

NURSING CARE FOR A PREGNANT WOMAN
WITH TYPE 1 DIABETES

by

Morgan T. Turley

Submitted in partial fulfillment of the requirements
for Departmental Honors in the Department of Nursing

Texas Christian University

Fort Worth, Texas

May 4, 2015

NURSING CARE FOR A PREGNANT WOMAN
WITH TYPE 1 DIABETES

Project Approved:

Supervising Professor: Lynnette Howington, BSN, MSN, DNP.

Department of Nursing

Lisette Allender, MSN, RNC-OB.

Department of Nursing

Karla O'Donald, MA.

Department of Spanish and Hispanic Studies

ABSTRACT

The role of the health care provider during any woman's pregnancy is to provide the necessary resources for a confident mother and a healthy baby. For women who are diagnosed with type 1 diabetes, pregnancy is an added stress to the everyday task of managing this disease. This study focuses on psychological difficulties and coping mechanisms of pregnant women affected by type 1 diabetes. In this pilot study, four type 1 diabetic mothers answer questions about the characteristics of their health care team, their support systems, and any difficulties experienced through pregnancy and the postpartum period. Margaret Newman's (1999) theoretical framework maintains that wholeness includes elements of mental and physical health and is coupled with a patient's active adaptation during times of uncertainty. Newman's theory states that the definition of wholeness does not require complete physical wellness, but can be compensated for with mental wellness. This study's purpose is to distinguish difficulties in pregnancy for a type 1 diabetic and identify implications for care based on these women's healthcare experiences during pregnancy.

TABLE OF CONTENTS

Title Page	i
Approval Page.....	ii
Abstract.....	iii
Table of Contents	iv
INTRODUCTION	1
Theoretical Framework.....	1
Review of Literature	2
Determination of the Evidence Base.....	9
Research Questions	10
METHODS	10
Data Collection	10
Data Analysis.....	11
RESULTS	12
Pilot Findings.....	12
Discussion	19
Limitations	26
Future Research	26
CONCLUSION.....	27
REFERENCES	29
APPENDIX A: LIST OF TABLES	31
APPENDIX B: RECRUITMENT LETTER.....	34
APPENDIX C: PARTICIPANT CONSENT FORM	35

APPENDIX D: INTERVIEW QUESTIONS39

INTRODUCTION

Establishing the unique difficulties of pregnancy for a woman with type 1 diabetes is essential in securing adequate coping methods and ensuring the desired outcome of a healthy mother and baby. The American Diabetes Association (ADA) defines type 1 diabetes as a disease where the body does not produce insulin (1995). Insulin is required to turn sugar into energy for the body, and insulin therapy currently is the only treatment for type 1 diabetes. The ADA currently recommends that women with type 1 diabetes obtain optimal glucose control for 3-6 months before conception. This is because excessive glucose and ketones pass through the placenta which increases the risk of miscarriage and birth defects. Recommended pre-prandial glucose levels are between 60-119 mg/dl and postprandial between 100-149 mg/dl. The pregnant woman risks complications of diabetic retinopathy, kidney problems, increased infections, hypoglycemia, and preeclampsia with hyperglycemia (ADA, 1995). Although physical recommendations exist, there is no universal psychological care plan for pregnant women with type 1 diabetes. Health care providers can take measures to provide psychological support; however, disparities remain throughout the care of these particular women. Medical professionals encourage support systems, but the health care provider does not always assume that role. This project will examine what healthcare providers can do to support a positive mental outlook in relation to the unique difficulties experienced by type 1 diabetic mothers.

Theoretical Framework

The “Health as an Expanding Consciousness” model created by Margaret A. Newman (1999) supports the purpose of this pilot study by describing the synchrony of a

nurse-client relationship in times of uncertainty (p. 227). Newman's theory explains that health is an expanding consciousness, coupling physical health and the influence of connection with others on quality of life. Newman's theory further states that the definition of wholeness only "takes on different forms" throughout life and that sickness does not eliminate wholeness (Newman, 1999, p. 228). The theory can guide nurses and healthcare providers who care for persons with diabetes, wherein absence of disease is unattainable. For type 1 diabetics, complete physical wellness is never possible because scientists have not found a cure (Diabetes.co.uk, 2014). A "whole" person is an actively adapting human being in a state of uncertainty. Newman holds that the relationship between the nurse and the client is vital in ensuring a healthy, dynamic transformation in the presence of pending disequilibrium. The characteristics of the healthcare team, the support system, and the unique difficulties of pregnancy for a type 1 diabetic are a part of this theory. Through psychological support and catering to the patient's needs, a woman with type 1 diabetes can have a healthy pregnancy.

Review of Literature

The study explored the clinical question with qualitative studies, clinical practice guidelines, and experimental studies. The literature examines the quality of life for pregnant women with type 1 diabetes and the differences in attitudes towards motherhood.

CINAHL and Medline databases and the National Guideline Clearinghouse were used to search the literature. Search terms included "type 1 diabetes" and "pregnan*" yielding 27 full text sources. To widen the search, "type 1 OR type I" and diabetes and "pregnan*" were used, yielding 1,255 full text sources. Articles used in this review were

published between 2005 and 2013. One qualitative article from 2005 was reviewed because it remains relevant to type 1 diabetic women's experiences with gestation. Ample quantitative data in the literature identified recommended blood glucose and A1c levels for women during pregnancy; however, the focus remains firmly on qualitative studies due to the psychological aspect of the clinical question.

The American Diabetes Association (ADA) clinical practice guideline provides preconception care recommendations for a woman with pre-existing diabetes.

Observational and nonrandomized studies validate these recommendations and the ADA's board of directors reviews these studies (American Diabetes Association, 2013). The ADA suggests that preconception counseling begin as soon as a woman with type 1 diabetes has childbearing potential. Recommendations state that before conception a woman with type 1 diabetes should have a hemoglobin A1c that indicates good control of diabetes (less than 7%); the health care provider needs to identify any dangerous medications prescribed to the mother in order to reduce congenital complications in the fetus.

Sacks, Feig, Liu, and Wolde-Tsadik (2006) investigated the effect of rigid versus less rigid glucose control on hypoglycemic episodes of women with type 1 diabetes. Rigid glucose control consisted of a tight margin in which blood sugar levels were maintained, and less rigid glucose control consisted of a larger margin in which blood sugar levels were maintained. In this randomized control trial, both objective and subjective hypoglycemia were reported more often among those in the 'rigid' glycemic control group. No statistically significant differences were found in birth weights between the two groups and no neonates perished in this study.

