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The Nature and Meaning of Insulin Pump Use in Emerging Adults with Type 1 Diabetes

Donna G. Hood

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THE NATURE AND MEANING OF INSULIN PUMP USE
IN EMERGING ADULTS WITH TYPE 1 DIABETES

By

DONNA G. HOOD

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Nursing

Gloria Duke, Ph.D., Committee Chair

College of Nursing and Health Sciences

The University of Texas at Tyler
October 2012

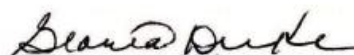
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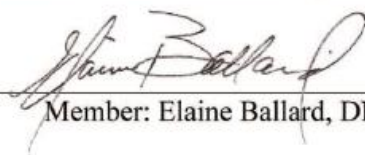
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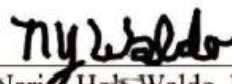
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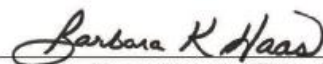
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Abstract

THE NATURE AND MEANING OF INSULIN PUMP USE IN EMERGING ADULTS WITH TYPE 1 DIABETES

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December 2012

Emerging adults (ages 18-25) with type 1 diabetes are a vulnerable population as they transition from the family home and their pediatric healthcare providers and deal with multiple competing demands. There is very little literature addressing those in this developmental group who use insulin pump technology for diabetes self-management. Listening to the voices of emerging adults who use insulin pump technology will increase our understanding of their experience and will give health care providers the opportunity to develop evidence based practices based on their lived experiences. This qualitative research, using the hermeneutic phenomenological approach described by Max van Manen, provides a deeper understanding of the day-to-day journey of the emerging adult. Four themes represent the essences that were ultimately viewed as strategies used by emerging adults as they crossed from adolescence to adulthood with type 1 diabetes and an insulin pump. This journey is presented metaphorically as learning to walk a tightrope.

Keywords: type 1 diabetes, insulin pump, CSII, emerging adult, phenomenology, van Manen

Chapter 1: Overview of the Research

An estimated 15,000 youth are diagnosed with type 1 diabetes (T1D) each year in the United States (Dabelea et al., 2007) and the incidence of T1D is increasing worldwide (Harjutsalo, Sjoberg & Tuomilehto, 2008; Patterson et al., 2009; Vehik et al., 2007). The use of continuous subcutaneous insulin infusion (CSII) for intensive diabetes self-management is becoming increasingly popular across the life span as a tool for self-management for those with T1D. Although technology for diabetes self-management continues to increase, research into the human experience with this technology has not kept pace.

Emerging adulthood includes persons between the ages of 18-25 years, and has been identified as a distinct developmental period characterized by change, exploration, and relative independence without the enduring responsibilities of adulthood (Arnett, 2000). For the emerging adult with T1D, this is a period of competing priorities that may detract from their focus on diabetes self-management (Peters & Laffel, 2011). It is during these years that the emerging adult typically moves from their childhood home as well as from their pediatric healthcare team. In addition, these are the years of poorest glycemic control (Bryden et al., 2001; Insabella, Grey, Knafl, & Tamborlane, 2007; Will, Scott, Swift, Davies, Mackie, & Mansell, 2003) and the years when diabetes complications begin to emerge (Bryden, Dunger, Mayou, Peveler, & Neil, 2003).

Only recently has this age group begun to receive attention by researchers and health care providers (Weissberg-Benchell, Wolpert, & Anderson, 2007). American Diabetes Association (ADA) standards of care (2012) stress the importance of team-based practices that emphasize a patient-centered approach tailored to the patient. The

ADA Transitions Working Group (Peters & Laffell, 2011) called for additional research during these crucial years of transition. With very limited empirical research to guide recommended practices for those in this developmental period, this phenomenological narrative will contribute to the reflective understanding of the lived experience of this population.

Purpose of the Study

The purpose of this study is to explore the essential meaning of living with an insulin pump as an emerging adult with T1D. Listening to the voices of emerging adults who use insulin pump technology will increase our understanding of their experience and will give health care providers the opportunity to develop evidence based practices based on their lived experiences. Participants for this research were 18-25 year olds who had been diagnosed with T1D for a minimum of one year and who had been using an insulin pump for at least six months.

Data generated through individual face-to-face interviews were analyzed using the hermeneutic phenomenological method as described by van Manen (1990). Phenomenological methods can provide the richness and depth that allow both the reader and the researcher to uncover the commonalities and idiosyncrasies that lead to greater understanding and sensitivity of care. The identification of emerging themes from the participant narratives and the back-and-forth descriptive-interpretive writing provide an increased understanding of the patterns, needs, concerns, beliefs, and actual practices of this age group at this point in time (van Manen, 1990). This comes not through generalizations, but from an understanding of how persons make sense of their experiences (Myers, 2000). With attention to sensitivity and mindfulness, the

phenomenological researcher searches for a “pathic” understanding using relational, situational, corporeal, temporal and actional knowing (van Manen, 2007, p. 20).

As a registered nurse and nurse educator working with emerging adults for 20 years and as the mother of a daughter who uses an insulin pump, this study began with a personal passion. In preparation for this phenomenological approach, I immersed myself into a deeper phenomenologic learning through a summer intensive workshop, Qualitative Analysis II: Phenomenological and Narrative/Discourse Methods with Dr. Margarete Sandelowski at The University of North Carolina (UNC) at Chapel Hill School of Nursing and again the following summer for the 17th Annual Institute in Qualitative Research: Writing Qualitative Research Proposals and Reports at UNC. Throughout the research process I maintained a personal reflexive journal (Munhall, 2007) in order to reflect on my preconceptions prior to interviews and throughout the process of analysis. This included my feelings, concerns, struggles, and emerging meanings.

Introduction of the Articles

The first manuscript “Continuous Subcutaneous Insulin Infusion for Managing Diabetes: Women’s Health Implications” (Hood, 2012), was published as the featured continuing nursing education (CNE) article in the refereed, clinical practice journal *Nursing for Women’s Health*. This journal of the Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) targets professionals who provide nursing care for women and provides practical application of evidence on topics important to women’s health, obstetrics and neonatal care. The article provides a review of the insulin pump literature as it applies to women from emerging adulthood through menopause, and provides to practicing nurses essential background information to provide supportive care

to clients who use insulin pump technology. This sets the stage for my research study of the insulin pump experience of emerging adults.

The second manuscript entitled “The Nature and Meaning of Insulin Pump Use in Emerging Adults with Type 1 Diabetes” is a report of original hermeneutic phenomenological research and is prepared for submission to *The Qualitative Report*. This manuscript was developed from an interpretive analysis of nine interviews with emerging adults and was written for health care professionals who provide care to this age group. It presents four themes that represent the day to day experiences of emerging adults as they crossed through the years 18-25 from adolescence to adulthood. This journey is presented metaphorically as learning to walk a tightrope.

Chapter 2

Continuous Subcutaneous Insulin Infusion for Managing Diabetes:

Women's Health Implications

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August 2012

Abstract

The use of continuous subcutaneous insulin infusion (CSII), also called insulin pump therapy, is increasing for management of type 1 diabetes. This article provides a comprehensive background on CSII, reviews recent studies comparing it to multiple daily insulin injections, offers strategies to troubleshoot potential problems, and discusses the implications of CSII for women's health across the lifespan.

Keywords: Continuous subcutaneous insulin infusion, diabetes, insulin pump, type 1 diabetes

*Permission to include this manuscript was provided (Appendix A).

Manuscript

The use of continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy, is increasing worldwide for management of type 1 diabetes. Potential candidates for this type of insulin administration range from infants to older adults, and reported estimates indicate that approximately 25 to 41 percent of people with type 1 diabetes use CSII (Insabella, Grey, Knafl & Tamborlane, 2007; Ying et al, 2011).

With the increasing prevalence of diabetes in women of childbearing age (Lawrence, Contreras, Chen, & Sacks, 2008; Patterson et al., 2009), and the growing numbers of people using CSII for their diabetes management, nurses in women's health settings must understand the principles of pump therapy and know how to access the resources that provide pump support for our patients.

This article discusses the benefits of CSII versus insulin injections and the basics of pump use, and gives suggestions for troubleshooting potential problems. Concerns specific to CSII in women of childbearing age women and areas needing additional research are also included.

Diabetes Self-Management with Insulin

The benefits of intensive insulin therapy, using CSII or multiple daily injections (MDI), were demonstrated in the Diabetes Control and Complications Trial (DCCT Trial Group, 1993) and continue to be recognized in the follow-up Epidemiology of Diabetes Intervention and Complication (EDIC) study (Nathan et al., 2005). A recent meta-analysis of 20 studies comparing CSII with MDI – which was defined as three or more subcutaneous injections of insulin per day- found a lower hemoglobin A1c (HbA1c) in

people using CSII compared with MDI, although this difference (0.3%) was relatively small (Misso et al., 2010).

Measuring HbA1c is considered standard care for those with diabetes; it is expressed as a percentage that reflects a person's average glucose for the prior 2 to 3 months and has been used as the gold standard for measuring glycemic control. The typical recommended HbA1c for someone with diabetes is $< 7\%$. The American Diabetes Association *Standards of Medical Care* (ADA, 2011) states that self-monitoring of blood glucose (SMBG) should be performed a minimum of three times per day for those using CSII. Davidson, Bode, Steed and Hebblewhite (2007) found a significant association between improved HbA1c levels and increased frequency of glucose self-monitoring.

In an effort to continue to improve the potential for glycemic control, a number of advances in technology are available to people with diabetes. Progress with insulin analog development and insulin delivery and glucose monitoring systems provide people with diabetes new tools for greater involvement in their daily self management. However, these new tools present new challenges to nurses caring for those with diabetes in both acute and community settings.

Basics of CSII

CSII was introduced in the 1970's with an external insulin pump device the size of a backpack. Today's insulin pumps are about the size of a small cell phone and can deliver insulin in as small as 0.025 unit increments. Some pumps contain the capability for built-in continuous glucose monitoring. Today's smart pumps are able to calculate the necessary bolus dose of insulin based on the individual's insulin sensitivity (the amount of glucose that is lowered by one unit of insulin), the carbohydrate ratio (the number of

carbohydrate grams covered by 1 unit of insulin), individual glucose targets, carbohydrate grams eaten, and any insulin estimated to be still “active” in the body. Although different pumps can have different features, there are pump fundamentals that are important for nurses to know. There are two basic pump configurations. Some pumps deliver insulin directly from the reservoir through a small cannula that is placed in the subcutaneous tissue and programmed by a separate handheld controller. This “patch pump” does not require external tubing. Other pumps connect the insulin reservoir to the cannula by a thin tube. The battery powered pump is worn clipped to a waistband, placed in a pocket, or tucked into clothing. With either type of pump, rapid-acting insulin is contained in a reservoir that should be changed by the user, along with the infusion set, every 2 to 3 days.

