used each time a girl/woman has sex.	<input type="radio"/>	<input type="radio"/>
59. A girl/woman is most likely to become pregnant if she has sex about two weeks after her period begins its cycle.	<input type="radio"/>	<input type="radio"/>



Salient Beliefs*/Personal Goals/Sexuality Attitudes

On a scale from 1 to 5, where "Strongly disagree" is number 1 and "Strongly agree" is number 5, please choose the number that best describes how much you agree or disagree with the statement.

	Strongly disagree			Strongly agree	
	1	2	3	4	5
60. I want (wanted) my daughter to continue her education or training.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61. I want (wanted) my daughter to have a career.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62. I want (wanted) my daughter to be married.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63. I want (wanted) my daughter to have a child of her own (biological).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64. I feel (felt) adopting a child would be better for my daughter than going through a pregnancy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65. I would rather my daughter had her "tubes tied" rather than go through a pregnancy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66. *My daughter's using birth control is immoral. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
67. Sexual intercourse before marriage is wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68. I worry a lot about my daughter getting pregnant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69. If my daughter does not use birth control, her chances of becoming pregnant are high.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70. *My daughter's use of birth control takes away the worry of her becoming pregnant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71. I'm afraid of my daughter using birth control. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72. It is good for my daughter to use birth control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73. I would not want my daughter to consider having an abortion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74. *My daughter's seeking of preconception counseling and care is a hassle. (R)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75. *My daughter's seeking of preconception counseling and care will improve her chances of having a healthy baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76. *My daughter's seeking of preconception counseling and care will help her to have normal blood sugars (tight control).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77. I would feel comfortable about my daughter asking a professional for birth control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Preconception Counseling and Care

78. Before filling out this questionnaire, did you know that special medical advice and/or care called "preconception counseling and care" existed for women with diabetes who are planning a pregnancy?

- ☐ 1 Yes ----> How did you find out about preconception counseling and care (e.g., health professional, media, read about it, know someone who had it)?
- ☐ 2 No

(For Office Use Only)

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79. Did you ever ask about preconception counseling and care for your daughter or did the doctors/nurses tell you about it?

- ☐ 1 Sought information
- ☐ 2 Told about information

80. Has your daughter ever received preconception counseling and care (e.g., told about risks of pregnancy)?

- ☐ 1 Yes ----> From whom did your daughter get this preconception counseling and care?
- ☐ 2 No

(For Office Use Only)

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Thank You !

ITEMS WERE SELECTED, PATTERNED, OR ADAPTED FROM: Diabetes Knowledge Test IDDM (MRDTC), Pregnancy and Diabetes Assessment Form (Magee), Diabetes in Pregnancy Knowledge Screen (Spirito, et al), Knowledge of Maternal Diabetes (St. James, et al), Pregnancy & Diabetes Attitude Scale (Janz, et al), Health Belief Model Scale (Given, et al), Diabetes Care Profile (MDRTC), National Survey of Family Growth (Fontbonne, et al), Handbook of Adolescent Sexuality & Pregnancy (CARD), Self-Esteem (Rosenberg)

Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Parent-Adolescent Communication

Parent Form

Center for Research in Chronic Disorders

ID Number:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Administration Date:	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	(month) (day) (year)
Test:	1 <input type="radio"/> 2 <input type="radio"/> Month 3	(FOR STAFF USE ONLY)		

Please use the following example to answer all questions:

Shade circles like this:



Not like this:



	Strongly Disagree 1	Moderately Disagree 2	Neither Agree Nor Disagree 3	Moderately Agree 4	Strongly Agree 5
1. I can discuss my beliefs with my child without feeling restrained or embarrassed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Sometimes I have trouble believing everything my child tells me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. My child is always a good listener.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I am sometimes afraid to ask my child for what I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My child has a tendency to say things to me which would be better left unsaid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. My child can tell how I'm feeling without asking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree 1	Moderately Disagree 2	Neither Agree Nor Disagree 3	Moderately Agree 4	Strongly Agree 5
7. I am very satisfied with how my child and I talk together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. If I were in trouble, I could tell my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I openly show affection to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. When we are having a problem, I often give my child the silent treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I am careful about what I say to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. When talking to my child, I have a tendency to say things that would be better left unsaid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. When I ask questions, I get honest answers from my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. My child tries to understand my point of view.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. There are topics I avoid discussing with my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I find it easy to discuss problems with my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. It is very easy for me to express all my true feelings to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. My child nags/bothers me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My child insults me when she is angry with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I don't think I can tell my child how I really feel about some things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Parent-Adolescent Communication

Adolescent and Mother Form

Center for Research in Chronic Disorders

ID Number:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Administration Date:	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	(month) (day) (year)
Test:	1 <input type="radio"/> 2 <input type="radio"/> Month 3	(FOR STAFF USE ONLY)		

Please use the following example to answer all questions:

Shade circles like this:



Not like this:



