

**EXPLORING THE ROLE OF THE PARISH NURSE IN PROVIDING DIABETES  
EDUCATION AND PRECONCEPTION COUNSELING TO AFRICAN AMERICAN  
WOMEN USING A COMMUNITY-ENGAGED MIXED METHODS APPROACH**

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# **EXPLORING THE ROLE OF THE PARISH NURSE IN PROVIDING DIABETES EDUCATION AND PRECONCEPTION COUNSELING TO AFRICAN AMERICAN WOMEN USING A COMMUNITY-ENGAGED MIXED METHODS APPROACH**

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University of Pittsburgh, 2014

**Purpose:** The purpose of this study is to explore the experiences of parish nurses (PNs) in providing diabetes education and preconception counseling (PC) to women (especially African American [AA] women) with type 1 diabetes (T1D) and type 2 diabetes (T2D) and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes; and to describe the parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC.

**Methods:** A mixed-method concurrent embedded design using focus group methodology as the primary method and a quantitative descriptive design with three self-report measures (demographic, PC self-efficacy, and PC knowledge) as the secondary method was utilized. Forty-eight parish nurses participated in one of eleven focus groups. Qualitative content analysis was conducted and combined with descriptive measure analysis.

**Results:** Seventeen qualitative themes emerged from the discussions with the PNs: 1) role, 2) approach, 3) challenges, 4) support network 5) practice and programs, 6) diabetes practice and programming, 7) diabetes and pregnancy and PC practice and programs, 8) awareness, 9) experience, 10) formal training, 11) importance and usefulness, 12) willingness, 13) forming a social network of wise women, 14) confidence, 15) need for training, 16) recommendations for PC training for PNs, and 17) recommendations for PC tool for patients. PNs' knowledge scores were low (mean= 65%, range= 40-100%) with only moderate levels of self-efficacy (mean= 99,

range = 27-164). Self-efficacy had a significantly positive association with knowledge, as knowledge increased self-efficacy increased (Pearson  $r = .292$ ,  $p = .05$ ).

**Conclusions:** Quantitative results confirmed PNs' qualitative statements. PNs were unaware of PC and lacked both knowledge and teaching self-efficacy as it related to PC/diabetes education. Understanding PNs' experiences with women with diabetes and identifying their needs to provide education and PC will help tailor training interventions that could impact maternal and fetal outcomes.

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## **PREFACE**

As a pediatric nurse practitioner and a nurse in a labor and delivery unit, I have gained insight into and experience with pregnancies complicated by diabetes and problems of infants/children born to mothers with diabetes. This experience opened my eyes, not only to the complexity and delicacy of this period of life, but also the impact of public health on health disparities and lack of empowerment of women and ultimately their families. This experience led me to the pursuit of a certificate in Women's Studies. I have also worked as a pediatric nurse practitioner in the Pittsburgh Public Schools, which gave me experience as a Nurse Practitioner, and also working hands-on in a community setting in an area with disadvantaged children. This experience furthered my interest in minority health and health disparities and cultural competence, which influenced me to obtain a certificate in Health Equity through the School of Public Health at the University of Pittsburgh. The completion of these two certificates has equipped me to better understand the population of study, parish nurses for the current dissertation phase and AA women with diabetes who are childbearing for the larger program of research. In addition, I obtained a certificate as a parish nurse and understand the role and its potential to fill the gap of disparities related to health education in the community.

The evolution of this topic was not only influenced by the education and experiences that I have gained through my clinical practice and the pursuit of my education and various

certificates, but also in large part to my dissertation committee and faculty at the University of Pittsburgh. For that I am truly grateful and sincerely thank my mentors for all that they have contributed. I am also indebted to the parish nurses who so willingly and selflessly volunteered their time to participate in my study. This group of special nurses also includes the former manger of a parish nurse and health ministry program, Dorothy Mayernik, who served this project and her fellow parish nurses, to include myself, so humbly and with utter grace. My sincerest thanks and praise I give to her. I must also extend thanks to all of my fellow students in the PhD program who have helped, encouraged, and supported me along this journey. Finally, I thank my family, who without their support I would not have come to the place that I am. I cannot thank them enough for their devoting and sacrifice.

## 1.0 INTRODUCTION/STUDY PROPOSAL

Diabetes is a public health crisis whose escalating costs require innovative, inexpensive community-based solutions. Compared to Caucasian women, African American (AA) women have nearly twice the prevalence of type 2 diabetes (T2D) (Centers for Disease Control and Prevention [CDC], 2011) and are more vulnerable to developing diabetes complications (Holcomb, Mostello, & Leguizamon, 2001). In general, AAs have increased rates of diabetic retinopathy (AAs 50% more likely compared to Caucasians), nephropathy (2.6-5.6 times as likely as Caucasians), and lower limb amputations (2.7 times compared to Caucasians) (ADA, 2014). Because AA women have greater disease burden than their Caucasian counterparts, (Williams, 2005) they could greatly benefit from services delivered in their community (Owens, 2006), especially those with low income and limited access to health care (Williams, 2005).

Faith-based programs have been particularly successful in AA communities in increasing glycemic control (Newlin et al., 2008), physical activity (Peterson & Cheng, 2011), and weight loss (Hye-cheon et al., 2008). Given that AA women make a strong connection between their health and spirituality, as reported in qualitative literature and evidenced by impact on glycemic control ( $\beta = .289$ ,  $SE = .032$ ,  $p = .028$  and  $\beta = - .358$ ,  $SE = .030$ ,  $p = .006$ ) (Bopp et al., 2007; Drayton-Brooks & White, 2004;), and to their faith-based communities (Newlin, 2008), the parish nurse becomes an excellent untapped resource.

PNs are nurses who practice from a holistic perspective, incorporating spiritual health “defined as the ability to find comfort/strength through spiritual beliefs” (Goel, Sharma, & Galhotra, 2010, p. 540), in a faith-based setting (church) with a main role of providing health education and health promotion activities (Chase-Ziolek & Iris, 2002; King & Tessaro, 2009; McDermott & Burke, 1993; Tuck & Wallace, 2000, 2001). Parish nurses are underutilized community resources who can play a pivotal role in providing education and health promotion at the community level (McGinnis & Zoske, 2008; Wallace, et al., 2002). Could parish nurses fill a void for women with diabetes?

Compared to Caucasian women, AA women have higher infant mortality rates (13.31/1,000 for AAs and 5.63/1,000 for Caucasian) (MacDorman & Mathews, 2011), higher risks of negative pregnancy outcomes such as low birth weight (140/1,000 for AA and 73/1,000 for Caucasian) (Martin J., Hamilton B., Sutton P., et al., 2007) and preterm delivery (184/1,000 for AA and 117/1000 for Caucasian) (Martin, Hamilton, Sutton, et al., 2007), higher rates of pregnancy related death (three to four fold increase over Caucasian women) (Harper et al., 2007), and the highest rate of unintended pregnancies (92/1,000 AA vs. 38/1,000) (Finer, 2014). Women with T1D and T2D who have unplanned pregnancies have a two to threefold increase in rates of major congenital abnormalities among their infants (American Diabetes Association [ADA] 2004, 2007; Kitzmiller et al., 1991). PC can mitigate this.

The ADA defines preconception counseling (PC) as comprehensive care and education that begins at puberty (ADA 2011) and includes: 1) counseling about the risks of malformations associated with poor glucose control; 2) effective contraception methods until glycemic control is achieved; “3) patient education about the interaction of diabetes, pregnancy, and family planning; 4) education in diabetes self-management skills; 5) physician-directed medical care

and laboratory testing; and 6) counseling by a mental health professional when indicated to reduce stress and improve adherence to the diabetes treatment plan” (ADA 2004, S76). When PC is utilized and a pregnancy complicated by diabetes mellitus (DM) is planned, risks of reproductive complications can be reduced from 10% to 2% with PC (ADA 2004, 2011).

Parish nurses have had positive effects on patient outcomes related to diabetes, obesity, and other chronic diseases (Garber Mendelson et al., 2008; White et al., 2006). To date there is only one study that examines the use of parish nurses with a pregnant population. Mexican American women who had gestational diabetes and participated in a community-based parish nurse intervention had improved Health Promoting Lifestyle Profile II scores (measures aspects of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management) pre- and post- intervention ( $F=5.980$ ;  $p=.016$ ) (Garber Mendelson, et al., 2008). However, to our knowledge studies have not focused on parish nurses delivering PC to AA women in the community. The role of the parish nurse in providing diabetes education as it relates to pregnancy and PC to women with diabetes is unknown.

## **1.1 PURPOSE AND SPECIFIC AIMS**

Therefore, the **purpose** of this community-engaged mixed-methods study is to explore the experiences of parish nurses in providing diabetes education and PC to women (especially AA women) with T1D and T2D and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes; and to describe parish nurses’ knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC.

Using community-engaged research is innovative and can be an ideal way to study complex, socially situated health problems (Higgins & Metzler, 2001). Specifically, research studies that utilize community members in all aspects of the research project to include: study implementation and analysis, can reveal key information that will influence the delivery of interventions that are culturally relevant and useful for the individuals for whom they are intended (Garwick & Auger, 2003).

### **Research Question 1**

What are the experiences of parish nurses in providing diabetes education and PC to women of childbearing age with T1D and T2D, especially in AA women?

### **Research Question 2**

What is parish nurses' understanding of diabetes as it relates to pregnancy and pregnancy outcomes?

### **Research Question 3**

What is the parish nurses' level of knowledge about diabetes as it relates to pregnancy, pregnancy outcomes and PC?

### **Research Question 4**

What are parish nurses' teaching self-efficacy as it relates to diabetes, pregnancy and PC?

### **Primary Aims**

**Specific Aim 1:** To qualitatively explore parish nurses' experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women.

**Specific Aim 2:** To qualitatively explore parish nurses' understanding of diabetes as it relates to pregnancy outcomes.

### **Secondary Aims**

**Specific Aim 3:** To quantitatively examine parish nurses' knowledge of diabetes as it relates to pregnancy and pregnancy outcomes and PC.

**Specific Aim 4:** To quantitatively examine parish nurses' teaching self-efficacy as it relates to diabetes, pregnancy and PC.

**Exploratory Aim:** To explore the association of knowledge and self-efficacy of parish nurses as they relate to diabetes and pregnancy and PC.

## **1.2 BACKGROUND AND SIGNIFICANCE**

### **1.2.1 Diabetes and pregnancy**

Among pregnancies with diabetes, embryonic disruption of development was found to be caused by multiple mechanisms (Eriksson et al., 2000). Overall, there is a disruption in the role of the metabolism of inositol, prostaglandins, and reactive oxygen species (Eriksson et al., 2000). Warso & Lands report (1983), excessive levels of glucose in the fragile fetal tissues increases the disproportionate formation of oxygen radicles, which inhibits prostacyclin (as cited in, Moore & Catalano, 2009, p. 1044).

Due to the cellular disruption, fetal morbidity and mortality for infants born to mothers with diabetes may result. This includes miscarriage, congenital anomalies, intrauterine growth restriction, macrosomia, birth injury (Creasy et al., 2014), and stillbirth (Moore & Catalano, 2009).

Rate of spontaneous abortion (i.e. miscarriage) has been found to be directly related to glycemic control. Miodovnik and colleagues (1984) observed that women with more advanced classes of diabetes had increased rates of spontaneous abortions (Classes: C =25%, D=44%, F=22%). Conversely, women with well-controlled diabetes and good glycemic control were found to have a risk of spontaneous abortion equivalent to euglycemic women (Javonovic et al., 2005). In addition, Macintosh and colleagues work discuss rates of stillbirth are 4.7 times higher among women with diabetes compared to those without a diagnosis of diabetes (Macintosh et al., 2006).

Macintosh and colleagues (2006) further describe rates of congenital anomalies have been observed to be more than double the expected rate of the general population (3 out of every 1,000 live births, or 3%) (Knapp, Brogly, & Muenz, 2012) and can be as high as four times that of the general population (Towner et al., 1995). Historically, research has established that anomalies can occur when maternal blood glucose levels are above the normal range and usually occur early in the pregnancy, before the second month, often before the woman knows that she is pregnant (Mills, Baker, Goldman, 1979). A systematic review by Inkster and colleagues (2006) confirmed these findings, and reported that increased risk for congenital anomalies with poor glycemic control, pooled odds ratio 3.44 (95% CI, 2.30 to 5.15). The anomalies can be seen in multiple organ systems, including cardiac, nervous, craniofacial, gastrointestinal, musculoskeletal, and urogenital. They can be life limiting, or require surgical and medical

interventions that potentially result in disability (Ewart-Toland, Ynankowitz, & Winder, 2000). The most prevalent anomalies are cardiac (8.5 per 100 live births or 8.5% absolute risk) and those of the central nervous system, including anencephaly and spina bifida (5.3 per 100 live births or 5.3% absolute risk) (Beccera, 1990).

Diabetes can dangerously restrict or increase the growth of the fetus. Intrauterine growth retardation (also reported as restriction) (IUGR) occurs with pregnancies complicated by diabetes and independent association with higher HbA1C levels prior to conception ( $p < 0.0001$ ), first prenatal visit later in the gestation period ( $p = 0.01$ ), underlying vascular disease such as retinal ( $p = 0.0003$ ) or renal ( $p = 0.002$ ), increased maternal age ( $p = 0.0001$ ), and smoking during pregnancy ( $p = 0.001$ ) (Glinianaia et al, 2012). In rat studies, IUGR appears to be related to either poor function of the placenta or poor maternal-placental perfusion (Padmanabhan & Shafiullah, 2001).

Macrosomia, or overgrowth of the fetus, occurs directly in relation to exposure in utero to excessive amounts of glucose. Third trimester postprandial blood glucose appears to best correlate with birth weight outcomes. A larger number of infants were at or above the 90<sup>th</sup> percentile of birth weight when born to a mother with diabetes compared to the control (28.5% compared to 13.1%) (Jovanovic-Peterson, 1991). Infants born to mothers with DM are ten times more likely to have overgrowth (macrosomia) (Rudge et al., 2000) and 3-9 times more likely to experience adverse outcomes to include overgrowth (Yang, Cummings, O'Connell, & Jangaard, 2006). They also have twice the risk of serious birth injury, such as shoulder dystocia compared to their weight-matched control. Additionally, Cesarean delivery is associated with diabetes (Hayes, Feigal, Smith, & Fuddy) and has been seen to occur in one third of pregnancies complicated by diabetes (Feig, 2006).

In addition to fetal impact, women with diabetes experience higher maternal morbidity compared to the general population. This includes retinopathy, nephropathy, cardiovascular complications (chronic hypertension and pregnancy induced hypertension), preeclampsia, heart disease, and diabetic ketoacidosis. Retinopathy occurs due to the increased amount of glucose in the blood. The changes begin due to the increased vascular permeability. The progression begins with abnormalities that are mild and nonproliferative and accelerates through multiple stages to proliferative retinopathy. It is suggested that pregnancy can contribute to and hasten these changes (Schocket, Grunwald, & Tsang, 1999) and that duration and severity of diabetes prior to pregnancy may play an even more important role (Verier-Mine, Chaturvedi, Webb, Fuller, 2005).

Nephropathy occurs when the glomerular basement membrane becomes thickened due to increased levels of blood glucose. As the glomerular mesangium continues to change, diabetic glomerular sclerosis occurs and increased proteinuria is observed (Creasy et al., 2014). Similar to the progression of retinopathy during pregnancy, pregnant women with diabetes development of nephropathy will be closely related to glycemic control (Creasy et al., 2014). Women with diabetes who have underlying renal disease (nephropathy) prior to pregnancy have been shown to have increased risks (i.e. chronic hypertension, preeclampsia, and delivery at earlier gestational ages) when compared to women with diabetes who do not have nephropathy. However, there was no association between pregnancy and advancement or development of nephropathy (Young, Pires, Marques, de Oliveira, & Zajdenverq, 2011).

Cardiovascular complications including hypertension (chronic and pregnancy induced) (9%) and preeclampsia (4%) among women with diabetes, but risk of developing these conditions increases fourfold compared to the non-diabetic pregnant woman (Feig, 2006). It is

thought that this risk may be related to underlying renal damage (Feig, 2006). In addition, hypertension and preeclampsia occurs four times as often with women who have diabetes compared to those who do not. This risk is related to the duration of diabetes prior to pregnancy and any underlying nephropathy or hypertension (Feig, 2006). Reece and colleagues report, heart disease is not commonly experienced by women who have diabetes and are pregnant; however some women are affected and experience very poor pregnancy outcomes with maternal mortality at 50% or higher and perinatal mortality close to 30% (as cited by, Creasy et al., 2014, p. 18).