Insulin pump therapy is designed to imitate physiologic insulin as delivered by a healthy pancreas. Rapid acting insulin analogs (lispro, aspart, and glulisine) are used in most pumps (Bangstad, Danne, Deeb, Jarosz-Chobot, Urakami & Hanas, 2009). These insulins have a rapid onset and shorter duration than regular insulin. Insulin pumps have a basal insulin feature that provides a small amount of rapid-acting insulin as background insulin delivered every few minutes around the clock. The pump can be programmed to vary this basal insulin rate of infusion based on individualized needs of the person (such as with the dawn phenomenon, onset of menses, or with strenuous exercise). Typically about 40-50% of the total daily insulin is given as basal insulin although there is individual variation (Scheiner et al., 2009).

Bolus insulin delivery is used to correct high blood glucose readings and to give the rapid-acting insulin that is needed to cover carbohydrate intake. Cobry et al. (2010)

found a meal-time bolus given 20 minutes prior to a meal to be superior to bolus given with a meal or 20 minutes after a meal as long as pre-meal glucose is greater than 80 mg/dL. If an individual's glucose reading is low (below 80 mg/dL), the bolus can be delayed until the time of the meal.

Newer generation smart pumps calculate meal and correction boluses based on individual target blood glucose level, current glucose reading, insulin-to-carbohydrate ratio, and insulin sensitivity. These bolus calculators also take into account the calculated amount of active insulin or “insulin on board” that is anticipated to still be circulating in the individual's blood stream. The individual is able to accept and deliver the pump's calculation or make a change prior to starting the insulin delivery based on factors such as anticipated exercise.

Insulin pumps have a delivery option that insulin injections do not have. With an extended delivery option, the newer insulin pumps can be programmed to deliver the insulin bolus over an extended period of time. These “dual wave,” “square wave,” or “extended wave” options are designed to fine-tune insulin delivery to match meals that may contain carbohydrates consumed with a meal of higher fat content (e.g. pizza) or with meals that may be consumed over a longer period of time (e.g. holiday meal or business dinner). Another indication for this option is the delayed gastric emptying and delayed carbohydrate absorption in the case of diabetic gastroparesis (Heinemann, 2009; Zisser et al., 2008). Although there are varied bolus options for individualized fine-tuning of insulin, there is limited quality evidence to direct the pump user to the optimal choice based on the complex factors of life (Heinemann, 2009).

Women's Health Implications of CSII Across the Lifespan

Preconception

The risks of diabetes are significant. In addition to microvascular and macrovascular complications, major birth defects have been reported in 5 to 10 percent of pregnancies and spontaneous abortions in 15 to 20 percent of pregnancies in young women with poorly controlled diabetes before conception and in early pregnancy (Centers for Disease Control [CDC], 2011). Preconception care for the women of reproductive age with preexisting diabetes has been recommended for the past 35 years, but studies find that these recommendations are followed in only one-third to one-half of these women (Chen et al., 2007; Temple, 2011).

The relationship between glucose control, fetal malformations, and spontaneous abortions points to the need for improved glucose control before conception (Temple, 2011). de Valk and Visser (2011) emphasize the importance of optimal insulin therapy planning during the preconception visits. Chuang, Velott and Weisman (2009) explored pregnancy and preconception health knowledge and attitudes. Most women in their focus groups recognized the importance of preconception glycemic control but acknowledged that control was difficult. Several women in the study expressed that CSII should be implemented for diabetes self-management in preparation for pregnancy.

The choice for intensive control is between MDI and CSII. The short-acting insulin analog aspart, used in CSII and as one component of MDI, has been shown to be safe during pregnancy (de Valk & Visser, 2011). Continuous glucose monitoring (CGM) has been determined to be a useful tool for lowering HbA1c in select adults with type 1 diabetes and a helpful supplement to self-monitoring of blood glucose for those with

hypoglycemia unawareness or frequent hypoglycemia (ADA, 2011). The role of continuous glucose monitoring in achieving metabolic control for those with insulin pumps is still under investigation.

At this time, real time continuous glucose monitoring uses a sensor, separate from an insulin pump insertion site, placed under the skin to measure glucose in the interstitial fluid every 1 to 5 minutes. This device requires calibration 2 to 3 times per day with standard blood glucose checks, and has a limited lifespan. Continuous glucose monitors provide awareness of hypoglycemia or hyperglycemia through an alarm, and have the potential to reduce the time spent with blood glucose out of the target range. With certain insulin pumps, glucose data can be displayed on the pump screen to assist the user with decisions on their balance of food, insulin, and exercise. However, continuous glucose monitoring is not tolerated by everyone, and inaccuracy up to 21 percent is reported in continuous glucose monitoring readings when compared to plasma glucose (Hermanidies, Phillip & DeVries, 2011).

Even though recent evidence-based guidelines were published by the Endocrine Society (Klonoff et al., 2011), research and development of the ideal sensor that will provide real time glucose monitoring with a patient-acceptable design is still on-going. The use of continuous glucose monitoring may play an important role for the woman planning for pregnancy and additional research in this area is needed.

Glucose Control During Pregnancy

Balancing glycemic control while minimizing the risk of severe hypoglycemic events is essential during pregnancy. However, hypoglycemia is common, particularly during the first trimester when there may be increased insulin sensitivity. This increased

sensitivity coupled with tight glucose control places the pregnant woman at increased risk for hypoglycemia. Hypoglycemia unawareness, a phenomenon when there is a blunting of the body's release of glucagon and epinephrine and the classic symptoms of hypoglycemia are not recognized (Beaser, 2007), is also more common during pregnancy (Hawthorne, 2011).

It is essential that pregnant woman with diabetes and the people in their lives, recognize the signs and symptoms of hypoglycemia and are familiar with appropriate treatment, including the role of glucagon. Severe hypoglycemia - defined as an episode requiring the assistance of another person and marked by altered consciousness and possible seizure - is a potentially fatal complication and is associated with hypoglycemia unawareness (deValk & Visser, 2011). Because signs and symptoms may be missed or attributed to changes associated with pregnancy, increasing the frequency of self-monitoring of blood glucose to six or more times per day is recommended (Hawthorne, 2011).

Individual insulin requirements vary. Two additional factors can complicate the regulation of insulin levels. After about 20 weeks gestation insulin resistance increases and there is often an additional rise in blood sugar and, therefore, a rise in insulin requirements between 4 a.m. and 6 a.m. related to the release of cortisol and growth hormones (de Valk & Visser, 2011). The potential hyperglycemia from this “dawn phenomenon” and the changing basal insulin requirements make the use of CSII with individualized programming of different basal insulin delivery rates especially appealing. The addition of continuous glucose monitoring provides alarms to alert the individual to interstitial glucose readings outside the set limits. Continuous glucose monitoring also

stores data reflecting almost continuous glucose changes, and this can assist with the fine-tuning of insulin requirements and pump settings during pregnancy.

The American Association of Clinical Endocrinologists (AACE) published a consensus statement on insulin pump management that includes a suggested protocol of insulin pump use during pregnancy (Grunberger et al., 2010). This protocol addresses suggested basal and bolus insulin infusion rates through the stages of gestation, as well as recommendations for changes based on time of day.

Diabetic Ketoacidosis and Pregnancy

Diabetic ketoacidosis is the result of acute insulin deficiency in a person with diabetes and consists of hyperglycemia, ketosis and acidosis (Kisiel & Marsons, 2009; Koul, 2009). The resulting dehydration from osmotic diuresis and electrolyte imbalance increase the risk for complications and potential death. Although diabetic ketoacidosis is not a frequent occurrence, it is a medical emergency and does carry an increased risk to both mother and fetus if it occurs during pregnancy (Hawthorne, 2011). A pregnant women presenting with nausea, vomiting and persistent hyperglycemia should be evaluated for diabetic ketoacidosis (Hawthorne, 2011). Grunberger et al. (2010) emphasize that during the state of accelerated ketosis related to pregnancy, a few hours without insulin infusion can lead to hyperglycemia and ketosis.

Labor, Delivery and Postpartum

There is a paucity of research directing the use of CSII during labor. However, the lay literature encourages women to discuss the possibility of continuing CSII with their obstetric healthcare providers. The AACE Consensus Statement (Grunberger et al., 2010) points out the physical demands of labor and the need for glucose substrate to prevent the

depletion of hepatic glycogen stores. It is important to stress that if the demands of labor and delivery result in the patient's inability to maintain a steady glucose level with frequent blood glucose checks and adjustments to insulin pump settings, or if the patient's provider is not familiar with the necessary alterations in insulin adjustments, then the patient's glucose can be managed by the RN with IV insulin infusion. Patient safety can be jeopardized if the patient adjusts her pump without the supervision of her provider. Medical supervision is essential, as the patient may be unfamiliar with changes in her insulin needs during labor and postpartum, and may end up chasing her blood sugar toward either extreme as a result.

During or immediately after delivery, insulin requirements decrease rapidly. de Valk and Visser (2011) recommend decreasing the insulin dose to 25 to 40 percent of a woman's pre-delivery dose to avoid hypoglycemia in both patients who deliver vaginally and those who undergo caesarean surgical delivery. Breastfeeding should be encouraged and initiated. Insulin analogs can be safely used with lactation, and the health care team should note that insulin requirements decrease with breastfeeding, as well (de Valk & Visser, 2011). A snack before nursing may be indicated to prevent hypoglycemia. Aggressive glucose control can be relaxed a bit during this period to avoid significant hypoglycemia (Beaser, 2007). The mother-baby nurses should be alert to signs and symptoms of hypoglycemia and recognize that hypoglycemia unawareness is possible during the postpartum period.

The results of the intense efforts toward glycemic control during the preconception period and pregnancy may serve as an encouragement and may motivate women with type 1 diabetes to continue to seek intensive glycemic control following her

pregnancies. The entire health care team should support and encourage their efforts to maintain glycemic control from this point on.