Examining psychosocial difficulties of women with type 1 diabetes during pregnancy requires a discussion of attitudes towards prenatal care. McCorry, Hughes, Spence, Holmes, and Harper (2012) investigated attitudes of type 1 diabetic women towards preconception care. A sample of fourteen women in Northern Ireland with a diagnosis of type 1 diabetes participated in semi-structured interviews to explain views of preconception care and risks posed to a pregnant type 1 diabetic woman. Four themes emerged in the experiences of these women: emotional complexity of childbearing decisions, preferences for information related to pregnancy, health care provider familiarity with the patient, and frustrations with the medical model of care. All participants reported fears about macrosomic newborns and congenital malformations in the fetus. All participants were aware that blood glucose levels needed rigid control during pregnancy, but some stated uncertainty as to why it was necessary. Researchers found value in relational stability between doctor and patient. Preconception care was effective when the provider understood the woman's history with diabetes, family plans, and personal circumstances. Eight of the fourteen women expressed frustration with the lack of holistic care provided in relation to patient goals and individual needs. Researchers found evidence that anxiety inhibited some women from seeking preconception care; however, an early recommendation from a health care provider may act as motivation to seek care before conception. Some participants felt that the focus on controlling blood glucose levels inhibited care providers' ability to address personal difficulties. This finding led researchers to note the importance of "relational continuity" between doctor and patient (McCorry et al. 2012, p. 400). This study suggests that nurses' education techniques have a large impact on preconception views, can reduce

maternal anxiety, and can help to establish rapport with type 1 diabetic patients (McCorry et al., 2012).

Berg's (2005) study on the psychological cognition of a woman with type 1 diabetes is still a focus of current research due to its focus on psychological cognition. The framework for this study included a life-world perspective which addresses the daily experiences of special populations – in this case, pregnant type 1 diabetic women. Researchers conducted forty-eight open-ended interviews and identified clusters of experiences. The researchers stated that participants identified the need to master the disease or be enslaved by it. This idea concerns three theme subgroups with the titles “Meaningfulness/Meaninglessness, Reconciliation/Conflict, and Shared Control/Unwillingly Controlled” (Berg, 2005, p. 25).

A variation existed between each positive and negative dimension in each woman although some drifted predominantly one way or the other. The women's social network, including “health professionals...[the] husband/partner, parents, other close relatives, friends, and [the] employer” was an important coping mechanism (Berg, 2005, p.29). The pregnancy was “meaningful when [it] and the child were accepted and when hope and a feeling of being normal dominated” (Berg, 2005, p. 29). The woman achieved reconciliation when she accepted the presence of a chronic disease that required special care, comprehended her body's behavior, and was able to rejoice in the current pregnancy. A feeling of “enslavement” by these women consisted of feelings of “meaninglessness, conflict, and being involuntarily controlled” (Berg, 2005, p. 29).

The researchers identified coping mechanisms of education, social support, reconciliation, and maintenance of hope. The study found that “the women with type 1

[diabetes] had difficulty daring to hope” and that “thoughts and plans for the future and the child’s arrival were rare or absent” resulting from the strain of diabetes care (Berg, 2005, p. 30). The nursing implications from this study include that a health care provider nurturing a woman’s hope can promote the feelings of “normal” expectant mothers. Key support persons and health care providers must encourage the woman’s “mastery” of the disease, not enslavement.

Jennefer Richmond (2009) examined fluctuating glucose levels of pregnant type 1 diabetic women in relation to their experiences. The purpose of this qualitative, phenomenological study was to identify individual experiences with identity during pregnancy. Women with previous poor glucose control before pregnancy found motivating factors to improve control during pregnancy such as a desire for a healthy child, guilt for not complying with a care regimen, and pressure from health care providers. Researchers also identified barriers to achieving good control: frequency of blood testing, insulin doses, nausea, vomiting, anxiety about other children’s care, and constant medical attention (Richmond, 2009, p. 87). Experiencing a hypoglycemic episode when no support person was present was a concern of type 1 diabetic women during pregnancy. In addition, the meticulous care of blood glucose levels caused some women to ignore the joys of impending motherhood and to feel “robbed of any enjoyment which they may have otherwise gained from being pregnant” (Richmond, 2009, p. 90). Researchers found that the majority of the women interviewed “made tremendous efforts to improve their blood glucose levels during the pregnancy itself, compromising their own self-identity” (Richmond, 2009, p. 91).

The article by Marie Berg and Carina Sparud-Lundin (2009) illustrates the experience of pregnant women with type 1 diabetes with health care providers. Researchers found that during pregnancy, mothers felt pressure, felt prioritized, and felt disconnected when traveling to separate health care providers. Researchers concluded that the pressure felt by women during pregnancy was related to “constant worry for the baby” and that “information given by care providers could contribute to and increase worry” (Berg & Sparud-Lundin, 2009).

The care providers’ focus on the pregnancy was a negative perception in that mothers felt doctors’ attentions were directed at the baby’s health, and not the mothers’. The mothers who had more than one healthcare provider at different locations described feeling “burdened...with the role of messenger, reporting which follow-ups and treatments had been performed” (Berg & Sparud-Lundin, 2009).

Additionally, women needed to share their experiences with fellow type 1 diabetics. In childbirth, researchers discovered that these women felt abandoned, felt pressure to be self-sufficient, and had a varied range of trust and mistrust towards their provider’s “diabetes-obstetric competence” (Berg & Sparud-Lundin, 2009). While in labor, the expectant mother or father often became responsible for monitoring the blood glucose. For some, this responsibility increased a sense of control; for others, it led to a sense of abandonment and worry. Researchers came to the overall conclusion that each party needs to clarify roles of responsibility. For instance, these women want to achieve glycemic control although it is the responsibility of care providers to minimize adverse outcomes. Researchers recommend that “a multi-professional team should manage care of pregnant women with diabetes...with as few care providers as possible” to diminish

the probability that the woman will have to play messenger between providers (Berg & Sparud-Lundin, 2009). There must be an individual plan for each pregnant woman with type 1 diabetes.

Carina Sparud-Lundin and Marie Berg (2011) published a secondary article titled “Extraordinary exposed in early motherhood – a qualitative study exploring experiences of mothers with type 1 diabetes”. The authors used a life-world, reflective research approach to interview 23 women with type 1 diabetes who were 6-24 months postpartum. Researchers assessed experiences of breastfeeding, glycemic control, and support and well-being. Overall findings included that mothers had difficulty breastfeeding and controlling hypoglycemic episodes. Women experienced extreme fluctuations in blood glucose levels which resulted in a feeling of vulnerability. Women felt inadequate in controlling glucose levels and caring for the newborn. Participants gleaned contradictory advice and insufficient information about breastfeeding from health care providers. Mothers are in need of intense support in the postpartum period related to breastfeeding and controlling glucose levels (Berg & Sparud-Lundin, 2011).

The quasi-experimental study by Dalfrà, Nicolucci, Bisson, Bonsembiante, and Lapolla (2012) assessed the quality of life among pregnant type 1 diabetic women during pregnancy. Populations included women with gestational diabetes, type 1 diabetes, and non-diabetics (control). Women with type 1 diabetes reported better physical functioning and health perception, but scored lower on the mental component portion during pregnancy. Researchers maintain that the presence of a chronic illness will complicate a pregnancy, and attribute the higher scores on the physical component of the survey to the rigor of care required by type 1 diabetic women during gestation. Researchers also

identified a marked decline in physical and psychological wellness in type 1 diabetic women during the postpartum phase, which highlights the need for supportive care (Dalfrà et al., 2012).