Diabetic ketoacidosis (DKA) is a possible complication, but occurs much less frequently than in past decades. DKA results when insult to the body occurs and insulin action becomes inadequate and cellular level hypoglycemia occurs (Creasy et al., 2014).

In order to understand how to prevent these complications we look to the seminal work done on this topic. Kitzmiller and colleagues (1991) who reported that having tight glucose control prior to and during conception is significantly related to decreased rates of congenital anomalies and inversely; having higher blood sugars prior to and during conception was significantly related to increased rates of congenital anomalies ( $\chi^2 = 40.9$ ,  $P < .001$ ). A prospective study done by Fuhrmann (1983) reports similar findings, stating that malformation rates among women with diabetes can be prevented with glycemic control prior to and during the beginning of pregnancy ( $\chi^2 = 7.84$ ;  $P < 0.01$ ). Additionally, a systematic review reported that for each 1% decrease in HbA1c levels, a relative risk reduction for congenital malformation varied from 0.39 to 0.59 (Inkster et al., 2006).

### **1.2.2 Pregnancy outcomes T1D vs. T2D**

Differences in rates of perinatal mortality (fetal or neonatal death) have been observed between women with T1D and T2D. Clausen and colleagues (2005) found that “perinatal mortality increased four- to nine-fold (4/61, 6.6%) and the rate of congenital anomalies more than doubled (4/60, 6.7%) (Clausen et al., 2005, p. 323)” for women with T2D compared to women with T1D. In addition, “high initial HbA1C and T2D were independently associated with serious adverse outcomes (perinatal mortality and congenital anomalies)” (Clausen et al., 2005, p. 323). Historically, it was thought that high HbA1c levels were the cause of this difference. However, in this study, the women had comparable HbA1c levels to each other, those with T2D were even slightly better, suggesting that factors in addition to glycemic control impact pregnancy outcomes (Clausen et al., 2005). Thus the cause for these differences is not fully known and further research is warranted.

Two additional studies done in different parts of the world found similar results related to increased perinatal mortality and T2D. The first study showed high HbA1C and T2D to be related to increased rates of perinatal mortality (OR 5.3, 95% CI 1.5–19.0 and 3.4, 1.2–9.6, respectively) (Brydon et al., 2000; Dunne et al., 2000). Cundy and colleagues (2000) reported the perinatal mortality rate for women with T2D (46.1/1,000) to be threefold that of women with T1D (12.5/1,000), and pregnancies found to be complicated with T2D diagnosed during the pregnancy rather than prior to had poorer outcomes (Cundy et al., 2000). These studies report unknown causes for increased rates but speculate that obesity may be related.

Additionally, a systematic review of maternal and fetal outcomes in women with T1D and T2D reported that across the research, women with T2D compared to women with T1D had

lower HbA1c levels but higher risk of perinatal mortality [odds ratio (OR) 1.50, 95% confidence interval (CI) 1.15–1.96] (Balsells, Garcia-Patterson, Gich, Corcoy, 2009).

### **1.2.3 Racial differences for diabetes and pregnancy**

Diabetes is a public health crisis especially among AA women who have nearly twice the prevalence of T2D compared to Caucasian women (CDC, 2011). Furthermore, AA women have higher prevalence of pre-existing diabetes prior to pregnancy compared to Caucasian women (during study period prevalence almost tripled for AA women, from 0.96 (0.02) to 2.77 (0.04) compared to 0.61 (0.02) to 1.38 (0.03) for Caucasian) (Lawrence, Chen, Contreas, Sacks, 2008). AA women with diabetes have been found upon entrance to prenatal care to have higher initial HBA1C levels, or poorer glycemic control, compared to Caucasian women (8.7+/- 2% vs. 7.7 +/- 1.5%,  $P < 0.001$ ) (Holcomb, Mostello, & Leguizamon, 2001). Glycemic control is directly related to pregnancy outcomes with lack of glycemic control related to increased rates of congenital anomalies (Inkster, 2006).

Diabetes prior to conception has been established as one of strongest predictors of poor pregnancy outcomes among AA women. Diabetes was the second most important predictor (BMI 1st) of large for gestational age (LGA) infants, pre-term delivery, C-section delivery, admission to a neonatal intensive care unit, and perinatal death after CART analysis was performed with 17 predictors for nine adverse outcomes (Kiley, et al., 2011). In addition, AA women with diabetes were significantly more likely to have a preterm delivery (OR= 4.44, 95% CI: 1.90-9.93), and their infants were significantly more likely to have an admission to a neonatal intensive care unit (OR =5.40, 95% CI 2.25-12.56) (Kiley et al., 2011). Ehrental and colleagues (2007) published similar findings related to risk of preterm delivery among AA women with

diabetes. Additionally, Kieffer and colleagues (1998) reported that increased birth weight rates are much higher among AA women with diabetes when compared to Caucasian women with diabetes and women who do not have diabetes. For birth weight greater than 4,000 gms babies born to AA women with diabetes were nearly three times more likely compared to the general population while babies born to Caucasian women were nearly two times as likely (2.98 (95% confidence interval 2.89-3.12) for AA infants and 1.83 (95% confidence interval 1.78-1.89) for Caucasian infants). This is important because babies that are macrosomic, or have greater birth weights, are at increased risk for delivery complications (Kjos et al, 2001; Rudge et al., 2000).

#### **1.2.4 Preconception counseling**

The ADA and the American College of Obstetricians and Gynecologists (ACOG) recommends that PC should be introduced at puberty, and be given to all women with diabetes of childbearing age (ACOG, 2005; ADA, 2011). PC can and should be given by any health care provider who has interactions with childbearing women with diabetes (ADA, 2004). The goal of PC is to prevent congenital malformations by raising awareness about good metabolic control among women with diabetes. The goal for glycemic management is to achieve a hemoglobin A1C that is less than 1% above the normal range, comparable to the population without diabetes (ADA, 2007). A meta-analysis by Wahabi et al. (2010) reports that PC has shown to be effective in reducing rates of congenital anomalies, RR 0.25 (95% CI 0.15-0.42) in infants born to women with diabetes as well as reducing preterm delivery, RR 0.70 (95% CI 0.55-0.90), NNT = 8 (95% CI 5-23) and perinatal mortality, RR 0.35 (95% CI 0.15-0.82), NNT = 32 (95% CI 19-109).

Despite these positive findings, women with diabetes are not receiving PC. PC provision among women with diabetes has been documented at varying rates 26% (Dunne et al., 1999),

40% for women with T1D and 14% for women with T2D (Janz, Herman, Becker, & Charron-Prochownik, 1995), 28.7% for women with T2D vs. 40.5% for women with T1D;  $P < 0.05$  (Roland, 2005). Nearly two thirds of pregnancies among women with diabetes remain unplanned (ADA, 2011) compared with nearly half (51%) of all pregnancies in the U.S (Finer & Zolna, 2014). Hillman and colleagues (2006) reported only 16% of women with T2D and 22% with T1D ( $P = 0.175$ ) had received PC. None of these articles discuss why women do not receive PC or why more women with T1D compared to T2D receive PC. Hillman et al. (2006) does mention that women with T2D had a diagnosis of diabetes for a shorter duration but does not claim any causal relationships (5.7 □ 6 vs. 11.8 □ 7.1 years,  $P < 0.001$ ).

Janz and colleagues (1995) compared characteristics of women with T1D and T2D who received PC versus those who did not receive PC. Women who were less likely to seek preconception counseling did not graduate from college, were not married, were unemployed, had T2D, or were of a racial minority (Janz et al., 1995). More specifically, of those who had sought and received PC prior to their pregnancy, none were AA (Janz, 1995). Similarly, Holing and colleagues (2011) reported that women with diabetes who did not plan a pregnancy had considerably higher hemoglobin A1C levels at their first prenatal visit, were not married, were younger, had less education, and were less likely to be under the care of a diabetes specialist. In addition, women who experienced unplanned pregnancies were poorer, more likely to be a racial minority, less likely to have private health insurance, and had less connection with health care providers (Holing, Beyer, Brown, & Connell, 2011). Many of these factors represent health disparities experienced by many AA communities.

Reasons for women not seeking prepregnancy care, that includes PC, are reported by Murphy and colleagues (2010) and include: they conceived more quickly than they thought they

would (45%), they thought they would not get pregnant due to fertility issues related to high blood sugars (31%), they had experienced past negative encounters with health professionals (21%), they wanted to experience a normal conception/pregnancy experience (17%), and they had financial issues (10%). Additionally, health literacy is described as having a significant association with unplanned pregnancy ( $P = 0.02$ ) and lack of discussion with an endocrinologist or obstetrician ( $P = 0.01$ ) (Endres, Sharp, Haney, & Dooley, 2004). Another study revealed that young women with diabetes who had not planned their pregnancy did not consistently use birth control because they thought they would have difficulty conceiving (St. James, 1993). A qualitative study describing barriers to management of diabetes prior to pregnancy and included the following themes: accessing care and financial, healthy diet and exercise, lack of social support, difficulties with communication and diabetes care (Collier, 2011).

Holing and colleagues (2011) report that women with diabetes who had unplanned pregnancies were more likely to feel their doctors had discouraged pregnancy compared to women who had been told by their doctors about the possibility of having a healthy baby.

The strongest predictor for women to seek preconception care and plan their pregnancy was having been told by an OB/GYN health care provider (HCP) to seek PC, thus raising their awareness about PC (Janz et al., 1995). However, 30% of certified diabetes nurse educators (CDEs) report not routinely providing PC to their adult female patients and 40% have not provided PC to teenage patients (Michel & Charron-Prochownik, 2006).

### **1.2.5 Parish nurses**

Parish nursing, also known as faith community nursing, was initiated in the Chicago area by Reverend Dr. Granger Westberg in the 1980s. It has been a recognized nursing specialty since

1999. Parish nurses make the link between health and faith (Westberg, 1990); this includes: “the protection, promotion, and optimization of health and abilities; prevention of illness and injury; and responding to suffering in the context of the values, beliefs, and practices of a faith community” (American Nurses Association [ANA] & Health Ministries Association [HMA], 2012, p. 5). Parish nursing is an example of health practice rooted in the faith community, which bridges the gap between community, religion, and health. Parish nursing plays a critical role in providing education, health promotion, and disease prevention based on a holistic care model (King & Tessaro, 2009; O’Brien, 2014).

The main role of the parish nurses is to provide services that include health education and promotion, health counseling, referral agent, patient advocate, and referral agent. Parish nurses serve members of a faith community or church as well as members of the community. PNs are registered nurses that have five years of experience and complete a (40-hour) certificate program that utilizes the Foundations in Faith Community Nursing curriculum (ANA & HMA, 2012).

There are approximately 15,000 parish nurses in the US (IPNRC, 2011). Parish nurses are typically part of a health ministry in their church and nearly one third of churches have a health ministry (Catanzaro, Meador, Kuchibhatla, Clipp, 2007; Koenig, 2011). About 35% are in a paid position while the rest volunteer their practice (IPNRC, 2011).

A primary focus of the parish nurse model includes prevention and management of chronic disease at the community level (McGinnis & Zoske, 2008). Parish nurses know that chronic disease, particularly diabetes, is an important health issue for their patients (King & Tessaro, 2009; McGinnis & Zoske, 2008). Parish nurses are effective in providing health related education and interventions as evidenced by positive patient outcomes (i.e. increased physical activity, decreased blood pressure) related to diabetes, obesity, and other chronic disease (Garber

Mendelson, McNeese-Smith, Koniak-Griffin, Nyamathi, & Lu, 2008; White et al., 2006). Programs such as the Defy Diabetes Program, which used a chronic care model to teach healthy living to men and women (16% AA in group 1 and 2.7% AA in group 2) of all ages improved awareness of caring for health, follow-through with physician recommended testing, and influence on choice of healthy foods (Austin et al., 2013).

Clients' perceptions of parish nursing and care included being useful, meaningful, and effective (sample was comprised of two churches, one that was predominately AA and the other Caucasian) (Wallace et al., 2002). Interactions between the parish nurse and client included manner of care, focus of care, and achieved outcomes. In addition, characteristics of the setting of the nurse-client interaction were described including reflection of the connection of health and faith, time, convenience, and ambiance (Chase-Ziolek & Gruca, 2010). With proper training parish nurses can play a significant role in providing PC in the AA community.

### **1.2.6 Health care and health care providers in AA communities**

Low income African American women have limited access to health care and thus greater disease burden as evidenced by 30% higher death rates (nonspecific to diabetes) with a 2.3 AA/Caucasian ratio (MacDorman & Mathews, 2011). The literature suggests that individual as well community socioeconomic status (SES) are both independently associated with an increased risk for development of T2D among AA women when mediated by body mass index (BMI) “incidence rate ratios 1.28 (95% CI: 1.15, 1.43) for  $\leq 12$  years of education relative to  $\geq 17$  years, 1.57 (95% CI: 1.30, 1.90) for household incomes  $< \$15,000$  relative to  $> \$100,000$ , and 1.65 (95% CI: 1.46, 1.85) for lowest quintile of neighborhood SES relative to highest” (Krishnan, Cozier, Rosenberg, & Palmer, 2010, p. 564). Rationale for SES of communities

having a role in risk associated with diabetes relates to access to healthy foods and areas able to be utilized for physical activity (Auchincloss et al., 2009).

Community-based interventions targeting diabetes management and prevention have proven to have effective health outcomes in among AAs as well as other ethnic groups (Schulz et al., 2005; Two Feathers et al., 2005). Two Feathers and colleagues (2005) found a statistically significant ( $p < .0001$ ) decrease in HgbA1C levels among those who participated in a community-based culturally tailored diabetes lifestyle intervention compared to a group of patients with diabetes in the same healthcare system who did not receive the program. The Group Lifestyle Balance Program that was delivered by diabetes educators found significant weight loss (5.1%,  $P < .001$ ) among patients with diabetes (Kramer, McWilliams, Hsiang-Yu, Siminerio, 2011). These interventions are situated in settings more familiar to and convenient for the client, which enhances feasibility and outcomes (Schulz et al., 2005; Two Feathers et al., 2005). Learning about experiences of community members is essential in acknowledging ethnicity and culture as central components of research (Tillman, 2002).

In addition, healthcare workers located in the community are better able to better understand social, environmental, and political influences than individuals outside of the community (Owens et al., 2006). Due to unsuccessful traditional preconception care programs among high-risk women, using outreach and non-health related sectors should be considered for delivery of needed education in the clients' community. A stronghold among AAs is the faith-based community (Newlin, Melkus, Tappen, Chyun, & Koenig, 2011).

Studies have shown a positive relationship between health outcomes of AAs and participation in faith-based communities particularly with diabetes. Evidence has shown that religion and spirituality have a significant relationship with glycemic control ( $\beta = .289$ , SE =

.032,  $p = .028$  and  $\beta = -.358$ ,  $SE = .030$ ,  $p = .006$ , respectively) (Koenig, 2011; Newlin et al., 2008). Other successful programs have increased physical activity among women,  $t(17) = 2.29$ ,  $p < .05$  (Peterson & Cheng, 2011) and weight loss,  $p = .001$  (Hye-cheon et al., 2008). Of those who attend health promotion programs in the AA church 41.5% are women aged 18-49 (Odulana et al., 2014). AA women are reported to have the highest levels of “religious commitment compared to all other groups of men and women with 84% reporting religion is very important to them, and 59% report attending a religious service once a week” (PEW, 2009, Gender section). Furthermore, 76% of AAs aged 18-29 and 82% of AA’s aged 30-49 report an affiliation with a faith (Evangelical Protestant, Mainline Protestant, Historical Black Protestant, Catholic) (PEW, 2009). What is not evident in the literature is the percentage of women who report attending a religious service broken down by age as well as the percentage of AA’s who affiliate with a faith by age group further broken down by gender. Given that many AA women have a strong connection to their faith-based communities, the parish nurse is an excellent untapped resource for providing information and education around pregnancy and diabetes and PC.