Older Adulthood

With the improvements in diabetes management over the past years, there are a significant number of older adults who were diagnosed with type 1 diabetes earlier in life (Rizvi, 2002). Although limited research has been published specific to CSII in this population, the Center for Medicare and Medicaid Services now covers CSII use in patients with either type 1 or type 2 diabetes who are over 65 years of age and who meet specified eligibility criteria (Grunberger et al., 2010; Hainer, 2006). Improved glucose control and decreased hypoglycemic episodes were reported in a small group of older patients with type 1 diabetes who switched to CSII from MDI (Rizvi, Arnold & Chakraborty, 2001). Herman et al. (2005) found both CSII and MDI to be effective, safe and accepted in older adults with type 2 diabetes requiring insulin therapy. Rizvi (2002) pointed out that the use of CSII can even be a possibility in older patients in personal care homes and skilled care nursing facilities. With the increasing incidence of type 1 and type 2 diabetes, growing acceptance of insulin pump therapy, and the aging of the population, it is expected that nurses will be working with an increasing number of insulin pump patients in various settings and throughout the lifespan.

CSII in the Inpatient Environment

Reports indicate that patients who use CSII may be candidates for diabetes self-management when they are in the hospital setting (ADA, 2011; Bailon et al., 2009; Morviducci et al., 2011). These reports stress the importance of having policies and procedures in place with guidelines for inpatient insulin pump use, including regular

nursing documentation (at least daily) of basal and bolus insulin doses (ADA, 2011).

Opportunities exist for nurses to take part in policy development and participate in new roles such as diabetes resource nurse. Hospital personnel with CSII expertise are essential.

Pump Malfunctions and Implications for Pregnancy

Chen et al. (2007) compared CSII and MDI in a single-center study of pregnant women with preexisting diabetes. They reported no significant differences in maternal hypoglycemia events, HbA1c, gestational age at delivery, mean birth weight or cesarean rate. They did find a significantly higher rate of mild diabetic ketoacidosis in the CSII group (4 of 30), with all cases due to reported pump failure.

Even with the ongoing advances in CSII, pump malfunctions are a possibility that nurses and patients should anticipate. Guilhem et al. (2009) reported their findings from a study of pump failures in adults with type 1 diabetes. They reviewed 640 pumps from four pump manufacturers during the years 2002-2007 and found 36 percent of pumps encountered a mechanical malfunction. Of these cases, 17 percent resulted in hyperglycemia and one case was believed to have resulted in severe hypoglycemia. No participants required hospitalization related to pump malfunction during the study period.

Troubleshooting Potential Problems

The AACE recently released a consensus statement on insulin pump management, which emphasized the importance of a comprehensive pump management approach for all practices treating patients who use insulin pumps (Grunberger et al., 2010). In addition, everyone with an insulin pump should have around-the-clock access to support, should pump problems arise. These resources are also available to nurses caring for pump

users. Pump manufactures have staff available for ongoing technical support via 24/7 help lines. The help line number is located on the back of the pump device and on the product website. Additional detailed written or video instructions can be found on the product websites.

Troubleshooting problems with insulin pump therapy requires that clinicians be familiar with common problems. A pump should not be removed for more than 1 hour at a time, unless rapid acting insulin is given as an injection. Because insulin pumps deliver only rapid-acting insulin, any interruption in insulin delivery or insulin absorption risks hyperglycemia and the potential for diabetic ketoacidosis. If hyperglycemia is accompanied by ketosis, vomiting or alteration in consciousness, the diabetes care team should be contacted immediately (ADA, 2011).

Issues of hyperglycemia may be related to numerous factors. The stress of illness, trauma, or surgery may result in hyperglycemia and may precipitate diabetic ketoacidosis (ADA, 2011). Some women report hyperglycemia and difficulty with glucose control associated with menses. Ramalho, Andrade & Prates (2009) reviewed the literature on glucose control and the menstrual cycle and found no consensus related to glycemic variation in the limited number of published studies to date.

In addition, there may be a problem with insulin delivery. Ask the patient about the insulin itself. Opened vials of insulin may be left at room temperature if used within 4 weeks (Bangstad et al., 2009). This 4-week guideline considers issues for sterility and clinical potency. Unopened vials of insulin should be stored in a refrigerator (36° - 46° F) and may be used until the expiration date printed on the box. Insulin should never be

frozen. In hot climates insulin may become damaged and should be changed if the insulin or pump has been exposed to temperatures $> 98.6^{\circ} \text{ F}$.

Trouble can result from the site of the insulin infusion. The patient needs to place the infusion cannula in an area that has not been exposed to insulin infusion for a number of days. Pump guidelines state that soft cannulas made of Teflon can remain in the subcutaneous site for up to 72 hours (Scheiner et al., 2008). Tissue irritation and lipodystrophic changes in the subcutaneous tissue can occur if insulin infuses into the same region of skin for a prolonged period of time. As a result, insulin absorption may diminish, although this is a scenario that has not been well-studied (Heinemann, 2009).

To troubleshoot glucose readings that remain high despite delivery of recommended insulin, ask your patient how long the cannula has been in the current site. Also ask about her site rotation. If she uses only two sites and rotate back and forth, lack of insulin absorption due to lipodystrophic changes could be the issue.

Insulin pumps have several safety check features. Giving a bolus dose of insulin requires the user to confirm the dose with some pushes of a few buttons. The dose is not delivered unless the dose is confirmed. If there is unexplained elevated blood glucose, check the bolus history to verify that the intended dose was delivered. The pump alarms to alert the wearer to an occlusion; however, it is possible to have the insulin leak out from a poor connection between the tubing and the cannula without an alarm. It is also possible to have the infusion cannula come out of the skin (think about a laboring patient or an active child). The pump could be delivering insulin, but it is not going into the subcutaneous tissue and is therefore not available to the body.

What the Future Holds

Supporting today's women with diabetes requires nurses and other health care providers to understand the basics and the possibilities of CSII. As the number of people with preexisting diabetes increases and technology continues to improve, there is need for randomized controlled trials to determine best practices for women during pregnancy, labor and deliver, and the postpartum period, as well as CSII use in the years following menopause.

Although CSII was designed for use in people with type 1 diabetes, the use of insulin pumps with type 2 diabetes is receiving more attention. As patients with type 2 diabetes face declining beta cell function, most will require insulin therapy to provide glycemic control (Holman et al., 2009). Recent studies have not found CSII to be clinically superior to insulin injections; however, overall preference for CSII was reported by study participants due to convenience, flexibility and ease of use (Bode, 2010). Research and development of simpler insulin pumps and protocols for the population of patients with type 2 diabetes is in progress.

Work is on-going with efforts for a closed-loop system or "artificial pancreas." This system would consist of continuous glucose monitoring, an insulin pump and a controlling device using individualized algorithms to control insulin delivery. This sensor-augmented pump would automatically suspend basal insulin in response to low glucose readings (Choudhary et al., 2011).

Other potential technology may include combining insulin and glucagon delivery and the use of intraperitoneal insulin delivery. An experimental version of the artificial pancreas was recently tested in 10 pregnant women with type 1 diabetes in the hospital

setting. This study reported positive glucose control overnight, but issues remain in adequate control after ingestion of high carbohydrate meals (Murphy et al., 2011).

As the technology evolves and acceptance of advanced methods for diabetes self-management increase, so must research to direct best practices in all settings. From the best ways to fine-tune insulin delivery based on individual lifespan variations, to policies and procedures to support CSII in hospitalized patients, opportunities for research and quality improvement are available for the health care team.

Conclusion

Optimizing glycemic control before, during, and after pregnancy is critical to minimize maternal and fetal risks, and is important for people of all ages with diabetes. CSII is an important tool to assist with diabetes self management. As the population using insulin pump technology continues to increase and evidence-based practice guidelines are developed for CSII in inpatient and outpatient settings, it is necessary for nurses to become familiar with the basics of insulin pump use. Amid the growing complexity of health care, nurses must stay current with the rapid changes in technology.

Every patient encounter is an opportunity to encourage and motivate those with the on-going challenges of chronic illness, such as diabetes. Optimal diabetes management requires the collaboration of an up-to-date, patient-focused team. Nurses play a vital role on this team. Taking the opportunity to learn from our patients and the ongoing research in this field will provide personal professional growth and promote optimal care for women with diabetes.

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Chapter 3

The Nature and Meaning of Insulin Pump Use

in Emerging Adults with Type 1 Diabetes

Abstract and manuscript prepared for *The Qualitative Report*

Abstract

Purpose: The purpose of this study is to investigate the multidimensional meaning of living with an insulin pump for the management of type 1 diabetes while facing the challenges of life as an emerging adult. Through a phenomenological narrative, this study contributes to the reflective understanding of the everyday life experience of this population.

Methods: A hermeneutic phenomenological design was used for this study of nine emerging adults (age 19-24 years). Data was generated through face-to-face interviews and analyzed by the phenomenological approach of Max van Manen.

Results: Four themes represent the essence of day to day experiences of these emerging adults: seeking control, becoming responsible, staying connected, and accepting me.

Conclusions: A thorough and in-depth understanding of the meaning of daily experiences with insulin pump technology has the potential to impact how we provide care to these emerging adults. The human understanding gained through this study is essential to the development of evidence-based practice guidelines and resources for this vulnerable population.

Keywords: type 1 diabetes, insulin pumps, emerging adults, young adults, phenomenology, van Manen

Manuscript

Emerging adulthood has been identified in industrialized countries around the world as a distinct developmental period between adolescence and adulthood (Arnett, 2000). For those emerging adults with type 1 diabetes (T1D), this period has been identified as a time when glycemic control is at its worst (Bryden et al., 2001; Insabella, Grey, Knafl & Tamborlane, 2007; Will et al., 2003). According to the recent SEARCH for Diabetes in Youth study, approximately 15,000 youth are diagnosed with T1D in the United States every year (Dabelea et al., 2007), and data suggest that the incidence of T1D is increasing in the US and worldwide (Patterson, Dahlquist, Gyurus, Green & Soltesz, 2009; Vehik et al, 2007).

The period spanning adolescence through young adulthood is critical for diabetes control (Sparud-Lundin, Öhrn & Danielson, 2010) and is significant for both the emerging adult and the healthcare team as the emerging adult makes the transition from both the family home and their pediatric diabetes care team (Daneman & Nakhla, 2011; Peters & Laffel, 2011; Weissberg-Benchell, Wolpert, & Anderson, 2007). It is during these years that independent routines of self-care are established (Anderson & Wolpert, 2004). Bryden, Dunger, Mayou, Peveler & Neil (2003) in their longitudinal cohort study of 17-25 year-olds, found an alarming number of young adults (28-37 years) with clinical complications and psychiatric concerns. In addition, young women with T1D who do not have excellent glycemic control prior to conception have a much higher risk of congenital malformations and pregnancy loss than women without diabetes (Kitzmilller, Wallerstein, Correa & Kwan, 2010; Mills, 2010; Pearson et al., 2007). Weissberg-Benchell, Wolpert,

and Anderson (2007) proposed using the theoretical model of emerging adulthood (Arnett, 2000) as a framework for research with this vulnerable age group with T1D.

Continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy, is used by approximately 25-41% of individuals with T1D (Insabella et al., 2007; Ying et al, 2011). A meta-analysis of insulin pump studies found improvements in glycemic control and a reduction in severe hypoglycemia with insulin pump therapy (Pickup & Sutton, 2008), however few studies have assessed any aspect of psychosocial functioning in pump users. No studies were located that specifically examined the insulin pump experience in the emerging adult population in the United States. Although more intensive regimens with significant improvements in technology have become more common internationally, we have yet to fully understand why glycemic control continues to be an issue for this age group (Hoey, 2009; Hood, Butler, Volkening, Anderson & Laffel, 2004; Insabela et al., 2007; Weissberg-Benchell, Wolpert, & Anderson, 2007). The purpose of this study was to investigate the multidimensional meaning of living with an insulin pump while facing the challenges of life as an emerging adult. Through a phenomenological narrative, this study contributes to the reflective understanding of the everyday life experience of this population. A thorough and in-depth understanding of the meaning of daily experiences with insulin pump technology has the potential to impact how we provide care to these emerging adults. The human understanding gained through this study is essential to the development of evidence-based practice guidelines and resources for this vulnerable population.

Methods

Research Question and Phenomenological Approach

This research was conducted using the hermeneutic phenomenological method as described by van Manen (1990). Phenomenological methodology focuses on questions that address the way we experience the world in everyday life. In this study, I met with emerging adults who were engaged in their daily experiences with insulin pumps in their homes or on the university campus where they attended classes. Arnett's developmental theory of emerging adulthood (Arnett, 2000) and van Manen's (1990) lifeworld existential experiences of lived time (temporality), lived space (spatiality), lived body (corporality), and lived human relations (sociality) were used to provide the contextual richness and depth of interpretation that produced an expanded understanding of the patterns, needs, concerns, beliefs, and actual practices of this age group at this point in time. The research question for this study was: What is the meaning and significance of insulin pump use for emerging adults with type 1 diabetes?

Sample and Participant Selection

Participants were solicited in two southern states of the United States in person by the researcher and through letters from the researcher distributed by area diabetes educators. A purposive sample of nine emerging adults (between ages 18-25) reporting a diagnosis of T1D for a minimum of one year, and who had been using an insulin pump for diabetes self-management for at least six months, was adequate to reach information redundancy. Recruitment of participants took place between December 2011 and June 2012. The average age of participants was 20.9 years (range 19-24 years). They had lived with T1D for an average of 12.5 years (4.5-21 years), and used insulin pumps at an

average of 7 years (2.5-11 years). Six participants were female, three were male, and all were Caucasian. Their time demands ranged from full time employment to full-time student and part-time employment, to seeking a job. None of the participants lived alone. One participant lived at home with parents and one was married. Seven participants lived in apartments with roommates. The participants' last self-reported HbA1C ranged from 6.1% to 12%. The initial pump management for these participants was supervised by pediatric endocrinology practices in five southern states (Oklahoma, Texas, Arkansas, Louisiana, and Tennessee).

Protection of Human Subjects

The research proposal was approved by The University of Texas at Tyler Institutional Review Board (IRB) (Appendix B) and Louisiana Tech University IRB before implementation. Written informed consents (Appendix C) were signed by participants after validation of their understanding of the study. A \$25 gift card was given to participants to help compensate for their time.

Data Collection Procedure

A reflective journal was begun before initiating interviews to facilitate recognition of personal presuppositions and biases that existed due to researcher roles as a pediatric nurse, a university faculty member, and as a mother of an adolescent who uses an insulin pump. Journaling continued throughout the data generation and analysis process. Participants were asked to select a face-to-face interview location that would be quiet and comfortable for them. Interview locations included their home, a friend's home, and a university office. After providing written informed consent and selecting a pseudonym of their choice, the participant was asked to complete a brief demographic questionnaire

(Appendix D). The pseudonym was used during the interview and on the questionnaire in order to facilitate confidentiality of the transcripts. Interviews were recorded using an audio digital recording device. A semi-structured interview guide was used as a foundation for the interviews (Appendix E). As the participant responded to these questions, probes were used to gain a deeper understanding of their experiences as an insulin pump user in their university and/or work environments. Interviews ranged from 33 to 68 minutes (average 56 minutes). Immediately following each interview the researcher recorded field notes describing the setting, observations, interactions, and initial impressions to provide contextual information to augment the textual data.

Data Management and Analysis

Audio recordings were transcribed and transcripts were compared with the recording for accuracy by the researcher. The dynamic methodological process of thematic analysis, as described by van Manen (1990) guided this study. Individual transcripts and field notes were initially read in order to gain a sense of general holistic meanings from the interview. The transcripts were then analyzed line-by-line with key words and phrases highlighted and interpretive notes recorded on the transcripts. Audio transcripts were re-played for further reflection of key findings for each transcript. These initial meaning units were grouped and re-grouped across transcripts through a process of writing and re-writing until essential themes that reflected the meaning of insulin pump use for these participants were identified. Each transcript was read with attention to the impact of their experiences on their body, time, space, and relationships with others (Appendix F). A second researcher, experienced in phenomenological research, reviewed and suggested revisions in the coding which were accepted by the principal

investigator. Through an iterative process of writing and re-writing four final themes were identified that expressed the meaning of insulin pump use to these emerging adults.

Trustworthiness

Several strategies were used to ensure rigor in this study. The research proposal was evaluated by four qualitative researchers for appropriateness of research question, method, sampling criteria and analysis. All verbatim transcripts were reviewed with the audio recording by the researcher for accuracy. Field notes, made by the researcher immediately following each interview, provided additional richness to the data and were used in analysis. A second experienced researcher provided inter-rater reliability by reviewing initial coding of data and the identification of initial sub-themes.

Reflexivity through the researcher's on-going written reflections in a research journal provided a way to continually identify personal perspectives and to compare them with the iterative process of interpretation of meaning. This means of promoting mindfulness began prior to the initial interview and was on-going throughout the writing process. The research journal, coded transcripts, and drafts of the narratives provided an audit trail that was reviewed by the researcher's dissertation chairman to follow the iterative process that resulted in the final determination of the four themes of this study.

The narrative findings were reviewed by an emerging adult with an insulin pump who was not a study participant who verified that the findings resonated with her life experiences. A summary of the findings was sent to participants for member check. These participants concurred that the finding accurately reflected their experiences.

Findings

The journey through life with type 1 diabetes (T1D) is much like the process of learning the art of tightrope walking. Like living with diabetes, learning this art unfolds over time and requires the walker to return to the wire after inevitable falls. Tools can be used to help the walker maintain balance because tightrope walking requires the walker to respond to the slightest disturbance. CSII, also known as insulin pump therapy, is one of those balancing tools for someone with T1D. The lived experience of the emerging adult who has T1D and uses an insulin pump was represented as four primary strategies. These strategies were the tools they learned to use to maintain balance in life during the years spanning adolescence through young adulthood when the “tightrope” had been raised to a new level of elevation. They included: seeking control, becoming responsible, staying connected, and accepting me. Pseudo-names are used for direct quotes.

Seeking Control

Transitioning to the insulin pump meant hope for control as the emerging adults began using this sophisticated technological tool to gain control of their blood glucose (BG) and to regain control of their lives. Participants found themselves battling new variables in the university environment. They encountered vulnerability when they lost BG control and recognized that multiple factors must be considered in order to gain the control that they wanted.

Regaining control of life. Two participants made the transition just before starting college because of persistent difficulty with glucose control. Both had been encouraged to go to the pump earlier, but resisted until this point.

I had resisted my parents for years and years. I *did not* [emphasis added] want a pump. I hated the sound of a pump, the sound of anything – a needle, a catheter tube – to have anything attached to me 24/7 scared me to death (Anne).

These participants found that in gaining control of their BG, they also re-gained control of their lives and were glad to have the convenience and freedom that the insulin pump provided, “loved it . . . hated I waited as long to get it.” They had the freedom to eat when their friends were eating and to enjoy the spontaneous lifestyle of a typical university student. “It opened me up to do what I wanted when I wanted to” (Jim). However, even with the benefits of the insulin pump, keeping blood glucose (BG) levels in control was an elusive quest for the emerging adult.

Battling the variables. Transitioning to the university environment with T1D meant attempting to maintain balance as the emerging adult faced multiple variables that influenced their BG control. The daily balancing act of dealing with changing schedules, stressful exams, frustrating roommates, late night studying, and evolving new relationships continually challenged their efforts to maintain BG control. “If I’m stressed out, it’ll skyrocket . . . my menstrual cycle, it’ll jump.” Participants repeatedly described their experience as “every day is different.” Amy described her BG challenge as “You can eat the same thing for breakfast, lunch and dinner every day and you can be low one day and you can be high another.” Frustration was common when BG was running high and they had no idea why. Despite the lack of stability, using the pump brought a sense of hope. They had a tool with the potential for control.

Encountering vulnerability. Although BG control was desired, scary episodes of severe low and high BG brought the emerging adult face to face with their vulnerability.

Episodes of hypoglycemia were particularly frightening to the emerging adult. One participant described through her tears a severely low BG episode that occurred during her first year in college.

I kept getting lower and lower and my pod just automatically gives me [basal insulin]. My boyfriend called me and I don't even remember talking to him. I didn't know where I was or what time of day it was. That was like 3 o'clock in the afternoon and I was still asleep. . . I couldn't stand up. I was trying to get to the bathroom because in my mind I was like 'I need to take a shower. I need to get ready.' . . . My roommate knocked on the door and I somehow managed to get over there and she asked me if I was drunk. I was like, 'No.' I don't even drink, you know. I was laughing, but I was so scared when I actually came to. She started crying and she called her mom. . . When I finally came to, I realized what happened and like, the chair in my room was knocked over and a picture frame was broken. . . a bowl was completely shattered. . . It was real scary. My mom was completely beside herself. . . I was exhausted because of what had happened with my body. (Hannah)

Even though Hannah notified her physician so that pump changes could be made, her fear instigated a new routine for her. "[I would] usually go to bed with my blood sugar like almost to the 200's just because I was scared that it'd get so low." The challenge of maintaining tight BG control was at times at odds with the need to *be* in control.