Determination of the Evidence Base for the Question

The strength of evidence of each article was evaluated according to the Johns Hopkins Evidence Based Practice Research Evidence tool (Dearholt & Dang, 2012, p. 108). This tool labels quality of evidence in three categories: high (consistent results), good (reasonably consistent results), or low quality (inconsistent results). Sacks' et al. (2006) level I randomized control revealed high quality evidence of lessened hypoglycemic episodes with less rigid glucose control, although glucose control is still vital to a healthy pregnancy. Dalfrà's et al. (2012) level II quasi-experimental design study displayed high quality evidence, with definitive conclusions, that women with type 1 diabetes have decreased mental health during gestation and the postpartum period. Researchers McCorry et al., Richmond, Berg (2005), Berg and Sparud-Lundin (2009, 2011) of the level III qualitative studies used phenomenological methodology for analysis, but because of the subjective nature, consistency between each participant was varied. A good quality of evidence came from the individual articles and results correlated. The literature concludes that pregnant women with type 1 diabetes feel an intense amount of anxiety about pregnancy, the health of the baby, and the relationship with health care providers. Articles by Berg and Sparud-Lundin (2011) and Dalfrà et al. (2012) note an intense need for education and psychological support in the postpartum period. There is an equal finding in each article that women with type 1 diabetes need an

individualized care plan and that the health care team and support person play a pivotal role in encouraging the pregnant woman with type 1 diabetes.

Research Questions

Health care providers must treat pregnancy in women with type 1 diabetes differently because of the additional challenge of managing a chronic disease. These women are not inherently healthy because human management of blood sugars does not equal pancreatic management of blood sugars. Much research exists for the care for pregnant women with type 1 diabetes, but do these women believe that their psychological needs were adequately addressed during pregnancy? Little research has been conducted but evidence shows that women with type 1 diabetes report worse mental health during pregnancy (Dalfrá et al. 2012). In this study, the psychological difficulties and needs of women with type 1 diabetes during pregnancy are explored. Aspects of a routine pregnancy include care provided by a healthcare team, abetment provided by individual support systems, and psychological stress of pregnancy. These three topics were used to frame ten interview questions which are asked of participants to illuminate the type of additional hardships that women with type 1 diabetes experienced. The ten interview questions can be found in Appendix C. The purpose of this qualitative study is to contribute knowledge to the health care community as to the psychological needs and difficulties of type 1 diabetic women during the gestation and postpartum period.

METHODS

Data Collection

This qualitative study utilized semi-structured interviews with participants to gather data. Four interviews with women with type 1 diabetes who were either pregnant

or had given birth to a child within the past ten years were conducted. Participants were recruited through faculty contacts in the Harris College of Nursing and Health Sciences at Texas Christian University (TCU) and through one Facebook page. After receiving permission from the page administrator, the recruitment letter, found in Appendix A, was posted on the “JDRF Greater Fort Worth/Arlington Chapter” page. One participant responded through this Facebook page. Nursing faculty from the Harris College of Nursing and Health Sciences at TCU gave the primary investigator’s phone number to other contacts who fit the study criteria. Participants validated their interest in participating by telephone and questions related to the study process were answered. Each participant was sent and returned the approved consent form via email then arranged an interview date and time at their convenience. Each recorded interview, using the pre-approved ten questions, was conducted over the phone. Interviews ranged from 15-32 minutes in length, depending on the flow of conversation. Ten questions, as well as follow-up questions if needed, comprised the interviews. Each participant had an unlimited amount of time to answer the questions.

Data Analysis

Based on the literature review and the research questions presented in this study, participants were asked ten interview questions that were grouped under three aspects of pregnancy: characteristics of the participants’ healthcare team, characteristics of the participants’ support system, and any difficulties during pregnancy. Content analysis was used to analyze research data. No digital coding software was used and the interviews were transcribed verbatim. Based on answers to the interview questions, a priori coding was used related to Margaret Newman’s (1999) “Health as an Expanding Consciousness”

theory. Sub-themes for each aspect were identified after a collective content analysis of the research data from all four participants.

RESULTS

Pilot Findings

Each interview was transcribed in its entirety, while maintaining participant confidentiality. Data were compiled from all ten questions that comprised the phone interviews and three themes were identified in which questions were answered: characteristics of the participants' healthcare team, characteristics of the participants' support system, and any glaring difficulties during pregnancy and postpartum. Sub-themes of each subject identify psychosocial aspects of pregnancy. Identified sub-themes in relation to characteristics of the participants' healthcare team include: cohesiveness within the healthcare team, continuity of patient care throughout delivery, and patient education. Sub-themes under characteristics related to participants' support systems included normalizing the pregnancy, finding support through the Juvenile Diabetes Research Foundation (JDRF), and relying on healthcare providers. Hardships during pregnancy varied for each woman, and are discussed at length in the following discussion. Themes within the various hardships include a loss of control and independence in disease management, postpartum blame, and increased fear of causing harm to the fetus.

Characteristics of the Healthcare Team

Exploration of healthcare team characteristics yielded three sub-themes: cohesiveness of the health care team, continuity of patient care, and patient education. These sub-themes are vital to ensure a healthy pregnancy. Participants reported more

satisfaction when the healthcare team was cohesive. Many of the doctors on the healthcare team were comfortable with each other and were professionally aware of the others' practice. Overall, participants reported satisfaction with their healthcare team despite the many providers. Each team consisted approximately of a regular or high-risk OBGYN, an endocrinologist, primary care physician, and occasionally a perinatologist. Despite the large amount of healthcare providers on each team, participants stated contentment about their care; however, it was helpful when the doctors felt comfortable with the other team members.

Continuity of care applies to delivery in the hospital. Participants preferred interacting with their own endocrinologists at the hospital where they delivered. This was not always possible due to doctor privileges at certain hospitals. Participant four in particular reported receiving care from a separate endocrinologist during delivery because her original endocrinologist did not have privileges at the hospital in which she delivered. She reported feelings of concern even though her original endocrinologist had proactively prescribed her insulin regimen through postpartum. She reports that she did not feel as comfortable asking questions related to her type 1 diabetes to the new endocrinologist, because of the break in continuity of care. Healthcare providers provide support, yet this was not enough.

Participants agreed that patient education is helpful for a woman with type 1 diabetes who is going through pregnancy. A consensus among the participants was the stress caused by a constantly shifting insulin regimen. Each participant had an insulin pump throughout the pregnancy, but that did not negate the necessity of adjustments of basal insulin levels and even types of short-acting insulin. This caused stress for some

participants, yet, others expected the changes; however, a consensus is that it is helpful for the healthcare team to warn the patient about possible changes to the insulin regimen before they happen. Overall, participants reported satisfaction with the care received during pregnancy; however, healthcare providers need to warn patients of possible insulin regimen changes before they happen. Warning patients of possible insulin regimen changes can help mentally prepare these women during pregnancy. Participants' concerns were calmed when members of the healthcare team communicated well with each other and when there was continuity of care within the team.