Parish nurses can bridge the gap of lack of awareness of PC and limited access to healthcare for women with diabetes in their communities, especially in underserved AA communities. They can be a main health care contact, raising awareness of and providing PC to women with diabetes in an accessible faith-based location.

### **1.2.7 Gaps in knowledge**

The importance of PC and its profound impact on both maternal and fetal health is historically well documented (ADA 2004, 2011) as evidence by decreased rates of congenital anomalies (RR

0.25 (95% CI 0.15-0.42) (Wahabi et al., 2010). Despite these positive findings, PC is not being given by HCPs to women with diabetes with report of 30% of CDE's not routinely preconception counseling to their patients (Michel & Charron-Prochownik, 2006), especially AA women (Janz, 1995). There are few data explaining why AAs experience disparate rates of PC or literature describing barriers that they may encounter. A rationale for lower rates of both AA women receiving PC from their HCPs as well as seeking it also has not been reported. Furthermore, there remains a gap among literature discussing low rates of PC education for healthcare providers.

The literature describes women with T2D having worse outcomes compared to women with T1D but no studies have found cause for this difference. Likewise, the literature reports that women with T2D receive PC to a lesser degree than women with T1D but does not go as far as explaining the reasons for these differing rates.

Further investigation is needed to explore the role and proficiency of church health practitioners, such as parish nurses, who exist in the community to provide PC. Parish nurses who are uniquely situated in the community in a more trusting and consistent relationship compared to other practitioners have been underutilized to date.

Diabetes care for women, especially childbearing women, has made strides over the last decades with improvement of clinical guidelines, diagnostics, and treatment. However, more work needs to be done, particularly related to understanding why certain groups of individuals still do not receive care that has been proven through evidence to be crucial to improving maternal and fetal morbidity and mortality. We need to understand from the lived experience of both women who personify these disparities as well as those who care for them the barriers to meeting the needs of all stakeholders involved. To begin to fill these gaps we need to first

understand the experiences of parish nurses, many of whom provide health education to women in the communities in which they live and work.

### **1.2.8 Innovation and importance of proposed research**

This study is unique in that it explores the issue of the importance of community healthcare involvement in the delivery of culturally relevant PC for women with diabetes. In addition, this study begins to utilize community-engaged research to meet the initiatives of patient-centered outcomes research (PCOR), which seeks to include participants as part of the study implementation.

It first became evident through feasibility work (Devido, et al., 2012) and then later through the current study that parish nurses need to have a tailored PC training and education programs to increase their awareness and confidence level with diabetes and pregnancy and PC in order to deliver PC and meet the needs of women with diabetes in communities. By understanding the experiences and knowledge base of parish nurses regarding diabetes education, particularly related to pregnancy and PC, we can develop a tailored toolkit that can be utilized in the community setting to target underserved minority women.

Once these aims are accomplished the data will be used to inform the design and evaluation of a culturally sensitive community-engaged PC program that includes a training component for parish nurses, and a PC education program for AA childbearing women with diabetes. Based on the 2009 U.S. Census Bureau statistics, approximately 1,218,494 individuals resided in Allegheny County PA; 515,622 are between the ages of 18-49, and 12.9% were AA (approximately 66,515). Half of these AA individuals were females (33,258) (U.S. Census Bureau, 2009). According to the CDC (2011), 18.7% of AA women have diabetes. Therefore,

approximately 14,697 AA women who resided in Allegheny County have had diabetes and 6,219 would be between the ages of 18-49. In addition, there are 131 faith-based communities/churches in Pittsburgh alone that served AA individuals. Therefore, we expected our sample of parish nurses to have experience caring for a diverse patient population.

### **1.3 PRELIMINARY STUDIES**

As a Graduate Student Researcher on a funded NIH RO1 titled, “Reproductive Health Intervention for Teen Girls with DM” the PI became familiar with the data from the study and wanted to know more about PC communication between healthcare providers and teenage women, particularly AA teenage women. Therefore, the PI conducted a secondary data analysis of the data, which is described below. These data supported the goals of the PI’s research program related to understanding the role and experience of parish nurses in providing diabetes education to women with diabetes, particularly AA women because the results shows the connection between religion, decision making, and communication with health care providers.

1) “Characteristics of Young Women With Diabetes who Initiate Communication Regarding Preconception Counseling With Health Care Providers” Authors: Jessica Devido, MSN, CPNP, RN, Susan M. Sereika, PhD, Susan Cohen, PhD, CRNP, FAAN, Denise Charron-Prochownik, PhD, RN, CPNP, FAAN

The purpose was to examine the relationship between internal characteristics (age, race, and religiosity), external characteristics (sexual activity status, social support, type of routine

health care provider) and intention to communicate and actual communication with health care providers about PC among adolescent females with diabetes. This secondary analysis used baseline data (longitudinal study with multiple data collection points) from Dr. Denise Charron-Prochownik's study (Charron-Prochownik, Ferons-Hannan, Sereika, & Becker, 2008) of 110 female adolescents (92% T1D who participated in a PC intervention study called READY-Girls. Participants came from two study sites. Statistical analysis included descriptive statistics and multiple regression. Subjects' ages ranged from 13.28 to 19.95 years, 81.8% were Caucasian, 80% had never been sexually active, 58% had perceived low to moderate amounts of social support, and the pediatrician was reported as the HCP most frequently used. Only race and religiosity had an interaction effect with actual communication ( $p=.046$ ,  $B=2.706$ ). AAs who reported that religion had a moderate to large impact on their decision whether or not to engage in sexual activity had initiated more actual PC communication with a HCP when compared to Caucasians. Race and religiosity appeared to correlate to adolescent girls with diabetes initiating communication regarding PC with HCP. Therefore, these characteristics should be considered when providing PC. Religious beliefs were associated with increased communication between teen and provider among AAs. Therefore, we need to educate the HCP to empower young women to initiate communication about PC to their HCP. Further research with a larger more diverse sample is warranted to confirm these results. This manuscript is ready for submission. (see Appendix I)

Additionally, we wanted to ensure the feasibility of the current study design as well as effective recruitment strategies and data collection methods. So, a feasibility study described below was carried out in order to prove the effectiveness of these proposals.

2) “Using Parish Nurses to Deliver Diabetes Education/ Preconception Counseling To African American Women: A Mixed-Method Feasibility Study” (PI Jessica Devido). The purpose of this study was to investigate the feasibility of utilizing a mixed-methods study to explore the experiences and knowledge of parish nurses regarding diabetes education and PC. Components of feasibility included recruitment and attendance. A mixed-methods concurrent embedded design was utilized with focus groups and a cross-sectional quantitative descriptive design using three self-report measures with 6 PNs (33% serving primarily AA congregants). Parish nurses were not aware of PC, felt that it was important, and would provide it to their patients with diabetes if they had the resources (tools). Knowledge of diabetes and pregnancy and PC was low and self-efficacy was moderate. These results provide rationale for a larger cohort of parish nurses to further confirm these findings. The study was supported with funding from UPMC Diabetes Appropriations for DoD USAARMAA. Results were presented at the 2012 ENRS 24th Annual Scientific Session in New Haven, CT (see Appendix J).

### **1.3.1 Publications relevant to proposed research**

#### **Published Abstracts**

**Devido, J.A.**, Downs, J.S., Bruin de Bruin, W., Moltz, K.C., Charron-Prochownik, D. (2010). Awareness of pregnancy and preconception counseling among African American teens with diabetes. *Diabetes*, 50 (suppl.) A276.

#### **Oral Presentation**

**Devido, J.**, Bernardo, L Rodgers Fischl, A., Rogers Schubert, M., Cooper, L., Charron-Prochownik, D. Integrating Preconception Counseling into Clinical Practice with an On-line Education Program for Health Professionals. Third National Summit on PC Health and Healthcare. Tampa, FL June 12-14, 2011.

## **Poster Presentations**

### **Local**

**Devido, J.A.**, Downs, J.S., Bruin de Bruin, W., Moltz, K.C., Charron-Prochownik, D. (2010). Awareness of pregnancy and preconception counseling among African American teens with diabetes. School of Nursing Scholarly Presentations Symposium, February 4, 2011, University of Pittsburgh School of Nursing, Pittsburgh, PA.

**Devido, J.A.**, Mayernik, D., Dorman, J., Doswell, W., Braxter, B., Terry, M., Charron-Prochownik, D. Using Parish Nurses to Deliver Diabetes Education/ Preconception Counseling To African American Women: A Mixed-Method Feasibility Study. The 2nd Annual Scholarly Poster Presentation Symposium, September 7, 2013, University of Pittsburgh School of Nursing, Pittsburgh, PA.

**Devido, J.A.**, Mayernik, D., Dorman, J., Doswell, W., Braxter, B., Terry, M., Charron-Prochownik, D. Using Parish Nurses to Deliver Diabetes Education/ Preconception Counseling To African American Women: A Mixed-Method Feasibility Study. STTI Eta Chapter Annual Scholars Night, March 18, 2013, University of Pittsburgh School of Nursing, Pittsburgh, PA.

**Devido, J.**, Doswell, W., Braxter, B., Dorman, J., Terry, M., Charron-Prochownik, D. (2013). Parish Nurses' Perspectives on Diabetes Education/Preconception Counseling for African American Women: A Turning Point. The 3rd Annual Scholarly Poster Presentation Symposium, November 25, 2013, University of Pittsburgh School of Nursing, Pittsburgh, PA.

**Devido, J.**, Doswell, W., Braxter, B., Dorman, J., Terry, M., Charron-Prochownik, D. (2013). Parish Nurses' Perspectives on Diabetes Education/Preconception Counseling for African American Women: A Turning Point. STTI Eta Chapter Annual Scholars Night, March 26, 2014, University of Pittsburgh School of Nursing, Pittsburgh, PA.

### **National**

**Devido, J.A.**, Downs, J.S., Bruin de Bruin, W., Moltz, K.C., Charron-Prochownik, D. Awareness of pregnancy and preconception counseling among African American teens with diabetes. American Diabetes Association 70th Scientific Sessions, June 25-29, 2010, Orlando, FL. Poster Accepted for moderated tour session, 1 of 10 chosen.

**Devido, J.A.**, Mayernik, D., Dorman, J., Doswell, W., Braxter, B., Terry, M., Charron-Prochownik, D. Using Parish Nurses to Deliver Diabetes Education/ Preconception Counseling To African American Women: A Mixed-Method Feasibility Study. Eastern Nursing Research Society (ENRS) 24th Annual Scientific Sessions, March 28-30, 2012, New Haven, CT.

**Devido, J.**, Doswell, W., Braxter, B., Dorman, J., Terry, M., Charron-Prochownik, D. (2013). Parish Nurses' Perspectives on Diabetes Education/Preconception Counseling for African

American Women: A Turning Point. American Association of Diabetes Educators Annual Meeting and Exhibition, August 7-10, 2013, Philadelphia, PA.

## **1.4 RESEARCH DESIGN AND METHODS**

The methods outlined in this section are proposed methods for the dissertation. Adjustments or changes made to the proposed methods are detailed in the study summary section.

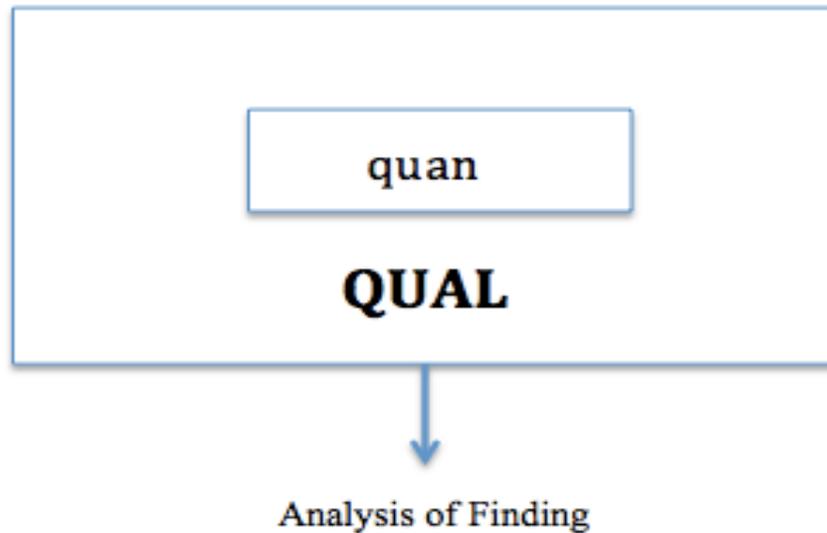
### **1.4.1 Study design**

A mixed-method concurrent embedded design was proposed to best accomplish the aims of the study. Qualitative inquiry was the primary method (i.e. focus groups) and quantitative inquiry as the secondary method (i.e. quantitative descriptive using demographic, PC self-efficacy, and PC knowledge measures) (see Figure 1). The primary method serves to guide the project while the secondary method serves in a supporting role. A concurrent qualitative/quantitative design ensured that the data were complementary and complete (Greene, Hare, Cloherty, Benacerral, & Soddner, 1989; Happ, Dabbs, Tate, Hricik, & Erlen, 2006) and allows for an integration of data that can provide an overall broader assessment of the data and enriches description (Creswell, 2009). The goal of this approach was to explore the experiences of parish nurses in providing diabetes education and PC to women (especially AA women) with T1D and T2D and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes using quantitative and qualitative methods to attain a deeper understanding and to triangulate information from multiple sources of data (Greene et al., 1989; Happ et al., 2006).

The **primary aim** of this study was accomplished using a qualitative approach with focus group methodology to explore the parish nurses' experience with educating and providing PC to women of childbearing age with T1D and T2D and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes for women, especially AA women, with diabetes. This approach aided in identifying attitudes towards delivering PC to women with diabetes.

A qualitative approach provides detail-rich data that allow for a fuller description of knowledge and experiences that cannot be derived from other methods (Sandelowski, 2000). The focus group structure promotes openness and disclosure by participants about the topic (Krueger, 1994; Wilkinson, 1998). The focus group methodology was chosen in order to gain a better understanding of the participant's lifeworlds (Wilkinson, 1998,). In other words, it gives us the ability to understand the experiences and activities that guide perceptions and understandings of the parish nurse. This methodology is appropriate when a goal of research is to understand the complex mix of attitudes, knowledge, and past experiences of the participants (Morgan & Krueger, 1998). It is an effective tool for exploration of attitudes, beliefs, and intervention development (Carey & Smith, 1994; Denning & Verschelden, 1993).

The **secondary aim** of this study used a quantitative approach with a descriptive design to examine parish nurses' level of knowledge of diabetes as it relates to diabetes and pregnancy outcomes and PC and teaching self-efficacy as it relates to diabetes, pregnancy and PC.



**Figure 1.** Concurrent Embedded Design

Permission granted for use of figure by Sage Publishing and author John Creswell (Creswell, 2009).

#### **1.4.1.1 Measures for the quantitative approach**

A descriptive design was utilized to administer three pencil-and-paper measures to participants prior to each focus group session. The first measure, “Preconception Counseling Knowledge for Certified Diabetes Educators” (Cothran et al., 2009) (see Appendix B) measures the level of knowledge the nurses possess as it relates to diabetes and pregnancy and PC content. It consists of 25 true-false questions and is scored by calculating the percentage of correct answers (score range from 0-100). Questions left unanswered are counted as incorrect. The measure has

content and face validity as it was adapted from several previously validated diabetes and pregnancy and PC knowledge measures (Pregnancy and Attitudes Scale) with additional questions developed from recommendations of the ADA on PC care of women with diabetes (Cothran et al., 2009).

The second measure, “PC Self-Efficacy for CDEs” (Cothran et al., 2009) (see Appendix C), a validated measure of self-efficacy, has been adapted for parish nurses. This measure consists of 17 11-point Likert-type scaled items, where 0 was labeled “not at all confident” and 10 was labeled “absolutely confident.” Possible score range is from 0-170. Higher scores indicate greater self-efficacy. This measure was given to gain an understanding of the parish nurses’ level of confidence to provide education about diabetes and pregnancy and PC. A panel of experts evaluated the measures for content validity and included the original theorist, Bandura. Bandura (1977) reviewed this measure for content validity. Items were retained based on theoretical decisions. Internal consistency reliability was measured with a Cronbach alpha of .65.