A sense of vulnerability also accompanied episodes of unexplained hyperglycemia. The fear experienced with extremely high BG values that were not

responsive to insulin boluses and infusion set changes brought heightened concern over “what next?” High BG could occur rapidly with insulin pump troubles and could also result in the participant’s BG plummeting to dangerous low levels as they faced vulnerability from both extremes. Burt reflected this concern when hospitalized for diabetic ketoacidosis (DKA) and felt his BG dropping to a scary level.

I had to get my dad to go get me something to eat. They [nurses] wouldn’t listen to me. . . It’s dangerous, you know? You can die from this. That surprised me though, when I first went to the hospital and woke up. Like, they didn’t know about it as much as I did.

Controlling placement and infusion set changes. Using the pump meant facing the on-going challenge and frustration of changing the infusion set. Current insulin pump technology requires changing the insulin infusion set every 2-3 days. Initial use of the pump often required gaining control over fear of pain associated with the infusion set changes. Burt, age 20 described his grandmother’s tactic of bribery and “numbing cream” to “break me of being scared.” Although there are devices that assist with the insertion process, inserting the infusion set carries a sense of reluctance and “sometimes . . . the button gets harder to press.”

Individual control over infusion set or pod placement was influenced by physical restrictions such as limited subcutaneous tissue or tissue changes that can result from years of pump use with limited site rotation. Practical restrictions such as difficulty reaching potential sites or discomfort from constant bumps of the infusion set from backpacks or jeans were challenges as were social concerns, such as visible bulges or exposed tubing. Trying new sites that were different from the comfortable, familiar

locations met resistance from the participants. These emerging adults typically waited to change infusion sets only when insulin in the reservoir was empty or almost empty or when BG readings were consistently high. Time constraints, economic concerns, comfort issues, and a general sense of dread came into play as primary motivators for delaying site changes for as long as possible.

Becoming Responsible

Just as the tightrope walker learned the art through a series of progressive steps, becoming responsible for diabetes self-care began as a gradual shift. Major markers occurred during the high school years such as gaining a driver's license and increasing independence from parents. Although these markers served as preludes for the transition to university life, the epiphany of suddenly feeling "on my own" came after moving from home and facing the "everydayness" of a chronic and potentially life-threatening disease that required on-going attention. With some, the epiphany came when they faced the reality of complications and the realization that "it was all me now." The tightrope walk to adulthood was a process of accepting more responsibility.

Thinking ahead: I still have diabetes. Enjoying the freedom that is possible with insulin pump technology required accepting responsibility for planning ahead to be sure there was enough insulin in the reservoir, enough battery life in the pump, a cool place for the insulin in the heat of the summer, and sufficient back-up supplies just in case they were needed. These emerging adults were beginning to understand that life with a pump meant planning ahead for where they would be and what they would be doing. Daily living activities of going to classes, to work, to long music or sports-related practices, or out of town for the weekend necessitated proactive planning. This understanding came

with experience. Anne described how she learned the hard way when she transitioned from college classes to work and realized she could not "just go home" for batteries, insulin, or a new infusion set. Stuck at work and unable to contact anyone for help, she described how her BG steadily increased until she got "sick as a dog." Now she has all of her necessary pump supplies as backup in her office. She and the other emerging adults recognized that in not accepting this responsibility, they would put themselves at risk.

Remembering and doing: I forget, but diabetes is never really forgotten.

Enjoying the freedom a pump can provide also meant accepting responsibility for self-management tasks. Burt shared, "(the pump) is such a great tool that sometimes you forget that you're still the one controlling it." Without accepting that responsibility and taking charge of self-management, the freedom is short-lived.

Forgetting pump management essentials that required the user to count carbohydrates, enter the data, and to give an insulin bolus with food was a common and irritating occurrence for all participants. They found that if their BG was trending higher it was usually due to forgetting to bolus for carbohydrates. "It's not necessarily the pump's fault. It's the user's fault . . . How do you forget to bolus? It's right there on your hip!" (Lily). The reality was that life gets busy and distractions mount. Amy described a typical struggle as "I do forget, not like forget-forget . . . you keep going and going and you never really stop to think about anything." However, it is the forgetting that is interrupted by the body's alarm system as a response to hyperglycemia or "feeling horrible." Keeping BG in the target range had a physical benefit: "You feel more energetic . . . more like yourself" (Amy).

BG monitoring before meals was also forgotten or just skipped with the emerging adult relying on “feeling” rather than self-monitoring by the glucose meter. Even though alternate site testing was an available option, all participants chose finger sticks for BG readings which became tiresome, and were described as “it gets so old.” Relying on how one feels as opposed to relying on BG checks with a glucose meter was not uncommon. This was especially true when the emerging adult was around other people and thinking that “I can usually tell what range my blood sugar is in.” Forgetting to check BG levels was commonly discussed by participants, “honestly, sometimes, you just forget . . . your routine breaks.” Forgetting was a struggle with the transition away from home without “constantly having Dad breathing down my neck and making [me].” Being willing to accept sole responsibility for the on-going daily tasks necessary for intensive self-management was a challenging part of emerging adulthood. “Nagging” reminders to check BG still came from family and significant others. Anne reflected on her feelings about reminders to check her BG and bolus her insulin.

As a young adult in college, I *hated* [emphasis added] it. I thought my parents didn’t trust me. I resented them all the time for holding me accountable. . . Now I tend to appreciate it a little bit more. I get busy. I forget things sometimes . . . It’s funny how that changes over time . . . At 18, I couldn’t stand it. . . I didn’t want people looking at my sugars. . . Things change over the years.

Recognizing this is risky business: The wake-up calls. The reality of the risks associated with diabetes began to have an influence on acceptance of responsibility and self-care as the emerging adult tried to balance their way toward adulthood. Michelle had

parents in the health care field “who always pep talk me” telling her about complications they see in people with diabetes.

[This] can be aggravating because I don’t want to hear about how I could lose my foot . . . or what can happen if I don’t keep my sugar under control. But then sometimes it’s good because, you know, it’s part of life . . . it makes you think, okay, I really wouldn’t want that to happen to me (pause). I keep checking my sugar.

Transitioning to university life from home-life often brought participants face-to-face with the blunt realization that they were on their own. Burt reflected on his history of not accepting responsibility which resulted in numerous hospitalizations due to DKA. “It feels like you’re dying, literally. I tried to stand up and I couldn’t even move. That was scary.” After being told, “‘If you don’t change what you’re doing, you’re going to be blind in about 10 years.’ That kind of woke me up. . . I don’t want to be blind.” Lily shared her reality check during her first solo visit to her adult health care provider (HCP).

It’s starting to hit me now . . . things that happen to my body and I don’t realize that the diabetes is damaging it. . . I’ve never had these complications. It was just kind of a wake-up call. I was just about to cry. . . I’ve got to take better control of this because it’s my responsibility, not my mom’s. . . I am on my own, kind of . . . it’s becoming more real now that I’ve got to take care of myself.

Female participants saw the risks associated with pregnancy and poor glycemic control as significant concerns for their future. Reaching the necessary BG control before pregnancy seemed like an unreachable task but was considered something to be

addressed sometime in the future. In their minds, that part of the tightrope lesson was for another day.

Taking charge: A work in progress. Participants typically used the basic pump features that they learned with initial pump training. Fine tuning insulin delivery through the use of square wave and dual wave boluses and temporary basal rates was uncommon among these participants. Although some expressed the desire to learn more about their pump, they did not seek out advanced instruction. These emerging adults were not comfortable with or had not bought in to reviewing their BG data and making pump adjustments independently, and they left pump changes to their HCP. Greg did not make changes independently unless “it’s high just continually. I’ll [change] the basal a little bit because they told me to, but mostly I leave it up to the doctor. They go through my readings.”

The paradox was, though, that this was a frequent source of tension with participants who felt HCPs made pump changes without taking into consideration other variables in their busy, non-routine lives. This was particularly challenging after their transition to adult care services that typically were perceived to lack the holistic approach of the pediatric diabetes team with which they were more familiar. “I don’t want my blood sugars to be high all the time or low all the time. But when you [the HCP] adjust stuff without looking at what’s actually going on or listening, it’s just kind of pointless,” (Amy). This point of passivity left the emerging adult wobbling on the high wire without optimal control.

Staying Connected: Is Anybody Out There?

Having a secure safety net is critical for the tightrope walker. However, emerging adults with T1D and an insulin pump often felt that they were walking the tightrope alone and without a safety net. The period of emerging adulthood was a time when the safety net of their family, friends, and pediatric endocrinology team seemed no longer there to catch them. However, this time offered new opportunities to make important connections.

Connecting with other pumpers. Living with diabetes, especially T1D with an insulin pump was often experienced alone. Most of the participants knew no other person with an insulin pump prior to receiving their pump, except for the three who attended a summer diabetes camp as a child. This daily sense of aloneness was common on a personal level and was compounded as participants, in their quest to be “normal,” tried to hide their insulin pump from the view of others. Anne shared her experience of seeing someone at a pump training meeting who had attended her high school. The two were unaware that they both had insulin pumps during their high school years. Hannah did not know anyone in high school with a pump, but since starting college she was pleased to meet two others with insulin pumps through her church.

We’re like, ‘how’s your blood sugar?’ You know, we’ll joke about it. It’s a lot more, kind of reassuring, that other people are going through it too, you know. So you don’t feel as weird . . . you feel kind of normal.

One young woman who was feeling the stress of being on her own in college without knowing anyone else with a pump was recently able to connect to other pumpers through blogs.

Those are really encouraging. I *love* [emphasis added] those . . . I'm always like, I know what that feels like! That happens to me! So it's really cool to kind of relate in that way.

She still longed for face-to-face support from others her age with pumps. In contrast one male participant stated the he did not “really need the support because I got it under control. I can do it myself.”

Connecting with health care providers. Transitioning from home to college typically occurred about the time the emerging adult also separated from their pediatric endocrinologist. These participants were involved with pediatric endocrinology teams from five different southern states. Most were very connected to their teams and voiced comfort, encouragement, and pleasure with their holistic and “up-to-date” health care experiences. Fran described her interaction with the diabetes educator on the pediatric team.

I looked forward to seeing her . . . she was positive . . . she gave tips on wearing the pump, losing weight, and what to eat for breakfast . . . we talked about clothes and shoes and other stuff besides diabetes.

In contrast, the abrupt shift to adult care providers brought a sense of frustration. The clinic atmosphere and interactions lacked the “upbeat” feeling to which they were accustomed. As they encountered changes in providers and approaches to care, the emerging adult in the adult clinic felt a disconnectedness with the other patients in the waiting areas who were typically older type 2 patients and more debilitated. Fran's insight into this type of situation reflected wisdom in her young age, “even adult people

need that encouragement and that uplift and stuff. It's hard to come by, I think, in an adult clinic."