	Strongly Disagree 1	Moderately Disagree 2	Neither Agree Nor Disagree 3	Moderately Agree 4	Strongly Agree 5
1. I can discuss my beliefs with my mother without feeling restrained or embarrassed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Sometimes I have trouble believing everything my mother tells me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. My mother is always a good listener.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I am sometimes afraid to ask my mother for what I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My mother has a tendency to say things to me which would be better left unsaid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. My mother can tell how I'm feeling without asking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree 1	Moderately Disagree 2	Neither Agree Nor Disagree 3	Moderately Agree 4	Strongly Agree 5
7. I am very satisfied with how my mother and I talk together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. If I were in trouble, I could tell my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I openly show affection to my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. When we are having a problem, I often give my mother the silent treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I am careful about what I say to my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. When talking to my mother, I have a tendency to say things that would be better left unsaid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. When I ask questions, I get honest answers from my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. My mother tries to understand my point of view.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. There are topics I avoid discussing with my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I find it easy to discuss problems with my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. It is very easy for me to express all my true feelings to my mother.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. My mother nags/bothers me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My mother insults me when she is angry with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I don't think I can tell my mother how I really feel about some things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Questionnaire for Mothers

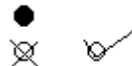
Initiating Discussion

Center for Research in Chronic Disorders

ID Number:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Administration Date:	<input type="text"/> <input type="text"/> /	<input type="text"/> <input type="text"/> /	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
			(month)	(day)	(year)
Test:	<div style="display: inline-block; text-align: center;">0 <input type="radio"/></div> <div style="display: inline-block; text-align: center; margin-left: 100px;">2 <input type="radio"/></div>	Month 3			
(FOR STAFF USE ONLY)					

Please use the following example to answer all questions:

Shade circles like this:
Not like this:



1. Have you ever started a discussion with or asked questions of your daughter's health care provider (doctor, nurse) regarding reproductive health, such as:

	Yes	No
	1	2
a.) Diabetes and Pregnancy?	<input type="radio"/>	<input type="radio"/>
b.) Diabetes and Sexuality?	<input type="radio"/>	<input type="radio"/>
c.) Diabetes and Birth Control?	<input type="radio"/>	<input type="radio"/>
d.) Diabetes and Preconception Counseling?	<input type="radio"/>	<input type="radio"/>

2. Have you ever started a discussion with or asked questions of your daughter regarding reproductive health, such as:

a.) Diabetes and Pregnancy?

☐ 1 Yes ☐ 2 No

b.) Diabetes and Sexuality?

☐ 1 Yes ☐ 2 No

c.) Diabetes and Birth Control?

☐ 1 Yes ☐ 2 No

d.) Diabetes and Preconception Counseling?

☐ 1 Yes ☐ 2 No

3. When was your most recent discussion?

1
☐
Within the past month

2
☐
More than 1 month ago

3
☐
More than 3 months ago

4
☐
More than 6 months ago

4. When you have had each discussion, how long do they normally last?

1
☐
Less than 5 minutes

2
☐
5 - 10 minutes

3
☐
10 - 20 minutes

4
☐
20 - 30 minutes

5. What specifically have you discussed?

(For Office Use Only)

6. Rate the following statement:

"I find it easy to discuss these issues with my daughter."

1
☐
Strongly Disagree

2
☐
Moderately Disagree

3
☐
Neither Agree Nor Disagree

4
☐
Moderately Agree

5
☐
Strongly Agree

7. Rate the following statement:

"I was very satisfied with my discussions with my daughter."

1
☐
Strongly Disagree

2
☐
Moderately Disagree

3
☐
Neither Agree Nor Disagree

4
☐
Moderately Agree

5
☐
Strongly Agree



8. Have you looked up information anywhere else on these topics?

- ☐ 1 Yes ----> Where have you looked? _____
☐ 2 No

(For Office Use Only)

Now, on a scale from 1 to 7, with number 1 as "Unlikely" and number 7 as "Likely," please rate your answer from 1 to 7 for the following statements.

	Unlikely						Likely
	1	2	3	4	5	6	7
9. I intend to speak with my daughter's health care provider about reproductive health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I intend to speak with my daughter's health care provider about preconception counseling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I intend to speak with my daughter about reproductive health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I intend to speak with my daughter about preconception counseling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



1 5 8

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0 6 9

Diabetes and Reproductive Health Communication Between Teen Girls and Moms

Questionnaire for Teens

Initiating Discussion

Center for Research in Chronic Disorders

ID Number:	<div style="border: 1px solid black; width: 100px; height: 20px; margin: 0 auto;"></div>	Administration Date:	<div style="border: 1px solid black; width: 30px; height: 20px; margin: 0 auto;"></div>	/	<div style="border: 1px solid black; width: 30px; height: 20px; margin: 0 auto;"></div>	/	<div style="border: 1px solid black; width: 100px; height: 20px; margin: 0 auto;"></div>
			(month)		(day)		(year)

Test: 1 2

○ ○

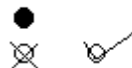
Month 3

(FOR STAFF USE ONLY)

Please use the following example to answer all questions:

Shade circles like this: ●

Not like this: ○



1. Have you ever started a discussion with or asked questions of your mother regarding reproductive health, such as:

	Yes	No
	1	2
a.) Diabetes and Pregnancy?	○	○
b.) Diabetes and Sexuality?	○	○
c.) Diabetes and Birth Control?	○	○
d.) Diabetes and Preconception Counseling?	○	○

If you answered "Yes" to any of these questions, go to question 2.