The third measure, “Reproductive Health Program for Women With Diabetes Sociodemographic Questionnaire,” (see Appendix A) was investigator developed for the study. The original questionnaire included nine questions and collected demographic data related to the parish nurse participants including: age, race, gender, highest level of nursing education, year of RN licensure and PN certificate, most prevalent aspects of role of parish nurse, most prevalent medical conditions of their parishioners, race percentage, female percentage, childbearing age percentage, diagnosis of diabetes percentage, and income level. Changes to this measure are described in the proposal changes section.

## **1.4.2 Procedures**

Prior to recruitment activities, IRB approval was sought and given as exempt. The IRB at the Catholic Hospital that houses the parish nurse program office that was utilized for the study required changing the terminology “birth control methods” to “birth regulation methods” on the measures in order to uphold ethical and religious directives of the Catholic moral teaching.

### **1.4.2.1 Setting**

Participants were recruited from a Parish Nurse and Health Ministry Program database which contains an estimated 900 parish nurses mainly from the Pittsburgh and surrounding areas in western Pennsylvania and also parish nurses from programs in other states including: Florida, Ohio, New York, and Arizona.

Location of focus groups was determined by service areas of participants’ PN practice for convenience of the participants and to encourage maximum participation (Wilkinson, 1998). This also included offering focus groups of a distance nature, those that were teleconference-based or webex format. Methods such as these allow for those participants whose location and/or schedule precludes them from joining physically and to engage a more geographically diverse sample (Cooper, Jorgensen, & Merritt, 2003; Hurworth, 2004). Focus groups that contained a distance format were limited to no more than five participants in order to allow for greater in-depth discussion. Size limitation is consistent with evidence suggesting that focus groups utilizing teleconference allow for the most meaningful interactions when kept small (Krueger & Casey, 2009).

### **1.4.2.2 Enrollment procedures**

The parish nurse and health ministry program that was utilized is a 34 hour, four day CE program that teaches nurses to help those with problems that affect the health of the body, mind, and spirit through counseling, referrals, and education programs that encourage a healthy lifestyle.

The former manager of the parish nurse and health ministry program that was utilized for the study acted as honest broker and assisted with recruitment. Potential participants (900) were contacted via email by the honest broker. The email described the purpose and procedures of the study and directed those interested to contact the PI via email or telephone. The honest broker followed up the second round of the recruitment email with a phone call to those potentially interested. Once participants contacted the PI they were asked their preference for location and time of focus groups. Location and time were chosen to fit the largest majority's requests.

### **1.4.2.3 Inclusion and exclusion criteria**

#### **Inclusion**

Eligible participants for both the qualitative and quantitative phases were parish nurses who:

- 1) had a nursing license (LPN, RN) or advanced degree (MSN, DNP, PhD);
- 2) practiced in a faith community setting;
- 3) functioned as a parish nurse (certification not required).

#### **Exclusion**

The exclusion criterion was inability to speak, read, or understand English. All questionnaires were in English; therefore, only English-speaking participants were recruited.

#### **1.4.2.4 Participants and sampling**

The PI proposed to conduct a minimum of 10 focus groups due to the large pool of participants available with six to twelve individuals in each (Krueger, 1994). The sample size was driven by the qualitative results, meaning when data saturation occurred, or no new data were emerging, recruitment and data collection concluded. Purposive sampling was used for recruitment to obtain broad representation. Parish nurses (estimated 900) who were part of the parish nurse database and met eligibility criteria were invited to participate in both the focus group and measurement data collection. Recruitment of the sample met the expectations of the proposed timetable (see table 1).

A total of 60 participants replied to the recruitment email for a response rate of 6.6%. Forty-eight of the 60 participants enrolled in the study after confirming a focus group date for an enrollment rate of 5.3%. There were a total of 11 focus groups/quantitative data collection times (including one feasibility focus group) with two to eight individuals in each between the dates of August 7, 2012, and September 4, 2013.

Five of the focus groups were conducted with participants on-site. Four of these were conducted at a parish nurse and health ministry program office and one took place at a church convenient for participants in northwestern, PA. Two of the focus groups involved both participants on-site as well as conference call. The four final focus groups were conducted via webex with PNs were Florida, Ohio, New York, and Arizona. Focus groups were conducted until saturation was reached in the data analysis and no new information was collected (Baum, 1998). This occurred at 48 subjects with eleven focus groups.

#### **1.4.2.5 Data collection procedures**

The PI distributed and collected the three paper-and-pencil measures to focus group participants prior to group sessions. PNs who were participating via a distance method were emailed the measures and asked to complete them prior to the start of the focus group. The participants either faxed or mailed back, based on their preference, the completed measures within the following week.

The PI conducted all focus groups as the facilitator with training from co-mentor Dr. Martha Ann Terry, which included formal coursework and practicum experience. Competency was achieved through practice and critique by the mentor. All focus groups were doubly digitally recorded using two different digital recorders with access to a back-up digital recorder and additional batteries. When possible, notes were taken by a second researcher in order to capture observations about the participants as well as to provide back up to the digital recorders (Krueger, 1994). Focus groups were conducted until saturation was reached in the data analysis and no new information was collected (Baum, 1998) (see project timeline, Table 1).

A structured focus group guide (see Appendix D) was developed and utilized to elicit and refocus the group discussion of parish nurses' experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes. However, the participants ultimately guided the discussion (i.e., concepts/new ideas brought up by the participants were investigated) (Krueger & Casey, 2009).

Participants received breakfast/lunch, diabetes education materials (booklets, brochures) to give to their patients, and free access to an online preconception counseling CEU program "Preconception Counseling for Adolescent and Adult Women with Diabetes" valued at \$80.

Currently, the program is set up to receive the four (4) contact hours participants must review the content, pass the test within two attempts with a 80%, and complete the evaluation for each module (Cothran, Sereika, Fischl, Schmitt, & Charron-Prochownik, 2009). To date three of the parish nurses have completed the CEU program; however, participants were notified when they received their voucher for the program that there was no expiration date, so it is possible that more may complete the program in the future.

#### **1.4.2.6 Data management**

All recordings were transcribed, and transcription was compared to the original recordings to ensure accuracy and add contextual clarification. All transcripts were stored in password-protected files on a computer, which only the research staff could access. Each participant was assigned a unique identifying number that corresponded to responses to focus group questions allowing for identification of a new speaker. For the quantitative measures, participants were assigned a unique identifying number. Original completed measures were stored in a locked drawer in the PhD office space and digital files of the data were stored on a password protected computer.

#### **1.4.2.7 Data analysis**

##### **Data analysis procedures**

##### **Primary Aims-Qualitative**

**Aims 1:** To qualitatively explore parish nurses' attitudes about and experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women.

**Aim 2:** To qualitatively explore parish nurses' understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women.

Qualitative content analysis, which offers an accessible and theoretically flexible approach, was chosen as the data analysis method for this aim. It was chosen in order “to provide a rich thematic description of the dataset” (Braun & Clarke, 2006, p. 86). An inductive approach was utilized in order to identify themes that are strongly linked to the data and not driven by a particular theory or theoretical interest area (Braun & Clarke, 2006). Analysis began after the first focus group was conducted and transcribed.

The process of collecting, coding, and analyzing data occurred simultaneously. Immersion in the data occurred by reading through a transcript several times in order to get a sense of the whole, and to search for patterns and meanings. Notes for ideas about coding occurred at this time (Braun & Clarke, 2006). The data were analyzed in naturally occurring units of meaning in the text. Based on the unique units of meaning that emerged from the discussion, initial codes were developed related to understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women. Coding was based on the repetition of specific words, phrases, and opinions; the use of language and general thought patterns, and topics generated during the focus group discussion. Through constant comparison, codes were applied to text where relevant. The PI shared the codebook and uncoded transcripts with M.A.T, who independently coded the same transcripts. Each interview was reviewed and discussed and agreement on the coded transcripts was reached through discussion and consensus coding was applied. The code list and definitions evolved and were refined with the coding process of each interview. When necessary new codes were created. This review process reduces bias and promotes consistency in the analysis of the data (Krueger, 1994; Morgan ed., 1993). Through constant comparison, codes were applied to text where relevant.

The data were then looked at from a broader level of themes emerging from the codes. In some instances several codes comprised a theme, where in others a single code might represent a theme (Braun & Clarke, 2006). A set of candidate themes was derived from the data and were reviewed and refined (possible removal or collapsing) related to understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women.

ATLAS.ti (7.1.7) was utilized for data management, as it allows for systematic organization of uploaded transcripts, and supports efficient data management and analytic queries. Use of the software provided easy access to text based on themes.

## **Secondary Aim-Quantitative**

### **Data Screening Procedures**

All forms were pre-coded to minimize coding errors. During data collection, forms were screened upon receipt for completeness of response. Data were then screened for accuracy, which included proofreading and range checking. Questionable values were reassessed. Continuous data screening assessed means and standard deviations, and for categorical data modes and medians were assessed. Next, outliers were assessed both univariately and bivariate. Techniques for assessment of outliers included: frequency screening (categorical), histograms, z scores, boxplots, normality probability plots, bivariate scatterplots, and mahalanobis distances (continuous). There was one subject considered to be an influential bivariate outlier when observing the scatterplot and then performing the analysis (Pearson Correlation) with and without the outlier. Ultimately, her data remained in the analysis as it was considered valid.

The number and patterns of missing data were assessed. Missing data were found to be missing at random. One subject did not complete the Knowledge and Self-Efficacy measures. Two additional subjects completed either the Knowledge or Self-Efficacy measures but not both. A mean of the subject's responses was computed and imputed for the missing item to calculate a total score as a strategy to handle the missing data point.

The demographic data measure was complete for 39 of the 48 subjects prior to the addition of demographic questions related to PNs' congregations (this addition is discussed in the proposal changes sections). After the additional demographic questions were added, 28 participants had complete data. Some of the nurses felt that they did not know the answers to some of the demographic questions or because they felt these five questions did not apply to them because of their current role as a parish nurse so they left them blank. T-tests and Chi Square tests were run between the groups of those who had present data vs. those that did not in order to ensure there were no differences between the groups. For the continuous variables (year of RN licensure and year of PN certificate) T-tests were performed and found that there was no statistically significant difference between groups,  $p=.075$  for year of PN licensure, and  $p=.605$  for year of RN licensure. The mean year of PN certificate was 2009 (3.777) for those who did not respond and 2007 (4.509) for those who did respond. The mean year of RN licensure was 1976 (7.411) for those who did not respond and 1975 (9.292) for those who did. For the categorical variables (age, race, and level of education), Fisher exact test were performed and found that there was no statistical difference ( $p=.883$  age,  $p=.251$  race,  $p=.220$  level of education) between those that had missing and those that had present data Descriptive analysis were performed on all available data.

Additionally, Pearson Correlation was performed to assess independence of observations. To ensure independence of observations one sample of parish nurses was studied at one point in time. Normality was assessed by observing for skewness (symmetry), kurtosis (peak), and Shapiro-Wilks. Finally, linearity was assessed with bivariate scatterplots.

### **Descriptive Statistics**

Descriptive statistics were computed using SPSS (version 20.0, IBM, Inc., Chicago, IL) for continuous variables including: knowledge (ratio), self-efficacy (approximately interval, (highly ordinal), and age (ratio). Statistics included: central tendency, mean, median, dispersion, standard deviation, range, skewness and kurtosis. Categorical variables included: gender (nominal), race (nominal), level of education (ordinal). For nominal data frequencies, percentages, modes, and ranges were computed. For ordinal data medians and inter-quartile ranges were computed.

### **Statistical Procedures**

**Aim 3:** To quantitatively examine parish nurses' knowledge of diabetes as it relates to pregnancy and pregnancy outcomes and PC.

Data analysis included the variables of age, gender, race, level of education, and knowledge. Descriptive statistics were used to explore and describe the data.

### **Statistical Procedures**

**Aim 4:** To quantitatively examine parish nurses' teaching self-efficacy as it relates to diabetes, pregnancy and PC.

Data analysis included the variables of age, gender, race, level of education, and self-efficacy. Descriptive statistics were used to explore and describe the data.

### **Statistical Procedures**

**Exploratory Aim:** To explore the association of knowledge and self-efficacy of parish nurses as they relate to diabetes and pregnancy and PC.

For the exploratory aim data analysis included the variables of knowledge and self-efficacy. Pearson product-moment correlation was performed to provide direction and strength of association, confidence intervals for the correlation for estimation were observed.

### **Internal Consistency Measures**

In order to determine the proportion of total shared variance in each of the measures utilized in this study a reliability assessment was conducted. For the “PC Self-Efficacy for CDEs” measure which consists of items with an ordinal level of measurement Cronbach’s coefficient alpha was obtained. The Kuder-Richardson 20 formula (KR-20) was used for the “Preconception Counseling Knowledge for Certified Diabetes Educators” measure as this scale had dichotomous T/F items (Pett, Lackey, & Sullivan, 2003). The overall reliability as well as the reliability if an item was deleted were examined.

#### **1.4.2.8 Potential limitations/strategies to address**

One of the main limitations is that the sample was obtained from contacts of a single parish nurse organization with subjects mainly from western Pennsylvania. Therefore, the study findings may be more related to the experience of the participants from these areas and not necessarily be representative of parish nurses across the country. To minimize this bias purposive sampling

was utilized to maximize variation of study participants. Furthermore, given the large sample pool of parish nurses in this organization, broad representation was achieved. Another limitation was the cross-sectional nature of this study, which did not permit test-retest reliability on the quantitative measures. Additional data collection points would have been preferred. Finally, the sample was a religious-based group and because of that may be limited in regards to what education they provide. Some PNs may have restrictions placed upon them for comprehensive PC, which includes a range of birth control methods. The participants were open and honest and one PNs’ response reflects this idea; “...depending on your faith traditions, what you could not discuss in relationship to contraception or family planning becomes an issue.”

Despite these limitations, strengths of the study include the mixed-methods design, which provide a broader understanding of the topic than a single method alone. To our knowledge, this comprehensive approach of data collection is the first study to describe PNs experiences, understanding, knowledge, and confidence related to diabetes involvement with pregnancy and PC. The quantitative data serves to enrich the description of the knowledge and confidence of the PNs related to pregnancy and PC. In addition, this study begins to utilize community-engaged research to meet the initiatives of PCOR, which seeks to include participants as part of the study implementation.

**Table 1: Originally Proposed Project Timeline**

	Months 1-3	Months 3-10	Months 10-16	Months 16-20
Recruitment	X	X		
Data Collection	X	X		
Data Analysis		X	X	
Reports and Publications				X

## **1.5 RESEARCH PARTICIPANT RISKS AND PROTECTIONS**

### **1.5.1 Risks to human subjects**

This mixed-methods study enrolled parish nurses. As per inclusion and exclusion criteria, participants 1) had a nursing license LPN, RN, or advanced degree; 2) practiced in a faith or community setting; 3) functioned as a parish nurse (certification not required), 4) were English speaking.

All potential subject members of a parish nurse and health ministry program database were contacted via email and given the opportunity to participate. Potential participants who responded to the initial email were then given options for a potential date and time of focus group if they chose to participate. An honest broker was utilized to contact the potential participants. Due to the exempt nature of the study, participation in the focus group acted as consent.

After the introduction of the study with description of consent as mentioned above, the following data were collected from participants: written personal demographic information (see Appendix A), written demographic information about those whom they serve (see Appendix A), knowledge related to diabetes and pregnancy and preconception counseling (see Appendix B), confidence related to providing information about diabetes and pregnancy and preconception counseling (see Appendix C), and audio-recorded and transcribed interview data pertaining to the experience of parish nurses in providing diabetes education and PC to women (especially to AA women) with T1D and T2D; and description of the parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC. Only the PI had access to personal

identifiers linking the participant to study data after enrollment. Protection of this information is described below. There were no risks of participation in the study.

### **Source of Materials**

The audio recordings of the parish nurse focus groups were transcribed. As the PI on the study, the applicant was named so on the IRB application. Due to the exempt nature of the study, participation in the focus group acted as consent.

### **1.5.2 Adequacy of protections against risks**

Measures to protect participant privacy and confidentiality are described in the data management section, and included assigning all participants a pseudonym used on all documentation in lieu of actual names, storing contact information and linkage information of the participants in a password-protected, user-restricted computer file, and storing all other study materials in a locked drawer (accessible only to the PI) within a locked room (the PhD student office area).