In addition to these challenges of transitioning to adult care providers, the emerging adult often faced their first clinic visit alone without the benefit of a familiar person present on his or her behalf. Lily, age 23, described that experience through her tears. Although the nurse practitioner was very friendly, Lily faced a sense of panic when told they were going to do "ultrasound on her thyroid".

She didn't tell me why we were going to do one. . . I'm just laying there. I was holding back tears. She's like, 'Are you okay? Your heart rate's going so fast.' I'm like, 'No, I'm not okay.' Then I just broke down. . . I'm thinking, 'Do I have cancer? Am I gonna die?' . . . I didn't know what was happening. . . I wanted to ask, but I really didn't want to break down on them. . . They were just like, 'Okay, it looks okay' . . . well I'm still in panic mode. . . Next time I'm probably going to get my sister or my mom to go with me. . . even just to hold my hand.

Not all experiences with adult clinic providers were negative. The need to connect to a HCP was important and that involved finding a good fit. Anne eagerly shared,

I love my doctor that I'm with now. . . . Her nurse gave me her email and said, 'If you ever need anything and you can't reach me, here is my email address. Just feel free to email me for anything or any problems.'

Some participants found reassurance and comfort that came from connecting with a HCP who displayed an understanding approach and caring availability.

Accepting Me: Just a Part of Who I Am

Becoming a well-balanced tightrope walker takes place over time after much practice and determination. This process of becoming is also seen in the life of those using insulin pumps. Social vulnerability was an issue for some, but not all participants.

You think people can see right through you and tell that you have [an insulin pump] or tell that you have diabetes. . . You expect everybody to see you as ‘not normal’ . . . For me, with my pump, I’ve learned to hide it very well, so nobody ever asks me anything. Nobody ever notices it unless I say something about it.

(Anne)

Amy, shared the tension of keeping her pump hidden because others might “think I am weird,” yet realizing it is “better that people knew.” Weighing the risks and benefits of exposure was part of what it meant to live with an insulin pump as an emerging adult. Attending university classes brought additional vulnerability as emerging adults faced different faculty and classmates in almost every course they attended. While transitioning to college, Anne was “always terrified” that her pump would alarm, vibrate, and light up during class or when talking with someone who was unaware of her pump, but she acknowledged that having the pump actually made it much easier to “pull out my machine and check real quick instead of making a big scene.”

Feeling normal again. The quest for normalcy was evident in the lives of these emerging adults. Some expressed that they have achieved a sense of comfort and normalcy while others continued to seek it. An insulin pump provided the ability to have a flexible lifestyle like others their age. “[Having the pump] made me feel normal again.

I'm like everybody else" (Jim). Having the pump visible to others was difficult for some, not an issue to others. Burt shared,

I was self-conscious about [the pump] at first . . . I was like, ugh, people will see it . . . but [going to diabetes camp] really got me out of my shell . . . It's so normal now. It's like telling someone I got a new tattoo. . . it's just a part of me.

Acceptance was a process with the pump eventually accepted as just a part of who they are.

Finding purpose. Several participants had progressed from being unable to talk to people about diabetes and their pump to being eager to share, teach, and encourage others. "I can use [my pump experience] to help other people rather than being bitter about it. . . it's part of my life" (Lily). As some participants neared graduation and looked back over their experiences with diabetes, they were able to see how their openness about the pump and diabetes may be helpful to others they may encounter in the future. One young student teacher incorporated teaching plans that dealt with potential health emergencies in the classroom. Looking for purpose was a way of validating meaning. While holding on to a cautious hope for a cure, one participant reflected, "maybe I'm supposed to have it (pause) for somebody else down the line" (Hannah).

These four themes represent the learning-while-living process that is experienced during the often unsteady tightrope walk between adolescence and adulthood for someone with an insulin pump. These themes intertwine with van Manen's existentials of time, space, body, and relationships. The emerging adult with an insulin pump experienced lived time with the never ending requirements of checking BG, bolusing insulin, and regularly changing the infusion set within the context of multiple competing

demands on their time. Living with an insulin pump through the emerging adulthood period meant progressing over time toward acceptance of responsibility for diabetes self-management along with being prepared to deal with the vulnerabilities of hypoglycemia and hyperglycemia. The emerging adult's lived body faced the real or perceived stares of others as they often struggled with the need to keep the pump hidden until they were able to reach a point of acceptance of the pump as part of who they are. With T1D they were not able to live with their bodies in a state of self-forgetfulness. Instead diabetes required on-going BG monitoring and the negative consequences that accompanied the impact of low and high BG on their bodies. Lived space was felt as the emerging adult moved from the comfort of their home environment to a new and changing university or work environment without the safety net of those who were familiar with their diabetes and pump. The limitations of physical space on the body presented an additional challenge as the emerging adult must regularly move the pump's infusion set to maximize effectiveness and to minimize physical harm. Some had the additional challenge of desiring to keep the pump hidden from view. All participants were in a continual search for a "good spot" to insert their pump. Lived relationships for the emerging adult were often enhanced by the flexibility and freedom associated with the insulin pump that allowed them to lead a fairly normal university life experience often driven by last minute plans and time spent in activities with an ever-changing group of people. Although the emerging adult had the freedom to be a part of the "normal" university and work world, living with the pump often carried a sense of traveling through this pump journey with an initial sense of aloneness until new connections are made with other pump users.

Metaphorical Description of Findings

The use of metaphors and the language of poetry often speak to the reader and provide an additional means to reflect on the phenomenon of study (van Manen, 1990). This excerpt from *The Tightrope Walker* communicates the perspective of the emerging adults in this research.

I look around me, and feel alone.
Like a tightrope walker, 20 meters above his public.
Every one watches, still he is alone.
From the safeness of the ground the public cries
Lean left! Lean right!
Go forwards! Take a step back!
Everyone knows how to help the tightrope walker.
But no one knows the wind that blows
Or the tension of the rope.
No one knows all facts, but the tightrope walker himself
I am a tightrope walker.

From *The Tightrope Walker* posted by duncanrust May 14, 2007

Discussion

This study unveils the everyday experience of emerging adults living with T1D and insulin pumps. These emerging adults often begin to live away from their family, have multiple changes in living arrangements, and switch from their familiar pediatric health care teams to a new adult care service. Four strategies were identified as part of the process of maintaining their balance during this period from adolescence to adulthood: seeking control, becoming responsible, staying connected, and accepting me.

Theme 1: Seeking Control

This study found insulin pump technology to be particularly suited for the lifestyle and competing demands of emerging adults as they faced what are typically the years of poorest glycemic control (Bryden et al., 2001; Insabella et al, 2007). Living with

an insulin pump as an emerging adult brought the possibility of improved BG control as well as freedom and flexibility that allowed them to regain some control of their everyday lives. Encouraging emerging adults to embrace a sense of control over their diabetes has the potential to impact their metabolic control. Aberle et al. (2009) found high internal locus of control associated with better glycemic control in adults with T1D who use insulin pump technology.

The frustration these participants experienced when dealing with the negative impact of physical and psychosocial demands on glucose control mirrored similar findings with diabetes self-management in university students in the northeast US and the United Kingdom. (Ramchandani et al., 2000; Balfe, 2009). Although Peters and Laffel (2011) report feelings of invulnerability in the early years of emerging adulthood, these participants came face to face with physical, social, and emotional vulnerability. This vulnerability was especially frightening when the participants experienced a lack of control that resulted from severe hypoglycemia or unexplained hyperglycemic excursions without the safety net of family around them. This is a more vulnerable group because it has been shown that persons between the ages 20-29 living with T1D are four times more likely to die than their peers without diabetes (Rapley & Davidson, 2010).

Deciding where to place the insulin infusion set was one area of control that the emerging adult in this study could claim. It was their decision to expose or hide their insulin infusion. Although not specific to insulin pump users, Dovey-Pearce, Doherty and May (2007) also found it important for young people to have control over disclosure of their diabetes to others. Those who attempted to keep the pump invisible to others and in a comfortable location reported struggling with the difficulty of “finding a good spot.”

This often resulted in these emerging adults delaying infusion set changes beyond the recommended 2-3 days.

Theme 2: Becoming Responsible

Findings from this study support Arnett's (2001) work that accepting responsibility is a process that occurs over time for the emerging adult. In spite of sudden wake-up calls that they are now "on their own," the emerging adult with an insulin pump must learn to plan ahead, have back-up supplies available, remember to check BG, count carbohydrates, and bolus insulin doses as they learn to adjust to the irregular routines of college life (Balfe, 2009). This process of becoming responsible often comes from "learning the hard way." Sparud-Lundin, Ohrn & Danielson, (2009) found this shift in responsibility for self-management was also a struggle for many parents who have to learn to step back in their own routine. No empiric data is available that addresses the self-efficacy of making pump changes in emerging adults. For these participants, taking responsibility for fine-tuning their insulin pump for improved glucose control was still a work in progress as most participants left the responsibility for pump adjustments with their HCP.

Theme 3: Staying Connected

A support network is necessary in the face of the continuous demands of diabetes self-management (Scott et al., 2005) and the role of peer support was found to increase during the adolescent years (Dovey-Pearce et al., 2007; Pendley et al., 2002). Although parents were often considered to be nagging during the adolescent and emerging adult years, these participants, as did participants in Dovey-Pearce et al. (2007) had times that they relied on the "safe base" of the family. After leaving home, these emerging adults

faced the loss of daily connections with family and friends who were familiar with their diabetes.

Markowitz and Laffel (2012) identified the need for emerging adults to discuss issues of daily living with others who are facing similar daily demands. Such support group connections had a positive impact on self-management and metabolic control. Only one participant in this study had regular face-to-face encounters with other pump users. Not knowing others their age with T1D and/or insulin pumps and a perceived lack of social support networks has been a finding in other studies (Kay et al., 2009; Perry et al., 2012).

As the emerging adult lost immediate family support with a move from home, they typically faced an abrupt switch from their familiar pediatric endocrinology team to a new adult HCP. This critical period of transition from pediatric to adult care providers for T1D is beginning to receive attention. Garvey et al. (2012), in the first study of the transition care experience for emerging adults with T1D in the US, found the mean age of transition to adult care was 19.5 years and fewer than half of those were given contact information for an adult HCP prior to “transition.” Gaps in care of > 6 months after leaving a pediatric care team have been identified in up to 40% of emerging adults (Daneman & Nakhla, 2011; Pacaud et al., 2005; van Wallegghem, MacDonald & Dean, 2008). Several participants in this study felt frustration with the change in adult health care provider practices after losing their connection to a holistic pediatric care team. Participant’s self-reported health care visits over the previous year, from endocrinologist to ophthalmologists, ranged from one HCP visit to seven visits.