Support Systems

Sub-themes of participants' support system include the need to normalize the pregnancy, obtaining support through JDRF, and obtaining support from their healthcare team. Most participants did not obtain support solely from other type 1 diabetics. Half of the participants did not have any support by individuals with type 1 diabetes; family members, friends, and the healthcare team provided the support for these women. Participants concentrated heavily on individual care of blood sugars, dietary habits, and speaking to their healthcare providers about their disease. They discovered the importance of conversing about the normal aspects of pregnancy, in addition to issues related to type 1 diabetes. Each participant desired an aspect of conventionality throughout pregnancy. They received this by talking with family and friends who knew about type 1 diabetes but did not have personal experience with it. Participants found that this type of support system, along with support from healthcare providers, was enough to sustain them through pregnancy.

Although all participants obtained support from family and friends, two of the four participants found great support through JDRF. This support came through a high-risk JDRF pregnancy clinic and other friends and acquaintances found through JDRF.

A consistent healthcare team is important and is part of the support system needed by women with type 1 diabetes during pregnancy. Each participant agreed that their healthcare team was instrumental in patient teaching and reassurance about the pregnancy. Participant three, in particular, stated that her endocrinologist provided “good support” for her and her spouse during her first trimester (Participant three, personal communication, Dec. 8, 2014). Those close to each participant provided most of the emotional support. Participant three shared that members of her family were healthcare providers. However, it is important to note that all participants had at least one person in their support system that understood diabetes and could help manage the disease.

Difficulties

Each participant described unique difficulties during pregnancy. Common themes were identified within these difficulties. Participants experienced a loss of control and independence, a sense of postpartum blame, and an increased fear of perpetrating problems in the pregnancy. According to participants, this loss of control occurred in and out of the hospital setting. In the home the majority of participants experienced dramatic low blood sugars that could not be anticipated. Participant two, in particular, reported experiencing dramatic lows in the middle of the night. She describes her lows as a “scary” event and had lows at least “two times a week” in the middle of the night. Participant two also tells a story:

“I had a super severe low blood sugar, and I was with a friend of mine who knew that I had diabetes, but didn’t understand diabetes. But, it was very important that she was there with me because she didn’t let me get in a car, I was trying to drive and confused. Anyway, my blood sugar was in the teens and I didn’t realize it.”

(Participant two, personal communication, Dec. 3, 2014).

These low blood sugars were much more frequent for these women than they were in a pre-pregnancy state. This presents issues such as how to monitor blood sugars in the middle of the night. In the event of hypoglycemic unawareness, a pregnant type 1 diabetic needs to have a person in their established support system to help monitor for signs and symptoms of low blood sugar. These events create a loss of control for these women because the unpredictability of pregnancy exists in addition to normal management of the disease. The majority of participants report these lows improving after the first trimester, but also having to deal with sudden insulin changes due to increased insulin resistance in the second and third trimester. Participant answers correlated in the fact that their healthcare providers played a vital role in educating them about what to expect of their blood sugars and insulin regime changes. Participant three described her hopelessness as others in her life had to intervene for her during her hypoglycemic episodes. She reported that suddenly she “couldn’t handle [her] whole entire life” as she had before (Participant three, personal communication, Dec. 8, 2014). This feeling was more prevalent during delivery. Participants reported a strong dislike of being put on an insulin drip in the hospital during delivery. This is due to the inability to manage all aspects of type 1 diabetes. Participant two, in particular described going on an

insulin drip as a “transfer of power” between the patient and nurses. She went on to explain:

“...I can tell you it’s a huge loss of control when the doctor wanted to put me on a drip...I was [having to] direct nurses for how much insulin to give because you’re trying to keep such tight glucose control, so I hated being on an insulin drip. Because you can’t do any of it yourself, especially if you’re used to doing everything on your own.” (Participant two, personal communication, Dec. 3, 2014).

Another prevalent theme surfaced during participants’ time in postpartum. Participants expressed a feeling of postpartum blame. Participants two and three discussed feeling judged by at least one of the nurses caring for them on the postpartum unit. Participant two describes an instance where a nurse told her she would cause hypoglycemia in her baby because she had to take insulin during her pregnancy. This is a misinformed statement because individuals with type 1 diabetes are required to take insulin to live. She describes feeling blamed by the nurses for a disease that she cannot control and how frustrating it felt for a misinformed nurse to provide her care. This interviewee felt as though the nurses “lumped” her in a broad definition of diabetes, including type 2 and gestational (Participant two, personal communication, Dec. 3, 2014). However, type 1 diabetes is a different disease and requires different management than gestational or type 2 diabetes.

Participant three reported a nurse having “problems” with the participant directing her own care after delivery (Participant 3, personal communication, Dec. 8, 2014). She says that most of the nurses allowed her to have control over her diabetes because she had

managed this disease her entire life, but one of the nurses wanted complete control. She attributed this to a personality difference between her and the postpartum nurse.

Participant four, in contrast, reported a “hands-off” attitude from her postpartum nurses (Participant four, personal communication, Feb. 9, 2015). She was in control of her diabetes management during postpartum and preferred it that way.

There was variance in nurse treatment of these patients during the postpartum stay. Subjects found that some nurses did not want to deal with the diabetes, and some had judgmental attitudes towards their patients related to type 1 diabetes. Participants agreed that blood sugars were extremely variable after delivery, and that it impacted breastfeeding and patient healing. However, data suggests that endocrinologists play a large part in managing patient blood sugars after delivery.

Another theme identified during gestation in these women is an uncanny sense of fear of causing harm to the baby. Participant one describes having many crying episodes throughout her pregnancy due to her fear for her child each time her blood sugar was outside the desired range. Present data may suggest that an unplanned pregnancy increases stress in type 1 diabetic women because of the necessity to rapidly obtain rigid control of blood sugars. Despite working in health care, participant two expressed surprise at how much work it took to keep herself healthy throughout her pregnancy. Participant three described her fear of passing on type 1 diabetes to her child, even after delivery, with reports of remaining vigilant about her child’s dietary habits and behavior. The fear is still present in her daily life. The participant said “I think to some extent you have to know what we live with day in and day out, we don’t want to pass that on, that’s something we don’t want our children to have to live with” (Participant 3, personal

communication, Dec. 8, 2014). Interviewee number four painted a picture of constant worry. To her, every blood sugar out of normal range was a threat to her child's health. She describes being preoccupied with perfection so no harm came to her child:

“...[I was] just being harder on myself, like if [my blood sugar] was a high number, like I can't do that again, what did you eat? What did you – you know – did you not take insulin, did you not take enough?” (Participant 4, personal communication, Feb. 9, 2015).