Participants were given verbal reminder prior to the start of the focus groups that during the course of the study, if they became uncomfortable they could exit the study at any point in time.

### **1.5.3 Potential benefits of the proposed research to human subjects and others**

There are no known direct benefits to the participants.

#### **1.5.4 Data and safety monitoring plan**

The audiotaped and descriptive data were used solely for the purpose of this study and was safeguarded by the PI and her committee. All data were identified by unique numeric identifier that was assigned to the participants of the study. The PI met regularly during active data collection with the dissertation chair and the qualitative methods expert committee member, in order to review aspects of data collection and analysis and any other pertinent issues that arose. There were no changes that needed to be discussed or instituted.

#### **1.5.5 Inclusion of women and minorities**

Women and minorities were not excluded from this study. Because this study is investigating parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC, men and women of all races who are parish nurses had the opportunity to participate. Participation in this study was 100% female. The study was representative of the PN database as the vast majority of them are female. African American PNs accounted for 17% of the sample. (See Table 2).

#### **1.5.6 Inclusion of children**

Children ages 18-21 were not enrolled in this study. The purpose of the study was to focus on experience, understanding, knowledge, and self-efficacy of PNs', therefore the sample targeted only participants older than 21 years of age.

**Table 2: Total Planned Enrollment**

**Total Planned Enrollment:** 48 nurses

<b>TARGETED/PLANNED ENROLLMENT: Number of Subjects</b>			
<b>Ethnic Category</b>	<b>Sex/Gender</b>		
	<b>Females</b>	<b>Males</b>	<b>Total</b>
Hispanic or Latino	0	0	0
Not Hispanic or Latino	41	0	41
<b>Ethnic Category: Total of All Subjects *</b>	41	0	41
<b>Racial Categories</b>			
American Indian/Alaska Native	0	0	0
Asian	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0
Black or African American	7	0	7
White	41	0	41
<b>Racial Categories: Total of All Subjects *</b>	41	0	41

\* The "Ethnic Category: Total of All Subjects" must be equal to the "Racial Categories: Total of All Subjects."

## 2.0 STUDY SUMMARY

The **purpose** of this community-engaged mixed-methods study is to describe the parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC based on quantitative data, and to explore the experiences of parish nurses in providing diabetes education and PC to women (especially to AA women) with T1D and T2D using focus group methodology.

The **primary aim** of this study was accomplished using a qualitative approach with a focus group methodology to explore the parish nurses' experience with educating and providing PC to women of childbearing age with T1D and T2D and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes for women, especially AA women, with diabetes. This approach aided in identifying attitudes towards delivering PC to women with diabetes.

The **secondary aim** of this study used a quantitative approach with a descriptive design to examine parish nurses' level of knowledge of diabetes as it relates to diabetes and pregnancy outcomes and PC and teaching self-efficacy as it relates to diabetes, pregnancy and PC. This approach aided in identifying content and skills needed, and barriers to delivering PC to women with diabetes.

Two manuscripts, directly related to these aims, are included in the following chapters. The first manuscript, formatted for the Diabetes Educator Journal, is the main results paper reporting the mixed-methods study findings. It focuses on the purpose of the study as well as

addresses the specific aims. The second manuscript, formatted for the Journal of Nursing Scholarship, reports additional qualitative data related to the role and practice of the parish nurse that are in addition to the qualitative findings in the first manuscript.

## **2.1 PROPSAL CHANGES**

Once data collection began, it was realized that the participants were providing a great deal of data about their parishioners. It was determined at that time to add five questions pertaining to the people in the congregations of the parish nurses. These questions asked about: race percentages, female percentages, childbearing age percentages, diagnosis of diabetes percentages, and income level. The last 24 subjects received these additional questions, while the previous 24 subjects were re-contacted to complete the measure once the IRB gave approval. Fourteen of these participants responded, eight were able to complete the questions after they were re-contacted while six felt these additional five questions did not apply to them because of their current role as a parish nurse program coordinator. The remaining ten did not complete the additional questions due to inability to contact them or because they did not respond.

Additionally, distance focus groups were incorporated to expand recruitment to accommodate more participants. This addition did not change the way in which the focus groups were conducted. With adding the element of technology, the facilitator had to be aware that issues could arise in order to work through any problems. There were no major problems to report. There were no obvious differences in qualitative results comparing focus groups data of onsite groups vs. those that incorporated distance methods.

## 2.2 STUDY RESULTS

### 2.2.1 Demographic

The sample of parish nurses (n=48) was 100% female and 83% Caucasian. Fifty percent of the sample was between 51 to 60 years old. Ninety-six percent were RNs, and the majority of those had a BSN degree or higher. The participants had obtained their nursing education on average 38 years ago (range 17-58 years) and their parish nurse education five years ago (range less than one year-18 years) (see Table 4). Additionally, there was no statistically significant difference between demographics of PA participants vs. out of state (OOS) participants when performing t-tests (p=.872 year of RN licensure, p=.390 year of PN certificate) or fisher exact tests (p=.641 age, p=.088 race, p=.276 highest level of RN education).

The majority (75%) of the sample reported having AA congregants in their church with a range of 0-100%. Overall, 65% of the congregants were reported to be female, 29% to be of childbearing age (100% of the PNs have percentage of childbearing women present), and 23% to have a diagnosis of diabetes. In addition, 13% of the sample reported having congregants in their church with a yearly income of less than \$15,000 (range of PNs with congregants at this yearly income 0-75%), which is just below the federal poverty level for a family of two.

### 2.2.2 Qualitative

In total, seventeen qualitative themes emerged from the data.

**Specific Aim 1:** To qualitatively explore PNs' experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women.

There were 6 themes that emerged that provided detail rich information about the experience of the parish nurse related to their practice and programs including diabetes education. Additionally, there were 8 themes emerged that described the PNs lack of experience with educating and providing PC to women of childbearing age with DM, including AA women.

**Specific Aim 2:** To qualitatively explore PNs' understanding of diabetes as it relates to pregnancy and pregnancy outcomes.

There were 2 themes that emerged related to the PN's understanding of diabetes as it relates to pregnancy that describe the PNs lack of awareness of PC and lack of confidence to provide PC.

## **Themes**

### **Role**

PNs describe their role to include that of a facilitator, advisor, and educator through direct and indirect care. They express that a diagnosis or health concern like diabetes often is not revealed until the patient is experiencing a problem that he/she would like advice or help with. They provide more holistic comprehensive care.

### **Approach**

PNs describe their approach as being more complete than traditional nurse-patient relationships because their care includes the body, mind, and spiritual health. The patients are in a familiar comfortable setting so it allows the establishment of trust between the PN and patient. The PNs see themselves in a supportive role, and they integrate spirituality into their practice.

### **Challenges**

The PNs also described some of the challenges they face including isolation. Therefore, their relationships with other PNs are very important. They also describe challenges their patients face such as inequity.

### **Support Network**

Because of the PNs' isolation, mentioned above, a support network becomes very important. They also describe the need for support networks among their parishioners.

### **Practice and Programs**

The PNs described those for whom they care as well as those who attend their faith-based communities/churches who could be potential patients. Because of limited funding, their ability to seek additional continuing education may be reduced. The PNs described in detail the variety of programming that they conduct and offer to their patients in their practice. These included any health services, education, and resources they provided to their patients and can be direct or indirect.

### **Diabetes Practice and Programs**

The PNs also described the experiences they have had providing care for patients with diabetes. These included informal discussions and formal programs and incorporate those who are at risk for diabetes as well as those who already have a diagnosis.

### **Diabetes and Pregnancy and PC Practice and Programs**

The PNs noted that women of childbearing age were present in their churches. Because of that, there was an opportunity for education and counseling despite having had little to no care interaction, programming or education around pregnancy to date.

### **Awareness**

PNs reported that they were unaware of PC for women with diabetes. They expressed that they were familiar with the idea of preconception care unrelated to diabetes.

### **Experience**

Most PNs expressed that they were not currently providing formal diabetes education regarding pregnancy or PC to their patients with diabetes, and the majority had never provided it.

### **Formal Training**

Parish nurses reported having receiving very little to no education in their nursing training or PN training related to PC and had never received any PC education specific to women with diabetes.

### **Importance and Usefulness**

Despite never having had any training on PC or experience providing it, they feel that PC is an important topic and that it is beneficial for themselves as well as the childbearing women with diabetes in their community.

### **Willingness**

The PNs described that they are willing to provide PC to childbearing women with diabetes they will encounter if they had training and a tool to use.

### **Forming a Social Network of Wise Women**

The PNs described that the childbearing women in the church seek out and feel comfortable among peers and a network of “wise women”.

### **Confidence**

Currently, the PNs felt that their confidence to provide any education to childbearing women with diabetes was low.

### **Need for Training**

The PNs expressed an interest in receiving education to increase their awareness, knowledge, and teaching self-confidence related to PC and diabetes.

### **Recommendations for PC Training for PNs**

The PNs recommended a training component for learning the basics of diabetes and pregnancy and PC to obtain baseline knowledge and understanding.

### **Recommendations for PC Tool for Patients**

The PNs provide recommendations for a teaching program or education tool for PC to be used in their practice and described it as a toolkit.

## **2.2.3 Quantitative**

**Specific Aim 3:** To quantitatively examine PNs' knowledge of diabetes as it relates to pregnancy and pregnancy outcomes and PC.

Quantitative data showed PN's had low knowledge which supported their description of lack of awareness and experience with PC.

**Specific Aim 4:** To quantitatively examine PNs' teaching self-efficacy as it relates to diabetes, pregnancy and PC.

Quantitative data showed PN's had moderate levels of self-efficacy to provide PC which supported their description of lack of self-efficacy (confidence) to provide PC.

**Exploratory Aim:** To explore the association of knowledge and self-efficacy of PNs as they relate to diabetes and pregnancy and PC.

There was a positive correlation between PC knowledge and teaching self-efficacy (confidence) related to diabetes and pregnancy and PC. As PC knowledge increased PC teaching self-efficacy (confidence) increased.

The PNs' baseline knowledge scores about PC were low (mean= 65%, range= 40-100%). Only two of the participants were LPNs, with PC knowledge scores above the mean of the group despite having less formal education than the RNs. The parish nurses only had moderate levels of self-efficacy (mean= 99, range = 27-164), which supports the qualitative data on confidence. Additionally, there was no statistical difference in knowledge and self-efficacy scores between participants from PA and those from OOS when performing t-tests ( $p=.656$  knowledge,  $p=.957$  self-efficacy). Self-efficacy had a significant positive association with knowledge (Pearson  $r = .292$ ,  $p = .05$ ). For every one unit increase in knowledge, self-efficacy score increased by .03.

Forty-five participants had complete data on the "PC Self-Efficacy for CDEs" measure. All 17 items were included in the analysis. The overall Cronbach's alpha of the "PC Self-Efficacy for CDEs" measure was  $\alpha = .956$  which is considered to have excellent ( $> .9$ ) reliability with (George & Mallery, 2003). Individual inter-item correlations varied from .308-.857. Thirty-five participants had complete data on the "Preconception Counseling Knowledge for Certified Diabetes Educators" measure. Thirty-seven participants had complete data on the "Preconception Counseling Knowledge for Certified Diabetes Educators". This smaller sample size is attributed to the fact that multiple participants did not respond to items for which they did not know the answer. Additionally, twenty-three of the 25 items were included in the analysis as two items, Preconception Counseling should include birth regulation methods and renal function may worsen transiently during pregnancy, had zero variance as all participants responded

correctly. The Kuder-Richardson coefficient of the “Preconception Counseling Knowledge for Certified Diabetes Educators” was  $\alpha = .705$  which is considered acceptable ( $> .7$ ) (George & Mallery, 2003). Individual inter-item correlations varied from .011-.673. Omission of a single item did not result in a notable change in reliability for either measure.

### **2.3 DISCUSSION OF RESULTS**

By using a mixed-method concurrent embedded design with a quantitative descriptive inquiry embedded within a qualitative focus group inquiry, we explored the role of the parish nurse and their experiences with educating and providing PC to women of childbearing age with T1D and T2D, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women, as well as their knowledge and self-efficacy related to diabetes and pregnancy and PC.

Both types of data from the results of this mixed-methods study supported each other. The PC knowledge scores were low and self-efficacy scores only moderate, which enriches and supports the statements made by PNs in the qualitative phase. Themes emerged from their discussion and confirmed quantitative scores. Parish nurses were unaware of DM education related to pregnancy and PC as evidence by their report and supported by low knowledge scores. Their knowledge was directly related to their confidence to provide such education. As their PC knowledge scores increased, their confidence to provide PC also increased. Many PNs also said that they were unaware of the importance and timeliness of this topic. They felt that training was important for both themselves as providers as well as for their patients and communities. Parish nurses are willing to provide PC education, but feel that they need adequate training to feel

confident doing so. They may be unaware of the topic or not receiving training on PC because of their volunteer nature and limited funding. This must be a consideration when developing PN training and tools.

Parish nurses are savvy at providing health education. They currently provide health education on multiple topics that they see as relevant for their patients. For those topics that they are less knowledgeable on they seek referrals and resources. What makes them unique in their approach to their patients is their connection and focus on spirituality to health. Future studies should explore the concept of spirituality or holism (“wholism”) in more detail.

With above mentioned themes, some related to the focus group questions and probes prepared by the facilitator while others evolved from the natural discussion of the group, such as, forming a social network of wise women. The PNs also describe possible inclusion of other members of the church that could be influential as providers of health promotion and prevention education. These individuals, most often described as a network of “wise women” could be nurses in the church that are not trained as PNs (trained to incorporate spirituality into practice), women’s ministry leaders, etc. In addition, parish nurses face unique challenges due to the nature of their care. One important challenge mentioned is isolation, thus making the parish nurse support network extremely important. Therefore, formation of a social network is not only important for the parish nurse but also the patient. Use of a social network for both support and education purposes could serve as a unique arena for increasing uptake of education among women, and thus empowering them, and increasing training among parish nurses to provide education, a central role they encompass.

The PNs also discussed that to date the majority of parishioners that they currently work with are beyond the childbearing years. However, they acknowledge that women of childbearing

age are present in their churches through regular church activities as well as outreach activities with the community. Furthermore, they note that PC for women with diabetes is an important topic, and that they would provide PC education if they had training and a tool to use. Considering that a range of childbearing age (13-45) women will be present in the churches, i.e. youth groups, youth choirs, church schools, vacation bible school; pre-marital counseling; mothers of children in church-based preschools; and women's ministries, different approaches to education for these groups should be considered. This also has implications for outreach, program development, and elements that would need to be included in the toolkit described by the PNs.

The PNs gave some very specific suggestions for the toolkit that they described. One of these points included that the toolkit include general information about PC in addition to specifics about diabetes and pregnancy. Other considerations might include education extending beyond the preconception period to when a woman becomes pregnant, post-partum and include information on lactation.

An article by Dyess, Chase, & Newlin (2010) reviewed the state of research for parish nursing. In this article the authors identify a content area as roles and activities of parish nurses. The authors discuss seven studies that include information about the role of the parish nurse. According to the review, all but one article describe the role of the parish nurse similar to the results of this study. Some of the main role topic overlap includes: spiritual care, holistic care, health promotion and education activities, counseling, referring, and active listening. Therefore, confirming results of this study would be included as a strength. Additionally, there is no discussion related to the health education theme incorporating anything related to pregnancy. Furthermore, to our knowledge there is only one study that has been done utilizing parish nurses

with women who have gestational diabetes. Therefore, this study is the first study to describe PNs' experiences, understanding, knowledge, and confidence related to diabetes involvement with pregnancy and PC.

## **2.4 STUDY STRENGTHS AND LIMITATIONS**

Strengths of the study included the mixed-methods design, which provided a broader understanding of the topic than a single method alone. The quantitative data serve to enrich the description of the knowledge and confidence of the PNs related to pregnancy and PC. This study used a comprehensive data collection approach that is the first to describe PNs experiences, understanding, knowledge, and confidence related to diabetes involvement with pregnancy and PC. This is important because of the potential for the role the PN can play in AA communities that experience lack of access and increased risk and complications related to diabetes. In addition, this study begins to utilize community-engaged research to meet the initiatives of PCOR, which seeks to include participants as part of the study implementation.

By understanding the experiences and knowledge base of parish nurses regarding diabetes education, particularly related to pregnancy and PC, we can develop a tailored toolkit that can be utilized in the community setting to target underserved minority women.