If you did NOT answer "Yes" to any of these questions, go to question 7.



2. When was your most recent discussion?

- | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|
| 1
<input type="radio"/> | 2
<input type="radio"/> | 3
<input type="radio"/> | 4
<input type="radio"/> |
| Within the
past month | More than
1 month ago | More than
3 months ago | More than
6 months ago |

3. When you have had each discussion, how long do they normally last?

- | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|
| 1
<input type="radio"/> | 2
<input type="radio"/> | 3
<input type="radio"/> | 4
<input type="radio"/> |
| Less than
5 minutes | 5 - 10
minutes | 10 - 20
minutes | 20 - 30
minutes |

4. What specifically have you discussed?

(For Office Use Only)

5. Rate the following statement:

"I find it easy to discuss these issues with my mother."

- | | | | | |
|----------------------------|----------------------------|-------------------------------|----------------------------|----------------------------|
| 1
<input type="radio"/> | 2
<input type="radio"/> | 3
<input type="radio"/> | 4
<input type="radio"/> | 5
<input type="radio"/> |
| Strongly
Disagree | Moderately
Disagree | Neither Agree
Nor Disagree | Moderately
Agree | Strongly
Agree |

6. Rate the following statement:

"I was very satisfied with my discussions with my mother."

- | | | | | |
|----------------------------|----------------------------|-------------------------------|----------------------------|----------------------------|
| 1
<input type="radio"/> | 2
<input type="radio"/> | 3
<input type="radio"/> | 4
<input type="radio"/> | 5
<input type="radio"/> |
| Strongly
Disagree | Moderately
Disagree | Neither Agree
Nor Disagree | Moderately
Agree | Strongly
Agree |

Now, on a scale from 1 to 7, with number 1 as "Unlikely" and number 7 as "Likely," please rate your answer from 1 to 7 for the following statements.

7. I intend to speak with my mother about reproductive health.

Unlikely						Likely
1	2	3	4	5	6	7
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. I intend to speak with my mother about preconception counseling.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

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APPENDIX D

PAC PERMISSION



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Permission to Use Parent-Adolescent Communication Scale

I am pleased to give you permission to use the **Parent-Adolescent Communication Scale** in your research project, teaching or clinical work with couples or families. You may either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgement should be given regarding the name of the instrument, the developers' names, and Life Innovations.

In exchange for providing this permission, we would appreciate a copy of any papers, theses or reports that you complete using the **Parent-Adolescent Communication Scale**. This will help us to stay abreast of the most recent developments and research regarding this scale. We thank you for your cooperation in this effort.

In closing, I hope you find the **Parent-Adolescent Communication Scale** of value in your work with couples and families. I would appreciate hearing from you as you make use of this inventory.

Sincerely,

David H. Olson, Ph.D.

APPENDIX E

INTERVIEW GUIDE

Study: IRB #0405395 Reproductive Health Program for Teen Girls with Diabetes (RHATD):
An Intervention Study (Outcome and Cost-Effectiveness Evaluation)

Sub-study 'Interview Guide' to be used to talk with mothers about reproductive health discussions they have with their teen daughters with diabetes.

Ms. (Mrs.) _____ thanks again for your time today. The study in which you and your daughter participated was about reproductive health issues, such as puberty, sexuality, birth control and pregnancy and diabetes, specifically the effects that diabetes can have on a pregnancy. Our conversation today is about your thoughts and experiences in discussing these issues with your daughter. I will be tape-recording this conversation in order to be sure I don't miss anything, is that okay with you? To assure confidentiality, the tape will be transcribed with only the study ID number that was assigned to you with no identifying information on the typed transcript. You may end this interview at any time. Okay, are you ready to get started?

First, I'd like you to tell me about discussing reproductive health issues, such as monthly periods, sex, birth control or pregnancy, with your daughter?

Tell me about any discussions you have had with your daughter about these issues.

Prompts if needed: Who initiate the discussions?

How long do you spend talking with your daughter about these issues?

Now, can you tell me about any discussions you have had with your daughter about her diabetes and its effect on her reproductive health, such as her periods, sex, birth control and pregnancy?

How do you think the discussions went with your daughter?

Using a scale of 1 to 10, with 1 being the worst and 10 being perfect?

How was your comfort level with these discussions with your daughter?

Using a scale of 1 to 10, 1 being extremely uncomfortable to 10 being extremely comfortable?

What percent of the time do you start the discussions with your daughter about these issues?

How would you have liked the discussions to be?

Would you have changed anything about your discussions with your daughter?

Is there anything else you would like to share with me?

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