Even with a planned pregnancy, this participant expressed a sense of severe self-blame if anything went wrong with the pregnancy, even if not related to type 1 diabetes complications. A theme presents itself in these answers: type 1 diabetic expecting mothers have an excessive amount of fear and stress if anything out of the ordinary occurs. Even with no complications present, these women report a continual and exhausting sense of worry and stress.

Discussion

The Healthcare Team

Much of the research identified throughout this study is in agreement with previous data in the literature review. Like McCorry et al. (2012) discovered, these women needed a trustful relationship with their healthcare team. The research data for this study supports this finding. All participants saw members of their healthcare team quite frequently. Participant two saw her endocrinologist as often as every two weeks. Participants agreed that gestation went smoothly when members of the healthcare team were familiar with the others' medical practices; however, this research suggests that, for the majority of participants, members of the healthcare team handled aspects of care

individually. For example, the high-risk obstetrician focused on the pregnancy, and the endocrinologist and perinatologist focused on diabetes control. Participants two and three reported that their healthcare providers were in-tune with diabetes care despite tending to their areas of expertise. Participants reported that their healthcare providers were knowledgeable of the other members of the healthcare team as many had worked together previously. Previous research suggests that patients feel uncomfortable with shifting from provider to provider within the healthcare team (Berg & Sparud-Lundin, 2009), but results from the present interviews did not suggest such findings. This could be attributed to a small sample size. However, participant three switched endocrinologists during pregnancy and found that distressing. Participant four reported that her endocrinologist did not have privileges where she delivered and had a new endocrinologist for her time in the hospital. Despite having written orders from her original endocrinologist, she reported being uneasy about being cared for by the other. She noted that it is “much nicer seeing [the endocrinologist] in person” at the hospital instead of dealing with a new doctor (Participant 4, personal communication, Feb. 9, 2015).

This research suggests that participants relied upon their healthcare providers and trusted them with care. They did not need a healthcare team that was constantly together, but one that was cohesive and aware of the other members and their roles. Participants prefer continuity of care in the hospital. Participants experienced less stress in the hospital when their original endocrinologists were present and caring for their diabetes. Another area of stress was the constantly shifting insulin regimen. Participants were adamant that patient education before drastic changes in the insulin regimen would be helpful. This is a task for the healthcare providers. The team must keep the patient abreast

of what may happen throughout pregnancy in relation to insulin therapy. Patient education and coaching may be necessary to alleviate fears of the patient with type 1 diabetes.

Support Systems

Dalfrá et al. (2012) found that women with type 1 diabetes report a poor perception of mental health during pregnancy. The support system is one way to combat this negative perception. Berg (2005) found that support systems are an important coping mechanism, and the present research supports this finding. Healthcare providers were an essential part of the support system for participants in this study. Participant three, in particular, noted that her endocrinologist was very supportive to her and her husband during pregnancy. Healthcare providers must be aware of the difficulties of pregnancy for type 1 diabetic women and be able to provide the necessary resources to ensure a healthy pregnancy.

The Juvenile Diabetes Research Foundation is an important resource. Two of the participants work with JDRF and therefore found adequate diabetes support through this organization. Three of the four participants had access to support from other women with type 1 diabetes, but all participants agreed that having spouses, healthcare providers, and friends is just as adequate. It is important to note that each participant had their own support system, and it was unique to each woman. Participant two, despite having support by other with type 1 diabetes, expressed that it is “important to normalize” the pregnancy (Participant two, personal communication, Dec. 3, 2014). She stated that she felt as though it was important to remember that being pregnant is a “whole new ride in itself”, not including aspects of the type 1 diabetes (Participant 2, personal communication, Dec.

3, 2014). Although mothers spent their days monitoring their blood sugars, they still worried about normal pregnancy issues. Healthcare providers must communicate with their patients and ensure a comprehensive support system, including those with type 1 diabetes knowledge and those without.

Difficulties

Participants experienced a loss of control and independence during pregnancy. This came in the form of dramatic low blood sugars, feeling as though they could no longer handle the demands of diabetes, and receiving an insulin drip during pregnancy. Sacks, Feig, Liu, and Wolde-Tsadik (2006) claim that hypoglycemic unawareness is a serious problem during pregnancy for pregnant women with type 1 diabetes. The findings of the current study reinforce this idea. As discussed by Richmond (2009), participant two was fearful of experiencing a hypoglycemic episode when nobody was around to help her. She states that her “husband at that time was working nights still, so being alone with two kids and being pregnant was scary” (Participant two, personal communication, Dec. 3, 2014). These women each have personal experiences during pregnancy that healthcare providers must ask about and be prepared to offer solutions. This is the responsibility of the healthcare team, to ensure the patient is taken care of outside of the hospital or doctors’ office setting. Present research suggests that these participants, despite managing their own disease for an average of 24.3 years, needed additional support and monitoring from their support systems.

This research also may suggest that insulin drips in the hospital during delivery are not necessarily effective ways to manage stress about blood sugars for pregnant mothers with type 1 diabetes. All participants report use of an insulin pump during

pregnancy. The insulin pump promotes independence with type 1 diabetes by reducing the amount of separate injections needed for optimal glucose control. However, the insulin drip during delivery, according to participant two, is frustrating and ineffective for management. Half of the participants did not have an insulin drip during delivery and reported more satisfaction with their delivery experience. This research suggests that independent control of type 1 diabetes in the hospital for these women may be a more effective way to manage diabetes during delivery.

Healthcare providers and nurses in the hospital must collaborate and work together to establish a birthing plan for the patient well before delivery. The patient then knows what to expect and does not feel the reported loss of control with an insulin drip. Nurses must advocate for the patient in the hospital. Establishing what the patient needs during delivery is vital to supplement a smooth delivery and improve patient outcomes. The aversion to insulin drips also calls for possible revisions to hospital policies about patients with type 1 diabetes in the hospital. Some hospitals have a policy that requires a diabetic to be on an insulin drip during pregnancy. Based upon data from the present qualitative interviews, use of an insulin drip during delivery does not positively contribute to some of these type 1 diabetic women's mental health.

Participants reported having uneasy times in the postpartum period due to a feeling of postpartum blame. Sparud-Lundin and Berg (2011) concluded that women with type 1 diabetes had difficulty with blood sugars while breastfeeding in the postpartum period. Participants agreed that breastfeeding was difficult because of fluctuating blood sugars. If the blood sugar is low, it affects the mother's ability to breastfeed the infant.

Present research agrees with this finding, but also suggests a need for education for postpartum nurses.