The data will be used to inform the design and evaluation of a future culturally sensitive community-engaged PC program that includes a training component for parish nurses and a PC education program for AA women with diabetes.

One of the main limitations is that the sample was obtained from contacts of a single parish nurse organization with subjects mainly from western Pennsylvania. Therefore, the study

findings may be more representative of parish nurses in this area and not necessarily of parish nurses across the country. To minimize this bias, purposive sampling was utilized to maximize variation of study participants. Furthermore, given the large sample pool of parish nurses in this organization, broad representation was achieved. Another limitation was the cross-sectional nature of this study, which did not permit test-retest reliability on the quantitative measures. Additional data collection points would have been preferred. Finally, the sample was a religious-based group and because of that may be limited in regards to what education they provide. Some PNs may have restrictions placed upon them for comprehensive PC, which includes a range of birth control methods. The participants were open and honest and one PNs' responses reflects this idea: "...depending on your faith traditions, what you could not discuss in relationship to contraception or family planning becomes an issue."

## **2.5 FUTURE STUDIES AND IMPLICATIONS FOR GLOBAL HEALTH AND NURSING**

The results of this work have prepared the PI to conduct a community-engaged research project to develop a prototype for a technology-based training program for parish nurses, as well as a prototype E-health education resource for parish nurses to use with African American women with diabetes. Both the training program and tool will be tailored from an already existing educational program and training component to be more culturally relevant for African American women and must expand beyond preconception to include information during the prenatal period about lactation.

Goal: Expand the PI's developing program of research in improving maternal and fetal outcomes and reducing disparities among African American women with diabetes utilizing parish nurses for usability testing of a prototype technology-based training program for parish nurses, as well as a prototype resource for parish nurses to use with African American women with diabetes, and intervention implementation.

Activities to Achieve Goal:

1. Conduct an independent research project developing and testing a prototype for a technology-based training program for parish nurses, as well as a prototype E-health education resource for parish nurses to use with African American women with diabetes. Both the education program and tool will be tailored from an already existing educational program and training component to be more culturally relevant for African American women and must expand beyond preconception to include information during the prenatal period about lactation.

### **Year 1**

Conduct focus group discussions with parish nurses utilizing think aloud technique. Parish nurses will be shown "Pregnancy Planning for Women with Diabetes: A PC Program" video clips of the current program and segments of the book and will be asked to respond to questions such as:

- Are there things you like about this program? Tell me about those.
- Are there things you don't like about this program? Tell me about those.
- What changes can make this program more acceptable to you?

- What else do we need to know about women in the faith setting to understand how best to change this program? (probe for local slang, gender roles, value of children, and knowledge about diabetes)
- How else could we change this program so you would use it?

Based upon the findings of the focus groups with parish nurses update and adapt a prototype training program for parish nurses from an already existing preconception counseling CEU program “Preconception Counseling for Adolescent and Adult Women with Diabetes” that the PI assisted in developing. The CEU program can be accessed at [www.nursing.pitt.edu](http://www.nursing.pitt.edu). Currently, the program is set up for the participant to receive the four (4) contact hours. The participants must review the content, pass the test within two attempts with a 80%, and complete the evaluation for each module (Cothran et al., 2009). In a preliminary study of the CEU program, all of the Certified Diabetes Educator participants achieved > 80% pass rate and were very satisfied with the program (Cothran et al., 2009).

Additionally, based upon the data that emerged from this study describing the influence of a social networks of wise women in the church setting, and further description of incorporating these wise women into PC training and eventual intervention, this network must be better understood. A separate focus group with key members of the church such as: health ministry team, women’s ministry, Deaconesses, youth ministry, to further explore this network and how it can be utilized and incorporated into the eventual intervention to increase support and awareness raising among childbearing women with diabetes. There is potential for these women to be involved to help women of childbearing age access referrals and resources. Additionally involving the Pastor in theses discussions is important. One important topic to clarify is the

difference between religiosity, spirituality, and religion and how these will impact providing PC in the intervention.

## **Year 2**

Conduct focus group discussions with African American women with diabetes in the community utilizing the think aloud technique. Women will be shown “Pregnancy Planning for Women with Diabetes: A PC Program” video clips of the current program and segments of the book and will be asked to respond to questions such as:

- Are there things you like about this program? Tell me about those.
- Are there things you don’t like about this program? Tell me about those.
- What changes can make this more acceptable to women like you?
- What else do we need to know about local women to understand how best to change this program? (probe for local slang, gender roles, value of children, and knowledge about diabetes)
- How else could we change this program so you would use it?

Additional questions will be asked during the focus group to ask which technology-based platform the participants think would be most effective to use with this educational tool to explore the mode of delivery

Final questions will ask about their experiences, opinions, and understanding of breastfeeding related to their diagnosis of diabetes and what they feel they would need or want to know about lactation with diabetes. This information will be used to build future prenatal and lactation education, which is currently missing from the preconception counseling program.

Based upon the findings of the focus groups with the women, update and adapt an already existing educational program for a prototype education tool to be up-to-date and more culturally relevant for African American women in a reformatted technology based platform.

In addition, to further verify the psychometrics of the measures used for this study the sample from the dissertation will be combined with a previous sample of healthcare providers (diabetes educators) who completed both surveys to perform reliability testing for the two instruments used in the dissertation. Results will be written for publication in a manuscript.

**3.0 MANUSCRIPT 1: EXPLORING THE ROLE OF THE PARISH NURSE IN PROVIDING  
DIABETES EDUCATION AND PRECONCEPTION COUNSELING TO AFRICAN  
AMERICAN WOMEN USING A COMMUNITY-ENGAGED MIXED-METHODS APPROACH**

**3.1 COVER LETTER TO JOURNAL EDITOR**

April 18, 2014

Dear Editors and Reviewers,

Please consider the attached manuscript, “Exploring the Role of the Parish Nurse in Providing Diabetes Education and Preconception Counseling to African American Women Using a Community-Engaged Mixed-Methods Approach” for publication in the Journal of Diabetes Educators. This paper describes the attitudes of, experiences with, and understanding of parish nurses providing diabetes education and PC, and their knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC to women with T1D and T2D (especially to AA women). Jessica Devido is serving as the first and corresponding author. Please feel free to contact her with any questions that may arise.

Regards,

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## 3.2 ABSTRACT

### **Purpose**

The purpose of this study is to explore the experiences of parish nurses (PNs) in providing diabetes education and preconception counseling (PC) to women (especially African American [AA] women) with type 1 diabetes (T1D) and type 2 diabetes (T2D) and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes; and to describe the parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC.

### **Methods**

A mixed-method concurrent embedded design using focus group methodology as the primary method and a quantitative descriptive design with three self-report measures (demographic, PC self-efficacy, and PC knowledge) as the secondary method was utilized. Forty-eight parish nurses participated in one of eleven focus groups. Qualitative content analysis techniques were conducted and combined with descriptive measure analysis.

### **Results**

Six qualitative themes emerged: 1) Need for awareness of PC, 2) Experience with PC, 3) Willingness and confidence to provide PC, 4) Need for PC training, 5) Forming a network of wise women, and 5) PC tool for patients. PNs' knowledge scores were low with only moderate levels of self-efficacy. Self-efficacy had a significantly positive association with knowledge, as knowledge increased self-efficacy increased.

### **Conclusions**

Quantitative results supported and confirmed PNs' qualitative statements. PNs were unaware of PC and lacked both knowledge and teaching self-efficacy as they related to PC/diabetes education. Understanding PNs' experiences with women with diabetes and identifying their

needs to provide education and PC will help tailor training interventions that could impact maternal and fetal outcomes.

### 3.3 INTRODUCTION

Diabetes is a public health crisis especially among African Americans (National Institute of Diabetes and Digestive and Kidney Disease, 2008). AA women with diabetes have been shown to have higher initial HBA1C levels during pregnancy compared to Caucasian women (Holcomb, Mostello, & Leguizamon, 2001). When HBA1C levels are high and glycemic control is not achieved, congenital malformations can occur (Inkster, 2006; Kitzmiller et al., 1991; Towner et al., 1995).

To prevent complications, maternal blood sugar levels must be normal at conception and throughout the pregnancy (ADA 2004, 2011). With anomalies occurring during the first month of the pregnancy, it is essential for women with diabetes to prevent an unplanned pregnancy and to begin PC early, well before a woman decides to become pregnant. When planning a pregnancy with PC, risks of reproductive complications can be reduced from 10% to 2% (ADA 2004, 2011).

Despite these positive findings, women with diabetes (DM) are not receiving PC (Dunne et al., 1999; Janz, Herman, Becker, & Charron-Prochownik, 1995; Roland, 2005), and nearly two thirds of pregnancies among women with diabetes remain unplanned (ADA, 2011) compared with nearly half (51%) of all unplanned pregnancies in the U.S (Finer & Zolna, 2014). Hillman and colleagues (2006) reported only 16% of women with T2D and 22% of women with T1D had received PC. Women less likely to seek preconception counseling did not graduate from college, were not married, were unemployed, had T2D, or were of a racial minority (Janz et al., 1995).

In order to impact disparate rates of pregnancy related complications among AA women with DM PC must be provided. AA women could greatly benefit from services delivered in their community (Owens et al., 2006). Faith-based programs have been particularly successful in AA

communities (Hye-cheon et al., 2008; Peterson & Cheng, 2011). Parish nurses serve members of a faith community or church as well as members of the community. The main role of the parish nurses is to provide services that include health education and promotion, health counseling, acting as referral agent, and patient advocate (ANA & HMA, 2012).

Parish nurses can bridge the gap of lack of awareness of PC and limited access for women with diabetes in their communities, especially in underserved AA communities. They can be a main health care contact, raising awareness of and providing PC to women with diabetes in an accessible faith-based location. Therefore, the purpose of this study is to explore the experiences of PNs in providing diabetes education and PC to women (especially AA women) with T1D and T2D; and to describe the parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC.

### **3.4 METHODS**

#### **3.4.1 Research design**

A mixed-methods concurrent embedded design was used, with qualitative inquiry as the primary method (i.e. focus groups) and quantitative inquiry as the secondary method (i.e. quantitative descriptive using demographic, PC self-efficacy, and PC knowledge measures) (see Figure 1). The primary method guides the project while the secondary method serves in a supporting role. A concurrent qualitative/quantitative design ensured that the data were complementary and complete (Greene, Hare, Cloherty, Benacerral, & Soddner, 1989; Happ, Dabbs, Tate, Hricik, & Erlen, 2006) and allowed for integration of data that can provide an overall broader assessment

of the data and enriches description (Creswell, 2009). The goal of this approach was to explore the experiences of PNs in providing diabetes education and PC to women (especially (AA women) with T1D and T2D and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes using qualitative and quantitative methods to attain a deeper understanding and to triangulate information from multiple sources (Greene et al., 1989; Happ et al., 2006).

### **3.4.2 Sample/Setting**

Forty-eight parish nurses participated in eleven total focus groups (including one pilot focus group) with two to eight individuals per group between August 7, 2012, and September 4, 2013. Eligible participants were PNs who: 1) had a nursing license LPN, RN, or advanced degree (MSN, DNP, PhD); 2) practiced in a faith community setting; and 3) functioned as a PN (certificate not required). The exclusion criterion was inability to speak, read, or understand English. All questionnaires were in English; therefore, only English-speaking participants were recruited.

Location of focus groups was determined by service areas of participant's practice, for convenience of the PNs in order to encourage maximum participation (Wilkinson, 1998). This also included offering focus groups of a distance nature (teleconference, webex). This allowed for those participants whose location and/or schedule preclude them from joining in a physical nature to participate and provided a more geographically diverse sample (Cooper et. al, 2003; Hurworth, 2004).

Five of the focus groups were conducted with participants on-site. Four of these were conducted at a parish nurse and health ministry program office, and one took place in northwestern, PA. Two of the focus groups contained both participants on-site as well as

conference call. The four final focus groups utilized webex with PNs were from Florida, Ohio, New York, and Arizona. Focus groups were conducted until saturation was reached in the data analysis and no new information was collected (Baum, 1998).

### **3.4.3 Procedures**

Parish nurses completed the paper-and-pencil quantitative measures first and then participated in a single focus group. PNs who were participating via a distance method were emailed the measures and completed them prior to the start of the focus group. IRB approval was sought as an exempt study prior to recruitment and data collections. The IRB at the Catholic Hospital that houses the parish nurse program office required changing the terminology “birth control methods” to “birth regulation methods” on the measures in order to uphold ethical and religious directives of the Catholic moral teaching.

### **3.4.4 Data Collection**

#### **Qualitative Focus Groups**

The PI conducted all focus groups as the facilitator. All focus groups were doubly digitally recorded. A structured focus group guide was utilized to elicit and refocus the group discussion (see Table 3). However, the participants ultimately guided the discussion (i.e., concepts/new ideas brought up by the participants were investigated) (Krueger, 2009).

#### **Quantitative Measures**

The following measures were adapted from a pre-validated questionnaire by Janz et al. (1992). The first self-report measure, “Preconception Counseling Knowledge for Certified

Diabetes Educators” (Cothran et al., 2009), consists of 25 true-false questions and is scored by calculating the percentage of correct answers (score range from 0-100) and measures the level of knowledge the nurses possess as it relates to diabetes and pregnancy and PC content. The measure has content and face validity as it was adapted from several previously validated diabetes and pregnancy and PC knowledge measures (Pregnancy and Attitudes Scale) with additional questions developed from recommendations of the ADA on PC care of women with diabetes (Cothran et al., 2009).

The second self-report measure, “PC Self-Efficacy for CDEs” (Cothran et al., 2009), a validated measure of self-efficacy, has been adapted for the parish nurses. This measure consists of 17 11-point Likert-type scaled items, where 0 was labeled “not at all confident” and 10 was labeled “absolutely confident.” Possible score range is from 0-170. Higher scores indicate greater self-efficacy. This measure was given to gain an understanding of the parish nurses’ level of confidence to provide education about diabetes and pregnancy and PC. A panel of experts evaluated the measures for content validity and included the original theorist (Bandura), theorist for the original study. Bandura (1977) reviewed this measure for content validity. Items were retained based on theoretical decisions. Internal consistency reliability was measured with a Cronbach alpha of .65.

The third self-report measure, “Reproductive Health Program for Women With Diabetes Sociodemographic Questionnaire,” was developed for the study. The original questionnaire included nine questions and collected demographic data related to the parish nurse participants including: age, race, gender, highest level of nursing education, year of RN licensure and PN certificate, most prevalent aspects of role of parish nurse, and most prevalent medical conditions of their parishioners. Once data collection began, it was realized that the participants were

providing a great deal of data about their parishioners. It was determined at that time to add five questions pertaining to the people in the congregations of the parish nurses. These questions included information about: race percentage, female percentage, childbearing age percentage, diagnosis of diabetes percentage, and income level. The last 24 subjects received these additional questions, while the earlier 24 subjects were re-contacted to complete the measure once IRB was approved.

The data collection process and focus groups lasted approximately 60 to 90 minutes. Participating PNs received breakfast or lunch, diabetes education materials (booklets, brochures) to give to their patients, and free access to an online PC CEU program "*Preconception Counseling for Adolescent and Adult Women with Diabetes*" valued at \$80. Currently, the program is set up to receive four (4) contact hours (Cothran, 2009).

### **3.4.5 Data management and analysis**

All recordings were transcribed, and transcription was compared to the original recordings to ensure accuracy and add contextual clarification. All transcripts were stored in password-protected files on a computer, which only the research staff could access. Each participant was assigned a unique identifying number that corresponded to responses to focus group questions allowing for identification of speakers.

Qualitative content analysis, which offers an accessible and theoretically flexible approach, was utilized. An inductive approach was utilized in order to identify themes that are strongly linked to the data and not driven by a particular theory or theoretical interest area (Braun & Clarke, 2006). The process of collecting, coding, and analyzing data occurred simultaneously. Once codes were initially developed, both the principal investigator (PI) and a qualitative

methods expert reviewed them for consistency and context and independently coded the transcripts. Each focus group transcript was reviewed and discussed and consensus was reached on all coded data during analytic meetings. The codes and definitions were further developed and refined with each focus group. ATLAS.ti (7.1.7) was utilized for data management, as it allowed for systematic organization and easy access to text based on themes.