Theme 4: Accepting Me

The emerging adult years are a time for identification of who one is as an individual as well as who they are as part of a community (Arnett, 2001; Arnett, Ramos & Jensen, 2001; Schwartz et al., 2011). The experience of emerging adults with T1D and insulin pumps in this study suggest the quest for a sense of normalcy. Consistent with findings of Kay, et al., 2009, most participants expressed concerns about being viewed as different or “weird” and often tried to keep their insulin pump hidden from the view of others. Although Dovey-Pearce, Doherty and May (2007) reported a shift in personal identity that seemed to take place before those newly-diagnosed with diabetes left the hospital, participants in this study demonstrated a self-acceptance of life with T1D and a pump as a process that occurs over time. Most participants gained a sense of acceptance as the pump eventually became a part of who they are, described by one young man as being just like “a new tattoo.”

Limitations

Several limitations to the study must be acknowledged. First, all participants were non-Hispanic white (NHW). Although T1D impacts a disproportionately large number of NHW youth, this study included no participants from other races. Second, demographic data from hemoglobin A1C to HCP visits over the past year were self-reported. Third, while this study has implications for emerging adults with T1D who have an insulin pump, the sample was derived from a 200 mile radius of the north-central part of Louisiana. It is not known if this population has different experiences from those who live in other parts of the US or who live internationally.

Implications for Practice

The findings of this study support Arnett's model of emerging adulthood and provide empirical support for the design and implementation of transition services for the emerging adult with T1D. Understanding the challenges and frustrations of desiring control of their life and their blood sugar amidst multiple competing demands is essential and comes through attentive listening to these emerging adults who are much more than BG numbers on a pump. It is important that the HCP recognizes that accepting responsibility for the endless demands of self-management is a process that occurs over time and involves on-going negotiations and open communication between the emerging adult, the parent and/or significant other, and the adult health care team as the bulk of responsibility shifts to the emerging adult. It is also vital to understand the emerging adult's need to connect in a period of time when there is often a sense of going through the diabetes journey alone.

This understanding opens the possibility of development of assessment tools and resources with the input of emerging adults. These resources should address specific needs such as glycemic control issues encountered with changes in routine at the start of a new semester or during final exams, relationship changes, or a change in residence. Attention to the developmental concerns of this developmental period such as career preparation and intimacy issues are important as well. Likewise, asking emerging adults about their support network can help the provider identify ways to connect them with others through university groups such as Students with Diabetes or College Diabetes Network, through blogs, or through community groups or groups within their own practice. Services with such social components can encourage increased responsibility,

provide support, and promote acceptance. The Maestro Project (van Wallegghem, MacDonald & Dean, 2008) is an intervention built on this need for connection with peers and with HCPs and has been used in Canada to decrease the number of emerging adults lost to follow-up care. This model is designed to facilitate relationships at a time when they are critically needed by a vulnerable population.

Collaborative goal setting with their HCP is a way to provide the emerging adult with a sense of control as well as to promote a growing sense of responsibility for their diabetes self- management (Haas et al., 2012; Scott et al., 2005). If emerging adults perceive adult care providers lack understanding of what is going on in their lives and make arbitrary changes that seem to just increase their insulin, this sense of disconnect may have a negative impact on their clinic visits at a time when they are most vulnerable.

Conclusions

Understanding the unique challenges and strategies of the emerging adult will assist HCPs as they design and implement evidence based, patient-centered care practices. Although this age group may seek control, accepting responsibility when abruptly facing the realization that “I am on my own” is a process that takes time. The emerging adult years can be considered a period of gradual acceptance of the on-going responsibilities and consequences associated with the everyday demands of diabetes management with an insulin pump. Recognizing the need for this age group to connect with others at similar points in the diabetes journey, the HCP needs to consider strategies that link the younger adult population through creative scheduling possibilities and communication strategies that consider the needs and preferences of this age group. Through a plan of care designed for this group that is no longer an adolescent but not yet

an adult, HCPs can assist the emerging adult through this vulnerable period with the tools and confidence necessary to successfully continue their journey.

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Chapter 4

Summary and Conclusion

Evaluation of the Project

The purpose of this research was to gain a deeper understanding of the experience of emerging adults using insulin pumps for diabetes self-management. Understanding the lived experience through phenomenological interpretation gives a voice to this group that has often been overlooked at a critical point in their life journey with diabetes. Through in-depth, face-to-face conversations, participants were able to share their descriptions of what it feels like to wear an insulin pump during the emerging adult years. Four themes were identified as essences of their experience between adolescence and adulthood: seeking control, becoming responsible, staying connected, and accepting me. These essences were ultimately viewed as strategies used by the emerging adult as they journeyed through their adolescent and young adult years while living with T1D and an insulin pump.

A challenge of this research was locating potential participants with insulin pumps in this specific age group. Purposive sampling was used to find participants willing to share the details of their experiences. It was anticipated that snowball sampling would assist with the identification of potential participants. Because a common finding was the sense of being alone as a pumper, the participants had very limited knowledge of any other pump users in this age group. As a result, the interview portion of this study required six months. A limitation of this study comes from having all participants being non-Hispanic white currently living in the state of Louisiana. No emerging adults of other races were identified. Although these participants received pediatric endocrinology care

varying from small clinics to large Children's Hospital centers from four different states, their emerging adult years were within a 200 mile radius of north Louisiana. Thus generalizability of these findings is limited.

Recommendations Based on the Findings

The findings of this research clearly indicate how critical it is for health care professionals (HCPs) to recognize the importance of the emerging adult having control over their lives. Along with the desire for glycemic control that allows individuals to feel their best physically, the emerging adult seeks the opportunity to feel in control of their daily lives. The opportunity to actively partner with HCPs in care decisions is one way to promote a sense of control. However, the findings also demonstrate that accepting responsibility for diabetes self-management with an insulin pump during these years of transition to independent living is a process that takes time. In the midst of multiple competing demands it may be unrealistic for the HCP to expect the emerging adult to suddenly transition to an adult care practice and accept the responsibilities of a typical adult pump patient.

It is important to note that emerging adults are working their way through these demanding years without the comfort of their familiar safety net. It is not uncommon for this age group to feel a sense of aloneness during their diabetes journey. Recognizing this need and facilitating opportunities for connections with other pumpers may be a strategy with promise for improving glycemic control, encouraging responsible self-management, and promoting a sense of normalcy.

Findings gleaned from this study pave the way for future research that targets the development and evaluation of interventions and resources specifically designed for

the emerging adult population. Research that focuses on the transition from health care in a pediatric practice setting to the adult care setting is also needed. The inclusion of emerging adults in the design and evaluation of support resources, such as campus organizations for students with diabetes, blogs, social media applications is essential. Interventional studies can follow that measure the impact of these tools on self-management, glycemic control and quality of life for this age group.

Two related areas for future research are with parents of emerging adults. Understanding the experience of “letting go” may be useful for both the parent and emerging adult. Additional research is also needed addressing the preconception and perinatal experiences of young women with T1D and insulin pumps from perspectives of these young women, their significant others, and the nurses caring for them.

Conclusion

Understanding the self-management practices of emerging adults with insulin pumps in the context of daily living is critical for the development of practice guidelines and resources that are developmentally appropriate for this group of insulin pump users. Recognizing the typical demands of this age group is necessary in the development of a framework of care that can effectively meet their needs. Major findings from this study reveal the importance of gaining control, the process of becoming responsible, the need for connection with others, including the HCPs, and the hope of acceptance that can come with time and support for the emerging adult with T1D.

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Appendix A

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Appendix B

The University of Texas at Tyler Institutional Review Approval

The University of Texas at Tyler
Institutional Review Board

October 6, 2011

Dear Ms. Hood:

Your request to conduct the study entitled *The Nature and Meaning of Insulin Pump Use in Emerging Adults* is approved as an expedited study, IRB #F2011-14 by The University of Texas at Tyler Institutional Review Board. This approval includes the use of the written informed consent that is attached to this approval letter. Please use this form for all persons, and ensure that each participant is able to repeat the purpose of the study, the voluntary nature of it, any risks involved, and who to contact other than you as the PI. In addition, ensure that any research assistants or co-investigators have completed human protection training, and have forwarded their certificates to the IRB office (G. Duke).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- This approval is for one year, as of the date of the approval letter
- Request for Continuing Review must be completed for projects extending past one year
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,



Danita Alfred, PhD, RN
Member, UT Tyler IRB

Appendix C

Informed Consent Form

Informed Consent Form THE UNIVERSITY OF TEXAS AT TYLER

Informed Consent to Participate in Research

Institutional Review Board # F2011-14

Approval Date: 10-06-11

- 1. Project Title:** The Nature and Meaning of Insulin Pump Use in Emerging Adults
- 2. Principal Investigator:** Donna G. Hood

3. Participant's Name:

To the Participant:

You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This consent form explains why this research study is being performed and what your role will be if you choose to participate. This form also describes the possible risks connected with being in this study. After reviewing this information with the person responsible for your enrollment, you should be able to understand and make an informed decision on whether you want to take part in this study.

4. Description of Project

The purpose of this study is to learn more about what it means to use an insulin pump from the view of individuals using an insulin pump to manage type 1 diabetes. You are being asked to take part in this study because you have type 1 diabetes, you use an insulin pump, and you are between ages 18 – 25.

5. Research Procedures

If you agree to be in this study, we will ask you to do the following things:

- Decide on an interview location that is comfortable for both yourself and Donna Hood.

Appendix C (Continued)

- Pick a different name (pseudonym) to be used during the interview so that no one reading or hearing your interview information, other than Donna Hood, will know your real name.
 - Answer some written questions about yourself and your diabetes/insulin pump history (demographic questionnaire). This will include your age, race, how long you have had diabetes, if you work or attend school, your last HgA1C, and your type of medical provider(s).
- Participate in at least one interview between yourself and Donna Hood where you will be asked questions about your experiences with your insulin pump.
- Allow the interview to be recorded by an auditory-recording device. You may ask to stop the recording at any time and the recording will be stopped.
- Face-to-face interviews are expected to last about one hour, but you may stop the interview at any time.
- Follow-up interviews may be requested and can be held in person, by phone, or by computer-assisted communication.
- Some quotes from your interview may be used in write-ups and presentations about this research study, but your real name will never be used.