In contrast with labor and delivery nurses, participants did not have good experiences with the postpartum nurses. Participant two, in particular found her experience difficult. Nurses need to be educated on the differences between type 1, type 2, and gestational diabetes. Management of each of these diseases is variable. Participants felt blamed by nurses in postpartum for having diabetes, when type 1 diabetes is not a preventable disease. Participants already feel responsible for anything that happens to the fetus during pregnancy, which will be discussed below. Participants should not have had to also face blame for having diabetes. Postpartum nurses need to be cognizant of the type 1 diabetic mother's extra needs and concerns during their hospital stay. Some participants reported a laissez-faire attitude from some of their nurses and found it helpful in promoting independence. Healthcare providers are also responsible for providing care all the way through postpartum for women with type 1 diabetes. Even though no longer pregnant, fluctuating hormone levels and energy needed for breastfeeding affects blood sugar levels.

In agreement with McCorry et al. (2012), participants reported continual stress about the health of the unborn baby. This is not normal, expected stress, it is a constant cycle of worry and self-blame when perfection is not achieved. Richmond (2009) identifies the desire for a healthy child as a motivating factor to achieve good glucose control. However, the pregnant woman with type 1 diabetes needs to maintain a balance between the excessive stress and motivation that this disease brings to pregnancy. In this study, healthcare providers were instrumental in lessening this fear. Participants reported

that there was an ultrasound performed at almost every doctor's visit and each time their provider assured them that nothing was wrong with the fetus. This calmed the mothers' fears. Participant four expressed her intense concern when doctors detected excess fluid by the baby's neck area. Although not caused by her type 1 diabetes, she thought it was. However, after repeated reassurance by her healthcare team, her fears were calmed. This is important information for healthcare providers because they are instrumental in maintaining the balance between anxiety and motivation for the type 1 diabetic woman.

It appears impossible to eradicate the fear that they will do something to harm the fetus, but healthcare providers and nurses in the hospital can do their part to diminish that fear. Data from the present interviews suggest that encouragement and validation of efforts by the healthcare team is important. Participants expressed surprise at the intense care required during pregnancy and reported exhaustion. Managing type 1 diabetes does not allow for any respite from care. Healthcare providers must do their part to encourage these women. Present research suggests that receiving early prenatal care could lessen these fears in type 1 diabetic women. Participant four in particular had preconception care for up to 1 year before pregnancy. Her pregnancy was planned, and data from her interview suggests that she had less fear about causing problems to the fetus, although concerns were still present. Endocrinologists, therefore, should make patient education about pregnancy an early topic of discussion for type 1 diabetics. Knowledge of the risks of pregnancy without tight glucose control could influence decisions related to pregnancy for type 1 diabetics. Women with type 1 diabetes are able to have healthy pregnancies, as long as blood sugars are controlled and psychological needs are addressed.

Limitations

Limitations to this pilot study include a small sample size of four participants. Although data collected is very individualized, a small sample size contributes to difficulty identifying collective themes to represent the entire type 1 diabetic population. Three out of the four participants have experience in the field of healthcare, which could have influenced their perception of the care received. One participant actually provides care to women with type 1 diabetes during gestation which influences her standard of care. However, this also contributes to more in-depth knowledge about insulin regimens and requirements for prenatal care. There is a lack of homogeneity of the sample studied as seen in initiation of prenatal care during their pregnancy. Some participants received early prenatal care in advance of pregnancy, and some did not. As discussed previously, early prenatal care may contribute to feelings of safety and efficacy of diabetes management during pregnancy. It also may alleviate fears of causing complications for the fetus because blood sugar levels are already relatively controlled. Despite these limitations, however, each woman's experience is highly individual and becoming a patient in this situation is different than being a healthcare provider. These limitations also led to more thoughtful discussion and differentiation between being a healthcare provider and being a patient.

Future Research

This pilot study supports the need for further research on this topic. Further research should be conducted about type 1 diabetic women's time during delivery and postpartum in relation to insulin drips, breastfeeding, and blood sugar monitoring. Present research should be relayed to nurses working in these units, and policies amended for this

special population. Collaboration between endocrinologists and nurses should be encouraged. This study can be expanded to assess nurses' knowledge about type 1 diabetes in labor and delivery and postpartum units. Gaps in nursing knowledge related to type 1 diabetes must be identified and remedied.

CONCLUSION

Pregnancy is a unique time in a woman's life that can be complicated by type 1 diabetes by adding stress to any woman affected. This chronic disease can cause a difficult gestation period. Although healthcare providers and nurses cannot cure type 1 diabetes, they can help alleviate any fears of these women during pregnancy. Proactive, anticipatory care must be provided for these women. The healthcare team must be cohesive, must provide continuity of care throughout the journey of pregnancy, and must provide patient education about unique aspects of pregnancy for type 1 diabetic women.

Healthcare providers are an important part of a support system for these women. Support systems are unique for each type 1 diabetic woman. It is important to normalize the pregnancy through those who do not deal with type 1 diabetes but also to receive support through healthcare providers or organizations like JDRF. Glaring difficulties during pregnancy include loss of control and independence in disease management, experiencing postpartum blame, and managing the stress and fear of complete and total responsibility for the health of the fetus based on an unpredictable disease. Although not a point of study in this project, it is important to note that type 1 diabetic mothers carry this worry throughout their child's life. Participant three explains her feelings about her child:

“So, days that she’s drinking more than normal...[as type 1 diabetics] we jump to [our kid getting type 1 diabetes]...But then I also realize she ate a whole piece of bread, she’s probably thirsty. I think that’s something that’s going to stick with me, and it’s probably going to be there the rest of my life, just kind of worrying...” (Participant 3, personal communication, Dec. 8, 2014).

Type 1 diabetic women are never completely physically healthy because human management of blood sugars is not synonymous with pancreatic management of blood sugars. However, in light of Margaret Newman’s health as an expanding consciousness theory, health is not just physical (Newman, 1999). Pregnant women with type 1 diabetes can have healthy pregnancies by being as physically healthy as they are able and by using their connection with their support systems and healthcare providers during gestation to positively influence their mental health. Improving and cultivating these women’s mental health helps to ensure healthy mothers and babies. As healthcare providers, it is our responsibility to provide competent and compassionate care for these women during one of the most life-changing times in existence.

REFERENCES

- American Diabetes Association (1995). *American Diabetes Association (Pregnancy)*.
Retrieved from <http://www.diabetes.org/living-with-diabetes/complications/pregnancy/?loc=lwd-slabnav>
- Berg, M. (2005). Pregnancy and diabetes: How women handle the challenges. *Journal of Perinatal Education, 14*(3), 23-32.
- Berg, M., & Sparud-Lundin, C. (2009). Experiences of professional support during pregnancy and childbirth - a qualitative study of women with type 1 diabetes. *BMC Pregnancy & Childbirth, 9*, 27-27. doi:10.1186/1471-2393-9-27
- Dalfrà, M., Nicolucci, A., Bisson, T., Bonsembiante, B., & Lapolla, A. (2012). Quality of life in pregnancy and post-partum: A study in diabetic patients. *Quality of Life Research, 21*(2), 291-298. doi:10.1007/s11136-011-9940-5
- Diabetes.co.uk (2014). *Diabetes Cure*. Retrieved from <http://www.diabetes.co.uk/Diabetes-Cure.html>
- McCorry, N., K., Hughes, C., Spence, D., Holmes, V., A., & Harper, R. (2012). Pregnancy planning and diabetes: A qualitative exploration of women's attitudes toward preconception care. *Journal of Midwifery & Women's Health, 57*(4), 396-402. doi:10.1111/j.1542-2011.2011.00143.x
- Newman, M. A. (1999). The rhythm of relating in a paradigm of wholeness. *Image: The Journal of Nursing Scholarship, 31*(3), 227-230. doi:10.1111/j.1547-5069.1999.tb00485.x
- Richmond, J. (2009). Coping with diabetes through pregnancy. *British Journal of Midwifery, 17*(2), 84-91.