Quantitative data screening procedures included assessment of outliers, both univariately and bivariately, with normality probability plots, bivariate scatterplots, and mahalanobis distances (continuous). There was one subject considered to be an influential univariate outlier, as she had high knowledge but low self-efficacy. She was found to be one of the oldest participants; otherwise her demographic information appeared to be similar to the other participants'. Her data remained in the analysis as it was considered valid. Missing data included: knowledge measure two subjects did not complete any of the measure, self-efficacy measure two subjects (one that also had not completed the knowledge survey and one additional that was not the same subject as the other that had not completed the knowledge measure). There was also one subject who had not completed one item on the self-efficacy survey. A mean of the subject's responses was computed and imputed for the missing item to calculate a total score as a strategy to handle the missing data point. Thirty-nine of the 48 subjects had complete demographic data prior to the addition of demographic questions related to PNs congregations. Missing data were assessed with MVA and found to be missing at random.

Demographic data were analyzed with descriptive statistics using IBM SPSS (version 21, International Business Machines, Corp., Armonk, NY). Frequencies were run with all available data. Scores for both the "Preconception Counseling Knowledge for Certified Diabetes Educators" "PC Self-Efficacy for CDEs" were calculated. The resulting scores for each scale

were analyzed and reported by descriptive statistics (mean, range). Pearson product-moment correlation was performed to provide direction and strength of association the variables of knowledge and self-efficacy.

## **3.5 RESULTS**

### **3.5.1 Qualitative**

Forty-eight parish nurses completed the measures and participated in the focus groups. The researchers identified the following five themes describing the PNs attitudes and understanding of, and experiences with providing diabetes education and PC to women with diabetes.

#### **Awareness**

Most had never heard of the term preconception counseling or that is was something that should be given to women who had diabetes before they become pregnant:

“I did not know how ignorant I was until I read the survey and I had no idea of how to answer.”

Some reported that they were aware of the general concept of preconception counseling but not specifically as it related to women with diabetes:

“I’ve heard the term, I don’t know specifics.... “ “It’s awareness. To get parish nurses aware, I think, that this is an issue.”

However, during the course of the focus group sessions they realized and verbalized the importance of PC for women with diabetes:

“I think that would be helpful to me because I have a mixed population in my church right now and I think it’s important for people to know....”.

## **Experience**

PNs expressed they were not currently providing formal diabetes education regarding pregnancy or PC to their female patients with diabetes, and the majority have never provided it:

“I have not taught anything about diabetes and pregnancy.”

## **Willingness and Confidence**

Despite having never providing PC, PNs feel that the church could be a place to disseminate diabetes education as it relates to pregnancy and PC:

“We could definitely use a program like that in our church.” They would be willing to provide PC to their female patients with diabetes, “I would say now that I know there’s something that should be done with preconception information. I would roll it all into...women’s healthcare education....”.

The PN’s describe low levels of confidence to provide education related to DM and pregnancy and PC:

“I have very little confidence in myself as far as...women with diabetes, first pregnancy planning, and going through a pregnancy, that I know nothing about.”

## **Need for PC training**

Parish nurses reported having received essentially no education in their nursing training or PN training related to PC and never having received any PC education specific to women with diabetes:

“As far as preconception before you got pregnant, I don’t remember anything even in nursing teaching that these are issues....”

The PNs recommended the following training components including: 1) learning the basics of diabetes and pregnancy and PC to obtain baseline knowledge and understanding:

“...a baseline class (related to PC)...”.

2) They felt that a multidisciplinary approach with insight from different medical professionals who have expertise related to diabetes and pregnancy and PC would be helpful:

“..well, its gotta be multidisciplinary too. A physician speaking, a dietician,”.

3) They would like case studies:

“...to have someone there who is willing to share their life story, their difficulties...being pregnant with diabetes.”

4) An algorithm to follow, a fact sheet, and a list of resources to access including where to refer their patients.

“I would want to know the resources in the community...”, “..like a checklist,..a factsheet...”, “...I like the algorithm type of thing because then we could go down and say okay here go here and then go here ...as an interview counselor...”

5) They felt the strategy should include technology, be interactive, and be on-line:

“...I like online...” “...flexible..like continuing education...”

They also expressed that a seminar, webinar, or a symposium would be helpful. This program would need to be inexpensive with their limited funding.

“Some of these nurses, you know, as far as continuing ed budget they have little to no money with that.”

6) It was also discussed that doing training with other groups/members in church who may have interaction with or be influential in the lives of childbearing women would be an additional way to increase awareness about the topic:

“...there are people in the congregation to whom people go, not necessarily the parish nurse, but (whom) they may also feel comfortable among...”.

### **Forming a Social Network of Wise Women**

The PNs described that the childbearing women in the church seek out and feel comfortable among:

“...their peers-an older wiser woman or another young mother who’s been there, done that. And if the parish nurse can connect with, that network of wise women with information to filter down...but there’s room for those other women to whom people might go.”

## PC Tool for Patients

The PNs provided recommendations for 1) a teaching program or education tool for PC to be used in their practice:

“We would love to have a toolkit that you put together with a fact sheet, web references...”

2) They expressed that it needs to give positive messages rather than negative consequences:

“A more positivistic approach...rather than consequence related.”

3) It needs to incorporate faith and how one looks at her faith in making health related decisions:

“I think it would be terrific to have a tool that would also bring in that faith piece, you know, ...”.

4) They feel it needs to start broader with self-care and being a good steward of your body and to include preconception in general for all women who are childbearing and then narrow down to diabetes:

“You start out with self-care.”

They described a resource as a toolkit and suggested that it include the following: 1) phases of readiness for pregnancy, 2) information from experts, 3) positive stories of women who had successful pregnancies with diabetes, 4) pictures to accommodate those with a lower reading level, discussion and pictures of pregnancy as it evolves and how this may be occurring before a woman even knows she is pregnant,

“I need pictures in my group, because my group doesn’t read too well.”

5) fact sheet with highlights for a take home, 6) and web references.

They had interest in a technology-based interactive component that would include a DVD, CD, or utilizes the web like an APP or social media:

“I just think that the whole generation is kind of tech savvy so I would think that it would be an interactive type thing. Whether it would be on the computer or whatever.” “...like an app...”

By doing this, a person who needed it would have the flexibility to use it when she had the time, was in her own home, and had privacy:

“..something more interactive, like on the computer, like a software program they could do at home...or online...”

In addition, they suggested one-on-one discussion time with the PN as well as group time (pre-marital counseling) with their peers and partners or family members to have support:

“I just feel...more ...face-to-face contact is by far the most important part of education.”

This group time could even be a collaboration of multiple churches:

“...collaborating among different programs would be-and to offer within a given area.”

One suggestion was that there should be something specific for a partner or family member on how to support the woman with diabetes:

“...but the other person I would include...is the father of the baby or the family, because it’s hard to stay on a diet or do one thing when you’re the only person doing it, but if you’re in the family...You need to have everybody on board.”

### **3.5.2 Quantitative**

The sample of parish nurses (n=48) was 100% female and 83% Caucasian. Fifty percent of the sample was between 51 and 60 years old. Ninety-six percent were RNs, and the majority of those had a BSN degree or higher. The participants had obtained their nursing education on average 38 years ago (range 17-58 years) and their parish nurse education five years ago (range less than 1 year-18 years). (see Table 5)

The majority (75%) of the sample reported having AA congregants in their church with a range of 0-100%. Overall, 65% of the congregants were reported to be female, 29% to be of

childbearing age (100% of the PNs have percentage of childbearing women present), and 23% to have a diagnosis of diabetes. In addition, 13% of the sample reported having congregants in their church who had a yearly income of less than \$15,000 (range 0-75%), which is just below the federal poverty level for a family of two.

The parish nurses reported that the most prevalent aspects of their role as a parish nurse included: providing health education, publications, teaching, and speaking (n=31, m=70%); acting as coordinator, facilitator, and leader (n=15, m=31%); acting as counseling and advisor (n=9, m=19%); providing spiritual and emotional care (n=9, m=19%); and increasing awareness (n=9, m=19%).

In addition, they reported the most prevalent health conditions that their congregants experience as: diabetes (n=32, m=67%); high blood pressure (hypertension) (n=30, m=63%); cardiovascular disease (n=22, m=45%); cancer (n=16, m=33%); and obesity and overweight (n=10, m=21%).

### **Knowledge & Self-efficacy**

The parish nurses' baseline knowledge scores (knowledge of PC) were low (mean= 65%, range= 40-100%) (see Table 5). Only two of the participants were LPNs, with PC knowledge scores above the mean of the group despite having less formal education than the RNs. Three knowledge questions were answered incorrectly by at least 78% of the subjects. These questions related to reducing the risk of congenital malformations through reduction of A1C early in pregnancy; fasting blood glucose level that is the goal for glycemic control; and increasing exercise tolerance prior to pregnancy. Four questions that the majority (93%) answered correctly were: PC and the inclusion of birth regulation methods; use of a multidisciplinary team; psychological counseling; and renal function during pregnancy. The parish nurses only had

moderate levels of self-efficacy (mean= 99, range = 27-164), which supports the qualitative data on confidence (see Table 5).

### **Association of Knowledge and Self-efficacy**

The association of knowledge and self-efficacy of parish nurses as it relates to diabetes and pregnancy and PC was explored. Self-efficacy had a significant positive association with knowledge (Pearson  $r = .292$ ,  $p = .05$ ). For every one unit increase in knowledge, self-efficacy score increased by .03.

## **3.6 CONCLUSION**

By using a mixed-method concurrent embedded design with a quantitative descriptive inquiry embedded within a qualitative focus group inquiry, we explored the role of the parish nurse and their experiences with educating and providing PC to women of childbearing age with T1D and T2D, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women, as well as their knowledge and self-efficacy related to diabetes and pregnancy and PC.

This design allows quantitative data to support qualitative findings (Creswell, 2009). Such was the case in this study. This is important because of the potential for the role the PN can play in AA communities that experience lack of access and increased risk and complications related to diabetes.

The knowledge scores were low and self-efficacy scores only moderate enriching the statements made by PNs in the qualitative phase. Six themes emerged from their discussion and confirmed quantitative scores. 1) Parish nurses were unaware of DM education related to

pregnancy and PC as evidence by their report and supported by low knowledge scores. Their knowledge was directly related to their confidence to provide such education. As their knowledge scores increased, their confidence to provide this also increased. 2) PNs also said that, many were unaware of the importance and timeliness of this topic. 3) They felt that training was important for both themselves as providers as well as for their patients and communities. 4) Parish nurses are willing to provide this education, but feel that they need adequate training to feel confident doing so. 5) In addition, a toolkit must be tailored for use in their practice with their patients. This toolkit may be broader to focus on diabetes education to be faith-based, and to be easily accessible to both provider and patient, including technology-based modes of delivery. Some themes related both to the focus group questions prepared by the facilitator while others evolved from the group such as forming a social network of wise women. These “wise women” could be nurses in the church that are not trained as PNs (trained to incorporate spirituality into practice), women’s ministry leaders, etc. In addition, parish nurses face unique challenges due to the nature of their care. One important challenge mentioned is isolation, thus making the parish nurse support network extremely important. Therefore, formation of a social network is not only important for the parish nurse but also the patient. Use of a social network for both support and education purposes could serve as a unique arena for increasing uptake of education among women, and thus empowering them, and increasing training among parish nurses to provide education, a central role they encompass.

In order to impact the disparate rates of PC and planned pregnancies among underserved AA women with DM, who experience lack of access to healthcare, innovative ways to provide PC and DM education must be considered. This education must be culturally relevant, located in a familiar and comfortable setting, and easily accessible to those who need it most. The parish

nurse becomes the ideal provider of such education in their faith-based setting where their patients get a more complete patient/healthcare provider relationship.

### **3.6.1 Limitations**

One of the main limitations is that the sample was obtained from contacts of a single parish nurse organization with subjects mainly from western Pennsylvania. Therefore, the study findings may be representative of PNs from this area and not necessarily be representative of parish nurses across the country. To minimize this bias purposive sampling was utilized to maximize variation of study participants. Furthermore, given the large sample pool of parish nurses in this organization, broad representation was achieved. Another limitation was the cross-sectional nature of this study, which did not permit test-retest reliability on the quantitative measures. Additional data collection points would have been preferred. Finally, the sample was a religious-based group and because of that may be limited in regards to what education they provide. Some PNs may have restrictions placed upon them for comprehensive PC, which includes a range of birth control methods. The participants were open and honest and one PNs responses reflects this idea, "...depending on your faith traditions, what you could not discuss in relationship to contraception or family planning becomes an issue."

Despite these limitations, strengths of the study included the mixed-methods design, which provided a broader understanding of the topic than a single method alone. To our knowledge, this is the first study to describe PNs experiences, understanding, knowledge, and confidence related to diabetes involvement with pregnancy and PC. The quantitative data serves to enrich the description of the knowledge and confidence of the PNs related to pregnancy and PC. In addition, this study begins to utilize community-engaged research to meet the initiatives

of patient-centered outcomes research (PCOR), which seeks to include participants as part of the study implementation.

### **3.7 IMPLICATIONS FOR DIABETES EDUCATION AND RESEARCH**

This study is unique in that it raises awareness of the importance of community healthcare involvement in the delivery of culturally relevant PC for women with diabetes. The correlation of knowledge and confidence supports the need to provide training to increase knowledge and thus confidence. Parish nurses need to have tailored PC training and education programs to increase their awareness and confidence level with diabetes and pregnancy and PC in order to deliver PC and meet the needs of women with diabetes in communities.

The results of this study support the need for future studies to address the development, implementation and evaluation of a community-engaged program of research including a technology-based training program for parish nurses, as well as a prototype E-health education resource for parish nurses to use with African American women with diabetes in their communities.

Table 3: Focus Group Questions with Probes

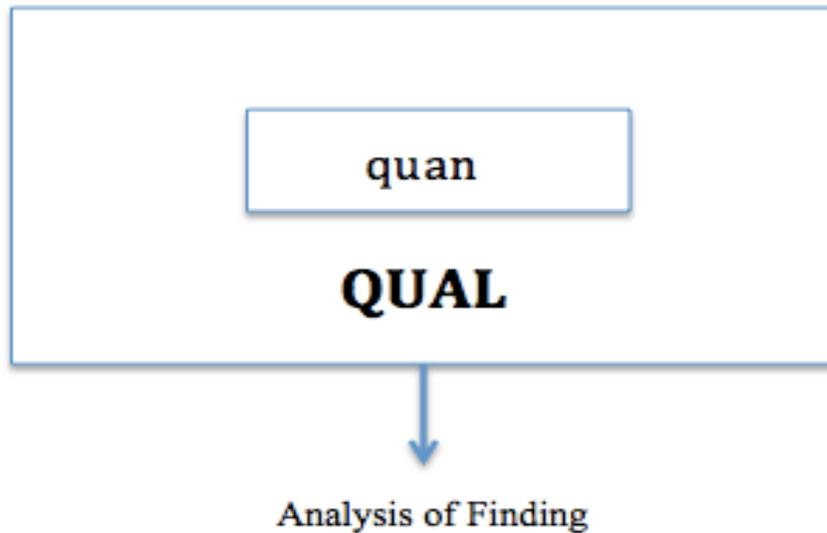
Focus Group Questions with probes
<p><b>Opening Statement</b>            Tell me about your role or practice as a parish nurse?</p> <p>a. Tell me about those you care for as a parish nurse?</p>
<p>1. What percent of your patients have T1D or T2D?            a. About what percent of these are female?            b. About what percent are within their childbearing years?</p>
<p>2. What do you teach your patients about diabetes?</p>
<p>3. Tell me about how you provide this education or programming?</p>
<p>4. How confident do you feel providing this education?</p>
<p>5. What more do you feel you need to know about diabetes to educate your patients?</p>
<p>6. What do you teach your patients about diabetes and pregnancy?</p>
<p>7. What do you know about preconception counseling?</p>
<p>8. Have you discussed preconception counseling to women with diabetes?</p>
<p>9. How might this information be helpful to have?</p>
<p>10. How confident do you feel providing preconception counseling?</p>
<p>11. What more do you feel you need to know about preconception counseling for women with diabetes in order to provide this education?</p>
<p>12. Have you ever gotten formal instruction about preconception counseling or pregnancy with diabetes? From where?            a. Would you benefit from further preconception counseling training?                i. If yes, what would an ideal training program look like?            b. Would your community benefit from further preconception counseling training?                i. If yes, what would an ideal tool or program to use with your patients look like?</p>

**Table 4: Demographics Frequency Table**

Variable	Total Sample n = 48	%
<b>Race</b>		
Caucasian	40	83
African American	8	17
<b>Age</b>		
41-50	2	4
51-60	23	49
>60	22	47
<b>Nursing Education</b>		
LPN	2	4
RN		
Diploma	13	27
Associates	3	6
BSN	18	38
MSN	9	19
DNP/PhD	2	4

**Table 5: PC Knowledge and Self-Efficacy Results**

Description	Possible Score Range	Mean	Actual Range
Knowledge	0-25 (0-100%)	16 (66%)	10-25 (40-100%)
Self-Efficacy	0-170	98.9	27-164



**Figure 2.** Concurrent Embedded Design

### **3.8 ACKNOWLEDGEMENTS**

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**4.0 MANUSCRIPT 2: EXPLORING THE EXPERIENCE OF THE PARISH NURSE  
PROVIDING DIABETES EDUCATION IN THEIR COMMUNITY**

**4.1 COVER LETTER TO JOURNAL EDITOR**

April 18, 2014

Dear Editors and Reviewers,

Please consider the attached manuscript, “Exploring the Role and Experience of the Parish Nurse Providing Diabetes Education in Their Community” for publication in the Journal of Nursing Scholarship. This paper describes the experiences of parish nurses in providing diabetes education to members of their congregation (including African American women) with Type 1 Diabetes and Type 2 Diabetes. Jessica Devido is serving as the first and corresponding author. Please feel free to contact her with any questions that may arise.