6. Side Effects/Risks

The interviews may cause uncomfortable feelings from sharing any stressful experiences related to your experiences of living with your insulin pump. Again, the interview can be stopped by you at any time and you can choose not to answer any questions.

7. Potential Benefits

Your taking part in this study may include the benefit of knowing that sharing of your story may help bring about better care for others with diabetes. You may also gain a deeper understanding of your experience with your insulin pump.

Understanding Of Participants

8. I have been given an opportunity to ask any questions concerning this research study and the researcher has been willing to answer my questions.
9. If I sign this consent form I know it means that:
 - I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
 - I know that I am free to not participate in this study and that if I choose to not participate, then nothing will happen to me as a consequence.

Appendix C (Continued)

- I know that I have been told that if I choose to participate, then I can stop being a part of this study at any time. I know that if I do stop being a part of the study, then nothing will happen to me.
 - I will be told about any new information that may affect my willingness to continue participating in this study.
 - The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.
 - The researcher will gain my written consent for any changes that may affect me.
10. I have been assured that my name will not be revealed in any reports or publications resulting from this study without my expressed written consent.
11. I also understand that any information collected during this study, including any health-related information, may be shared with the following as long as no identifying information as to my name, address, or other contact information is provided):
- Organization contributing money to be able to conduct this study
 - Other researchers interested in combining your information with information from other studies
 - Information shared through presentations or publications
12. I understand The UT Tyler Institutional Review Board (the group that ensures that research is done correctly and that measures are in place to protect the safety of research participants) may review documents that have my identifying information on them as part of their compliance and monitoring process. I also understand that any personal information revealed during this process will be kept strictly confidential.
13. I have been told of and I understand any possible expected risks that are associated with my participation in this research project.
14. I understand that I will not be compensated for any patents or discoveries that may result from my participation in this research.
15. If I have any questions concerning my participation in this project, I shall contact the principal researcher: Donna Hood, at (318) 548-8045, dhood3@patriots.uttyler.edu
17. If I have any questions concerning my rights as a research subject, I shall contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu, or the University's Office of Sponsored Research:

Appendix C (Continued)

The University of Texas at Tyler
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

I understand that I may contact Dr. Duke with questions about research-related injuries.

18. CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY

Based upon the above, I consent to taking part in this study as it is described to me. I give the study researcher permission to enroll me in this study. I have received a signed copy of this consent form.

_____	_____
Signature of Participant	Date

Witness to Signature

19. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. The participant was able to understand that this is a research study. He/she was able to describe basic purpose of the study; the risks involved; their role and approximate time commitment; the voluntary nature of participation; and who to contact other than the researcher if they have comments or questions about the study. I believe the participant understood this explanation.

_____	_____
Researcher/Principal Investigator	Date

Pseudonym _____

If I have your permission to contact you again in order to clarify or confirm your interview information, please provide your preferred contact information here:

Appendix D

Demographic Questionnaire

Pseudonym _____

- 1. Age:** _____
- 2. Race:** _____
- 3. Gender:** _____
- 4. Number of years since diagnosis of type 1 diabetes:** _____
- 5. Years (or months) of pump use:** _____
- 6. Do you currently work or attend school? Check all that apply.**
Work full time _____
Work part time _____
Student full time _____
Student part time _____
- 7. What describes your current living arrangements?**
Live in home with parent/parents _____
Live in home with extended family _____
Live in university housing with roommate (s) _____
Live alone _____
Live in apartment with roommate (s) _____
Other (describe) _____
- 8. How many hours per week do you typically spend in vigorous physical activity?**

Appendix D (Continued)

- 9. How many hours per week do you typically spend in moderate physical activity?**

- 10. Last HgA1C**_____

- 11. Type(s) of medical provider(s) you have seen at least once in the last year:
Check all that apply.**

Endocrinologist/ Diabetologist_____ adult/pediatric/adolescent

Diabetes Educator_____

Pump Specialist/Trainer_____

General practice physician_____

Internal medicine physician_____

Nurse practitioner_____

Registered Dietitian_____

Gynecologist_____

Psychologist_____

Ophthalmologist/Optomtrist_____

Appendix E

Interview Guide

Probes: How did/does that feel? What was that like? What does that mean to you?

1. What is it like to wear an insulin pump as a ____ year old? Tell me your story.
2. When did you first go to a pump? What was that experience like?
3. Tell me what it was like going from your high school days with a pump to university life . . . and now.
4. Describe your experience going from a pediatric endocrinologist to an adult care provider?
5. What has been the impact of your pump on your self-management?
6. What has been your experience as a pump wearer when you think about your interactions with other people? (roommates, friends, dates, faculty, employers, parents/family)
7. Do you ever find yourself manipulating your pump to . . . change something?
8. Tell me what it is like to deal with lows? High blood glucose?
9. What has been your biggest challenge with self management and/or your pump? Your biggest success?
10. If you were to give your pump experience a word or phrase – “Using this pump is ____” what would it be?
11. When you think about the future, what goes through your mind?
12. What else do you want to share anonymously with other people? “I think _____ need to know that . . .”
13. As we conclude, how do you feel about being a part of this study?

Appendix F

Example of Lifeworld Existential Analysis

Amy #1 Contextual Analysis

Amy is a 20 year old full time student who also works part time. She lives about an hour from home in an apartment with her roommate. She has had diabetes for 9 years and her pump for 8 years. Her last A1C was 6.1 and she has seen several HCPs over the past year.

Narrative on Meaning for Amy

Temporality- Time is a big component of the insulin pump experience for Amy. Before the pump her day was defined by time schedules for insulin injections and rigid eating times. Time continues to play a big role in her experience, now with the blessing of flexibility of time that we take for granted. The pump allows what she calls “temp basals” those multiple different patterns of insulin delivery that she has control over thus giving her much more control of her time. As a busy university student this is particularly important as she must adjust to changing and demanding schedules that include marching band, classes, and her social life. Diabetes still requires attention to time, but she finds she is dropping those programmed pump alarms that reminded her to check BG or change her infusion site because they are annoying when they go off during class. Time still has its challenges as Amy gets caught up in the “business of life” and forgets to check her BG or tell her pump to deliver insulin for her food. Time often slips by and she realizes that she forgot and that brings a cost that takes a toll on her body.

Corporeality – Amy’s body is dependent on exogenous insulin from her pump requiring her to check her BG regularly, count carbs, and interact with the pump in order

Appendix F (Continued)

to maintain normal BG. Normal BG gives her a calmer yet more energetic feel in her body. With high BG she gets frustrated easier, is tired, and doesn't feel as well. With low BG she gets shaky, flustered, and can't think straight. Normalizing BG makes her feel herself again. Self-management of her diabetes requires "stabbing" her fingers to check BG and changing her pump site about every three days. There are certain places on her body she can insert her pump (abdomen, thigh, hip) depending on adequate fatty tissue, access, and comfort. Since going to college she typically uses her abdomen for her insertion set and keeps her pump hidden in her bra to avoid questions and having it pulled out by the tubing. When she clips her pump to her waist or something, seeing it or having her hand brush up against it serves to remind her that it is there. Weight gain has not been an issue.

Spaciality – Lived space for Amy varies. She is an hour away from home and lives in a university apartment on the third and fourth floors. She has found this challenging when she has low BG and must get to a glucose source and has had to call her brother to come to apartment to help her. Although the pump has many advantages over insulin injections, Amy finds it "awkward" and "annoying" when she feels like she must step away to deal with a beeping pump during class or to program the pump with her carb count when out with friends.

Relationality – The experience with others continues to be challenging for Amy as she is torn between not wanting others to know she has a pump ("they might think I'm weird" or feeling "awkward" when explaining) to feeling like it is better when people around her know about her diabetes. That curiosity of others is uncomfortable. With

those who know about her diabetes, their reminders also bring a sense of struggle as she vacillates between thinking that sounds like her Dad hounding her with “overbearing” reminders to check her BG and if she is okay to being grateful that others around her care. Amy doesn’t feel restricted in her social life other than having to answer questions and not really wanting to.

Holistic Reading for Amy

Insulin pump use means freedom from a rigid structure of life which is really important as a university student. With the freedom comes a struggle of wanting to take control on her own but facing the business of life that leads to forgetting and frustration. Ultimately, she has to decide for herself that she will take control.

Appendix G
Biographical Sketch

NAME Donna G. Hood		POSITION TITLE Doctoral Candidate, University of Texas at Tyler Professor, Division of Nursing, Louisiana Tech University, Ruston, LA	
eRA COMMONS USER NAME (credential, e.g., agency login) dhood3			
EDUCATION/TRAINING			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
Northwestern State University	BSN	05/83	Nursing
Northwestern State University	MSN	05/93	Nursing
The University of Texas at Tyler	PhD	12/12	Nursing

A. Personal Statement

As a registered nurse and nursing faculty member, I have worked with university students and pediatric patients of all ages. I have had a particular interest in diabetes for the past 10 years. This interest became a passion when my daughter was diagnosed with type 1 diabetes. That passion and the gaps in the literature related to the emerging adult with type 1 diabetes guided me to this study. With my program of research centered around the impact of diabetes on the human lives, the aim of this study is to increase our understanding of the emerging adult population using insulin pump technology in order to support evidence-based interventions for this developmental stage. My participation in two intensive qualitative research institutes (2011, 2012) at The University of North Carolina at Chapel Hill, provided the immersion experiences necessary to being qualitative work.

B. Positions and Honors

Positions and Employment

2012	OV Clinical Trials Clinical Research Nurse, prn
2009	Health Information Technology Scholar
1992- present	Assistant Professor Associate Professor Professor, Division of Nursing, Louisiana Tech University, Ruston, LA
1989-1993	Staff Nurse, Outpatient Surgery, Lincoln General Hospital, Ruston, LA
1983-1989	Staff Nurse, Charge Nurse, Unit Manager, Level III NICU, St. Francis Medical Center, Monroe, LA

Other Experience and Professional Memberships

Sigma Theta Tau International Honor Society of Nursing, Beta Chi Chapter,
Northwestern State University, 1983 to present

Association of Women's Health, Obstetric and Neonatal Nurses, 2011 to
present

American Association of Diabetes Educators 2012

Alpha Chi National College Honor Scholarship Society, Texas Chapter, 2012

The Honor Society of Phi Kappa Phi, University of Texas at Tyler, 2011 to
present

C. Selected Peer-reviewed Publications

Hood, D. G.. (2012). Continuous subcutaneous insulin infusion for managing diabetes. *Nursing
for Women's Health*, 16(4), 308-318.