Sacks, D. A., Feig, D. S., Liu, I. L., & Wolde-Tsadik, G. (2006). Managing type I diabetes in pregnancy: How near normal is necessary? *Journal of Perinatology*, 26(8), 458-462.

Sparud-Lundin, C., & Berg, M. (2011). Extraordinary exposed in early motherhood - a qualitative study exploring experiences of mothers with type 1 diabetes. *BMC Women's Health*, 11(1), 10-10. doi:10.1186/1472-6874-11-10

APPENDIX A: LIST OF TABLES

Title, Author, Date, Journal	Design & Participants	Findings	Strength of Evidence
<p><i>Quality of life in pregnancy and post-partum: a study in diabetic patients</i></p> <p>Dalfrà, Nicolucci, Bisson, Bonsembiante, Lapolla, 2012</p> <p>Quality of Life Research</p>	<p>Quasi-experimental study using the SF-36 Health Survey, CES-D scale, diabetes-related stress questionnaire and diabetes health distress questionnaire.</p> <p>245 pregnant women -30 with type 1 diabetes -176 gestational diabetes -39 control</p>	<p>There is a worse perception of mental health in women with type 1 diabetes and gestational diabetes during and after pregnancy. Researchers identified a worse psychological <i>and physical</i> wellness in type 1 diabetic women during the postpartum phase.</p>	<p>High – consistent results</p>
<p><i>Managing type 1 diabetes in pregnancy: how near normal is necessary?</i></p> <p>Sacks, Feig, Liu, Wolde-Tsadik, 2006</p> <p>Journal of Perinatology</p>	<p>Randomized Control trial studying blood glucose levels with “rigid” glucose control and “less rigid” glucose control during pregnancy.</p> <p>22 pregnant type 1 diabetic women</p>	<p>Mean maternal glucose levels were significantly greater in the ‘less rigid’ glycemic control group in the first and second trimesters. Both objective and subjective hypoglycemia were reported more often among those in the ‘rigid’ glycemic control group. No statistically significant differences were found in birth weights between the two groups and no neonates perished in this study. The data does suggest that higher glucose targets may decrease the incidence of hypoglycemia in mothers while not increasing the risk of morbidity to the mother or fetus.</p>	<p>High – consistent results</p>
<p><i>Pregnancy Planning and Diabetes: A Qualitative Exploration of Women’s Attitudes Toward Preconception Care</i></p> <p>McCorry, Hughes, Spence, Holmes, Harper, 2012</p>	<p>Qualitative design with semi structured interviews</p> <p>14 non-pregnant women with type 1 diabetes</p>	<p>Women with type 1 diabetes have anxiety related to preconception care with the newborn, existing children, and ability to cope. Women reported a need for a trustful relationship with their doctor and were frustrated by the lack of holistic care in individual needs.</p>	<p>Good – small differences in consistency of results due to the qualitative nature of the study</p>

Journal of Midwifery & Women's Health			
<i>Coping with diabetes through pregnancy</i> Richmond, 2009 British Journal of Midwifery	Qualitative phenomenological methodology using purposive sampling 11 pregnant women with type 1 diabetes	Women with type 1 diabetes with poor glucose control found motivating factors during pregnancy such as a desire for a healthy child, guilt, and pressure from health care providers. Researchers identified barriers to achieving good control: frequency of blood testing, insulin doses, nausea, vomiting, anxiety over other children and constant medical attention. Constant worry of having a hypoglycemic episode when no support person was around was also a concern of these women during pregnancy. The meticulous care of blood glucose levels caused some women to ignore the joys of impending motherhood. Researchers found that the majority of the women interviewed compromised self-identity to maintain glucose levels.	Good – small differences in consistency of results due to the qualitative nature of the study
<i>Pregnancy and Diabetes: How Women Handle the Challenges</i> Berg, 2005 Journal of Perinatal Education	Qualitative, phenomenological study using a life-world perspective. 18 pregnant women with type 1 diabetes	Women interviewed fell under the defined theme of “to master or to be enslaved” by type 1 diabetes during pregnancy. This idea concerns three theme subgroups with the titles Meaningfulness/Meaninglessness, Reconciliation/Conflict, and Shared Control/Unwillingly Controlled. Reconciliation was achieved when the woman accepted the presence of a chronic disease that required special care, comprehension of her body's behavior, and being able to rejoice in the current pregnancy. The researchers identified coping mechanisms of education, social support, reconciliation, and maintenance of hope. Key support persons and health care providers must encourage the woman's “mastery” of the disease, not enslavement.	Good - small differences in consistency of results due to the qualitative nature of the study
<i>Experiences of professional support during pregnancy and childbirth – a qualitative study of women with type 1 diabetes</i> Berg & Sparud-Lundin, 2009 BMC Pregnancy and Childbirth	Qualitative, phenomenological study using a life-world approach. 23 type 1 diabetic women 6-24 months post-delivery	During pregnancy, mothers felt pressure, felt prioritized, and often felt disconnected when traveling to different health care providers. The prioritization of the mothers during pregnancy was a negative perception in that mothers felt doctors' attentions were directed at the baby's health, not the mothers'. The women had a need to share their experiences. In childbirth, researchers discovered that these women felt abandoned, felt that they had to be self-sufficient, and felt a varied range of trust and mistrust towards their provider's competence.	Good – small differences in consistency due to the qualitative nature of the study
<i>Extraordinary</i>	Qualitative study	During the postpartum stay, women felt	Good – small

<p><i>exposed in early motherhood – a qualitative study exploring experiences of mothers with type 1 diabetes</i></p> <p>Sparud-Lundin & Berg, 2011</p> <p>BMC Women's Health</p>	<p>using a hermeneutic, life-world research approach.</p> <p>23 type 1 diabetic women 6-24 months post-delivery</p>	<p>abnormal because of unstable blood glucose levels and the amount of care required. Breastfeeding was a struggle and women felt increased amounts of pressure, increased vulnerability, and insufficiency. Hypoglycemia during breastfeeding occurred in many women. Mothers felt a desire to control blood glucose levels so the child could be consistently cared for. Many mothers could not continue the rigid control in the postpartum period needed for adequate blood glucose levels. There was a need for additional education and social support.</p>	<p>differences in consistency due to the qualitative nature of the study</p>
---	---	---	--

APPENDIX B: RECRUITMENT LETTER

I am a senior nursing major at Texas Christian University (TCU). I am beginning work on a thesis involving type 1 diabetes and pregnancy. I would like to recruit 5-8 women in Fort Worth, TX with type 1 diabetes who are currently pregnant or within 8 months post-delivery who would be willing to participate in a focus group discussion about their experiences with prenatal and postnatal care. I am attempting to determine the potential population my research project will attract. My aim is to educate health care providers and nurses about the care based upon their individual experience as a pregnant patient.

Personal details of participants will not be revealed in my research or final project. The focus group discussion will be audio-recorded and will last approximately 60-90 minutes. Participation is completely voluntary; no monetary or material compensation will be given. Participants may withdraw from the study at any point in time with no penalty.

If you are interested or want more information, please contact me by email at morgan.turley@tcu.edu. You can also contact any of my honors thesis committee members listed below with questions or concerns.

Lynnette Howington

Nursing faculty

l.l.howington@tcu.edu

Lisette Allender

Nursing faculty

L.M.allender@tcu.edu

Karla O'Donald

Spanish and Hispanic Studies Dept. faculty

k.odonald@tcu.edu

APPENDIX C: PARTICIPANT CONSENT FORM



Texas Christian University

Fort Worth, Texas

NURSING CONSENT TO PARTICIPATE IN RESEARCH

Title of Research: Nursing Care for a Pregnant Woman With Type 1 Diabetes

Funding Agency/Sponsor: N/A

Study Investigators:

Morgan Turley, TCU nursing student

Lynnette Howington BSN, MSN, DNP

Lisette Allender RN, RNC-OB

Karla O'Donald MA

What is the purpose of the research?

The purpose of this qualitative study is to contribute knowledge to the health care community as to the self-perceived psychological needs of type 1 diabetic women during the pre and postnatal period. A secondary purpose might be that the researcher learns what other forms of support health care providers can offer during pregnancy care.

How many people will participate in this study?

The population for this study will include 2-6 type 1 diabetic women who are pregnant or have had a child in the past ten years.

What is my involvement for participating in the study?

Involvement in this study includes participating in a 30-45 minute interview about personal experiences during pregnancy through 8 months after delivery. The discussion will include reflection on your pregnancy as well as the post-delivery experience. The aim is to obtain aspects of pregnancy care that the health care system can improve on for the population of type 1 diabetic women.

How long am I expected to be in this study for and how much of my time is required?

The interview is the main time commitment, and will last 30-45 minutes. Time of the interview will vary depending on the flow of the discussion. Prior to the interview, a meeting lasting approximately 30 minutes will occur at the participant's convenience to explain the study, answer questions, and sign the consent form if residing in the state of Texas.

What are the risks of participating in this study and how will they be minimized?

There is a risk of a breach in confidentiality, but measures will be taken to minimize this risk. The interview will be audio recorded and the recording will be kept in a safe place, accessible only to researchers. Names and identifying facts will not be used in the final research project and numbers will be used to identify each woman, not her name. Interview notes from responses and consent documents will be kept on the primary researcher's private, password protected computer. The audio recordings will be kept on Morgan Turley's private, password protected phone and computer. Only the researchers and members of the research team will have access to these files. Additionally, there is a risk of emotional viability. Researchers would advise to have your gynecologist provider's number on hand to call for any emotional distress for an adequate referral.

What are the benefits for participating in this study?

The benefits of participating in this study include providing insight into the individual experiences of pregnancy of women with type 1 diabetes. This information will be used to adjust and improve the care these women receive from the health care team. A healthy relationship between nurses/doctors and the type 1 diabetic patient is vital to ensure a healthy, adaptive pregnancy. Your participation in this study will help the health care team deliver more effective care to meet the specific needs of a type 1 diabetic pregnant patient.

Will I be compensated for participating in this study?

There will be no monetary or material compensation for participation in this study. Participation is voluntary.

What is an alternate procedure(s) that I can choose instead of participating in this study?

If participating in a face-to face interview is not possible but you would still like to participate, a phone interview can be conducted. It will be audio-recorded and the rules of confidentiality will still apply. However, researchers will do everything in our power to meet at a time and place of your choosing.

How will my confidentiality be protected?

Confidentiality will be protected during the study. Researchers will not use names or identifying facts when analyzing the data. Research presented will remain anonymous. The audio recording and notes from the interview will be kept in a safe place where only the researchers have access.

Is my participation voluntary?

Yes, all participation is voluntary.

Can I stop taking part in this research?

You may stop taking part in this study without penalty and any information provided will not be utilized in the study.

What are the procedures for withdrawal?

Withdrawal procedures include notifying the researchers, in person or by email, that you would like to withdraw.

Will I be given a copy of the consent document to keep?

Yes, participants will all receive a copy of the consent form.

Who should I contact if I have questions regarding the study?

Morgan Turley

TCU nursing student

morgan.turley@tcu.edu

Lynnette Howington

Nursing faculty

l.l.howington@tcu.edu

Lisette Allender

Nursing faculty

l.m.allender@tcu.edu

Karla O'Donald

Spanish and Hispanic Studies Dept. faculty

k.odonald@tcu.edu

Who should I contact if I have concerns regarding my rights as a study participant?

Dr. Kenneth Lowrance, TCU Nursing Review Board Chair, Telephone 817-257-6929.
Dr. Debbie Rhea, Associate Dean of Research, HCNHS, Telephone 817-257-5263.

Your signature below indicates that you have read or been read the information provided above, you have received answers to all of your questions and have been told who to call if you have any questions, you have freely decided to participate in this research, and you understand that you are not giving up any of your legal rights.

Participant Name (please print): _____

Participant Signature: _____ **Date:** _____

Principal Investigator Name (please print): _____ **Date:** _____

Principal Investigator Signature: _____ **Date:** _____

Consent for Audio Recording

I give consent for my participation in the focus group discussion to be audio-recorded and released to this team of researchers. I understand that my information will be recorded and consent to this method of data collection. I understand that my information will only be accessed by the researchers.

Participant Signature: _____ **Date:** _____

Investigator Signature: _____ **Date:** _____

APPENDIX D: INTERVIEW QUESTIONS

1. How long have you had type 1 diabetes?
2. What year did you have your last child?
3. Any questions before we get started?
4. What specific care did your health care team provide in respect to your type 1 diabetes?
5. What were your responsibilities during pregnancy in relation to your diabetes?
6. What do you wish your health care team did differently in caring for you as a patient?
7. What would have helped you feel more confident in your pregnancy, delivery, and postpartum experience?
8. Did you have any support by other persons with type 1 diabetes? If so, please explain.
9. Elaborate on your encounters with any nurses during your prenatal care
***working this in for the questions above in possible follow up
10. What frustrations do you remember experiencing during your last pregnancy in relation to your type 1 diabetes? Explain.