Regards,

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Financial support was provided by the Sigma Theta Tau/American Association of Diabetes Educators Foundation Grant and the Sigma Theta Tau Int. Small Grant.

## 4.2 ABSTRACT

**Purpose:** To explore the experiences of parish nurses (PNs) in providing diabetes education to members of their congregation (including African American [AA] women) with Type 1 Diabetes (T1D) and Type 2 Diabetes (T2D).

**Design:** This study of parish nurses used a mixed-methods concurrent embedded design with one data collection phase and utilized qualitative data for the primary method and quantitative data for the secondary method. This paper reports on the qualitative phase, which used focus groups. Forty-eight PNs who were contacts of a western Pennsylvania parish nurse and health ministry program participated in one of eleven focus groups.

**Methods:** Focus group methodology was utilized to elicit experiences and attitudes and capture discussions with participants joining from both onsite and distance (conference call, webex) venues. The focus groups were digitally recorded, transcribed, and analyzed. Qualitative content analysis was used to identify common themes across the focus groups. A representative set of themes describing the data was identified.

**Findings:** Six qualitative themes emerged from the PNs: 1) parish nurse role, 2) parish nurse approach, 3) parish nurse challenges, 4) parish nurse support network 5) parish nurse practice and programming, and 6) diabetes practice and programming.

**Conclusions:** Parish nurses are uniquely situated not only because they exist in a community setting, putting them in closer proximity to the homes of clients, but also because they are in a setting where patients may attend on a regular basis and share a similar set of values due to their faith. This allows for a relationship that has many more dimensions, which leads to a greater sense of trust compared to a traditional nurse-patient relationship. The PN provides holistic care

that included the physical, mental, and spiritual aspects of a person; incorporating faith into care, health promotion and prevention activities.

**Keywords: Parish Nurse, Community Nursing, Minority Health and Health Disparities, Diabetes**

### 4.3 INTRODUCTION

Parish nurses practice in a faith-based setting and focus on health promotion and disease prevention education as their primary role. They practice from a more holistic prospective, incorporating an individual's spiritual health, (McDermott & Burke, 1993; Tuck & Wallace, 2000, 2001; Chase-Ziolek & Iris, 2002; King & Tessaro, 2009). Parish nursing, also known as faith community nursing, was initiated in the Chicago area by Reverend Dr. Granger Westberg in the 1980s and has been a recognized nursing specialty since 1999. Parish nurses make the link between health and faith; this includes: "the protection, promotion, and optimization of health and abilities; prevention of illness and injury; and responding to suffering in the context of the values, beliefs, and practices of a faith community" (American Nurses Association [ANA] & Health Ministries Association [HMA], 2012, p. 5). Parish nurses have had success with patient outcomes related to chronic diseases (diabetes and obesity) (Garber Mendelson et al., 2008; White, Dreschsel, & Johnson, 2006), and thus could play a pivotal role in providing education and health promotion at the community level for underserved populations (McGinnis & Zoske, 2008; Wallace, Tuck, Boland, & Witucki, 2002), such as women in AA communities, particularly those who are childbearing and have diabetes. AA communities have had success with faith-based programs (Hye-cheon et al., 2008; Peterson & Cheng, 2011). Given that AA women have a strong connection to their faith-based communities (Drayton-Brooks & White, 2004; Newlin et al., 2008), the parish nurse could fulfill a need in this underserved and vulnerable population.

Low-income AA women have limited access to health care (Williams, 2005) and could greatly benefit from services delivered in their communities (Owens, Kieffer, & Chowdhury,

2006). African American women have greater disease burden (Williams, 2005). More specifically, AA women have nearly twice the prevalence of type 2 diabetes (T2D) compared to Caucasian women (National Institute of Diabetes and Digestive and Kidney Disease, 2008) and are more vulnerable to developing diabetes complications (Holcomb, Mostello, & Leguizamon, 2001). Compared to Caucasian women, African American women have higher rates of neonatal and infant death, higher risks of negative pregnancy outcomes, higher rates of maternal mortality (Harper, Dugan, Espeland, Martinez-Borges, & Mcquellon, 2007), and the highest rate of unintended pregnancies (Finer & Zolna, 2014). Moreover, women with Type 1 Diabetes (T1D) or T2D who have unplanned pregnancies have a two- to threefold increase in rates of major congenital anomalies among their infants (American Diabetes Association [ADA], 2004; Kitzmiller et al., 1991).

## **4.4 METHODS**

### **4.4.1 Research design**

The overall study used a mixed-method concurrent embedded design with one phase that collected simultaneously both qualitative and quantitative data (see Figure 1). The primary method (qualitative) guided the study, while the secondary method (quantitative) provided support. Due to the secondary nature of the quantitative method, it was embedded within the qualitative method (Creswell, 2009). This paper describes the qualitative focus group data that explored parish experiences with educating members of their congregation with T1D and T2D (especially AA women). A qualitative approach provides detail-rich data that allows for a fuller

description of knowledge and experiences (i.e. parish nurses understanding, and knowledge of PC) that cannot be derived from other methods (Sandelowski, 2000).

In addition, the structure of a focus group allows for openness and disclosure by participants about the topic (Krueger, 1994; Wilkinson, 1998). This methodology facilitates the ability to obtain an in-depth understanding of the participants lived experiences (Wilkinson, 1998). The goal of research utilizing focus groups includes understanding the complex mix of attitudes, knowledge, and past experiences of the participants (Morgan & Krueger, 1998). As a tool it is effective for exploring attitudes, beliefs, and the development of interventions (Carey & Smith, 1994; Denning & Verschelden, 1993).

#### **4.4.2 Sample and Setting**

Parish nurses were recruited for both the qualitative and quantitative methods if they: 1) had a nursing license LPN, RN, or advanced degree (MSN, DNP, PhD); 2) practiced in a faith community setting; and 3) functioned as a PN (certification not required). All questionnaires were in English; therefore, only English-speaking participants were recruited.

Eleven focus groups (including one feasibility focus group) with two to eight individuals were conducted. Forty-eight PN participants (including six in the feasibility focus group) participated in the study. In order to facilitate maximum participation the location of focus groups was determined for convenience of the PNs (Wilkinson, 1998). This included distance focus groups that were teleconference-based or webex format. This allowed for individuals whose location and/or schedule precluded them from joining physically to participate and also for a more geographically diverse sample to be engaged (Cooper et al., 2003; Hurwarth, 2004). When the distance format was used, the researchers limited the group to no more than five

participants in order to allow for greater in-depth discussion. Size limitation is consistent with evidence suggesting that focus groups utilizing teleconference allow for the most meaningful interactions when kept small (Krueger, 2009).

Five of the focus groups were conducted with participants on-site. Four of these were conducted at the parish nurse and health ministry program office in western PA and one took place at a church in northern PA, convenient for participants in the area. Two of the focus groups included both participants on-site (parish nurse and health ministry program office) as well as via conference call. The four final focus groups utilized a distance webex format with PNs from Florida, Ohio, New York, and Arizona. Focus groups were conducted until saturation was reached in the data analysis and no new information was collected (Baum, 1998).

#### **4.4.3 Data Collection**

The principal investigator (PI) conducted all focus groups using a structured focus group guide that was developed and utilized to elicit and refocus the group discussion of PNs' experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes (see Table 6). However, the participants ultimately guided the discussion (i.e., concepts/new ideas brought up by the participants were being investigated) (Krueger, 2009). There was no time limit to the focus groups, which generally last about 60-90 minutes for this study. All focus groups were doubly digitally recorded, recordings transferred to a secure computer, transcribed verbatim, and reviewed for accuracy. Additionally, when possible notes were taken in order to capture observations about the participants as well as to provide back up

to the digital recorders (Krueger, 1994). The focus groups were conducted between the dates of August 7, 2012, and September 4, 2013.

#### **4.4.4 Analysis**

Qualitative content analysis, an accessible and theoretically flexible approach, was used (Sandelowski, 2000). An inductive approach was utilized in order to identify themes that are strongly linked to the data and not driven by a particular theory or theoretical interest area (Braun & Clarke, 2006). Analysis began after the first focus group was conducted and transcribed. ATLAS.ti (7.1.7), a qualitative database program, was used to facilitate the maintenance and organization of the data. The process of collecting, coding, and analyzing data occurred simultaneously and began with review by both the PI (J.A.D) and an experienced qualitative and focus group researcher (M.A.T).

The PI developed initial codes for naturally occurring units of meaning in the text taking place in the discussion. Coding was based on: the repetition of specific words, phrases, and opinions; the use of language and general thought patterns, and topics generated during the focus group discussion. The PI shared the codebook and uncoded transcripts with M.A.T, who independently coded the same transcripts. Each interview was reviewed and discussed and consensus on the coded transcripts was reached through discussion. The code list and definitions evolved and were refined with the coding process of each interview. When necessary new codes were created. This review process reduces bias and promotes consistency in the analysis of the data (Morgan ed., 1993; Krueger, 1994). Through constant comparison, codes were applied to text where relevant.

The data were then looked at from a broader level of themes emerging from the codes. In some instances several codes comprised a theme, where in others a single code might represent a theme (Braun & Clarke, 2006). A set of representative themes, agreed upon by the PI and expert, were derived from the data.

## 4.5 FINDINGS

Forty-eight PNs participated in the 11 focus groups. The researchers identified the following six themes related to parish experiences with providing diabetes education and PC to women (especially AA women) with T1D and T2D, and understanding of diabetes as it relates to pregnancy and pregnancy outcomes: 1) parish nurse role, 2) parish nurse approach, 3) parish nurse challenges, 4) parish nurse support network 5) parish nurse practice and programming, and 6) diabetes practice and programming.

### **Parish Nurse Role**

PNs describe their role to include that of a facilitator, advisor, and educator. They describe how they directly and indirectly care for patients, as their fellow parishioners may come to them seeking advice, guidance, or clarification about a health concern of a friend/peer or family member who does not attend the church:

“...they have daughters and they have grandchildren,..and they often talk about their concerns about their children and grandchildren. So that’s a way of getting information.”

There may actually be a trickle-down effect as younger women in the church may seek advice from a “wise woman” (older woman who may or may not be a relative or peer in the same age group) in the church:

“..they also feel comfortable among their peers an older, wise woman or another young mother who’s been there done that. And if the parish nurse can connect with that network of wise women with information, sending information to filter down...”

In addition, the PNs describe how a patient may reveal a diagnosis or health concern to them. This includes health status in general, diabetes, and pregnancy. They express that a diagnosis or health concern like diabetes often is not revealed to the PN until the patient is experiencing a problem that he/she would like advice or help with:

“..most of my contact with those who have diabetes have come because of, some other issue, and diabetes has come up...”

With this being said the PN may be unaware of a patient’s diagnosis until the patient is experiencing a problem or is in crisis:

“I think going back to the issue; it’s looking for opportunities to bring up these subjects because only in crisis do people come to us about the subject.” “They reach out when they start to go under.”

This may be related to lack of knowledge or education about a health condition on the part of the patient as well as unhealthy lifestyles:

“I know a lot of it is an unhealthy lifestyle. And they don’t know. They don’t understand. You know? They continue eating the Doritos, continue drinking the Pepsi.”

The PNs also describe their role as a member of the congregation and their relationship with their patients as being different than the standard nurse patient relationship and including a spiritual component to their healing, strong sense of trust and connection, and comfort with the setting. They provide more holistic comprehensive care:

“...you are in a place that they feel comfortable at, that instead of walking into a walk-in clinic or into some strange health fair and talking to a random person, you feel that there’s a little link there...they feel comfortable..”

## **Parish Nurse Approach**

PNs describe their approach as being more complete because their care includes the body, mind, and spiritual health:

“I think it’s more complete.” “...once the connection is made and once the person is heard, it just opens the door for all kinds of healing.”

They described time and how it does not dictate the care that they give which allows it to be more complete and allows for healing;

“I think a huge part of that is also that we have time, because we plan our own time...I was always limited in homecare and the push was for numbers. It’s not that way in parish nursing, because your time is how much time you want to spend with that person, which allows a lot more to happen, I think.”

Patients feel more comfortable talking to PNs because of their role:

“But a lot of people didn’t know me and yet trusted, almost anything I say, trust anything I say just because that’s the mindset of the faith community.”

The patients are in a familiar comfortable setting so it allows the establishment of trust between the PN and patient:

“...there was immediate trust..I think it’s because it’s in the faith community setting...”

They see themselves in a very supportive role:

“I recently had one of our youngsters who came down with juvenile diabetes and her parents were devastated. And so, they confided that to me in church, and basically, that’s what I did, you know, gave them spiritual and supportive assistance...”

They build trust with their patients and the community in order to make change in their patients’ lives:

“Building up relationships of trust in the community...But just building up trust relationships with people that live right next door and then, I noticed this almost right away when I was identified as a nurse.”

Parish nurses discussed their personal philosophies of how God works through them by using them as tool to help their patients, being in the right place at the right time:

“Well, our specialty is linking faith and health.”

The parish nurse integrates spirituality into her practice.

“So, all the other things, all of the medical things, and the referrals, and all of that, anybody can do that. The parish nurse is the one who remembers that the spirituality piece is the important piece we focus on, because that's so often missed in our health care today.”

They may incorporate the mind, body, and spirit:

“...it's a curriculum that integrates mind, body, spirit,...”.

They also discussed the use of motivational interviewing to help their patients discover how they approach and think through health related situations:

“...I certainly do see my role as someone who walk alongside them as they go through this but many other issues related to health and wholeness and their faith journey.” “...I see a strong role for me as a health minister to kind of help her assess what the effectiveness of all these are...Where she can turn so she's not overwhelmed and neglected and not having what she needs.”

They try to incorporate alternative medical therapies with an integrative approach. These therapies could be free or low cost and should be integrated with medical interventions that are being prescribed by their medical providers. Doing this bridges a gap in healthcare:

“And they feel so safe in the parish you know. It's a perfect place for the future of healthcare and integration in the community of faith and because there's trust there. So you can integrate faith with healthcare.” “...we are bridging the gap. Integrative medicine is I think coming forward.”

They also discussed how their holistic approach is different from general nursing practice. The PNs describe this process as a more complete caring that incorporates the idea of spiritual caring and support, the link of faith to health:

“...It's just all about education of body and spirit and combining what we can to provide a wonderful educational opportunities for our congregation.”

This approach includes the concept of being present and active listening, being with someone and supporting them through prayer and being there with them in a physical nature provide peace and comfort for both patient and nurse:

“I believe so strongly that, you know, when you have that connection with someone who is non-judgmental, who’s caring, who’s offering unconditional love, just being a presence, I think that just serves the person so much better than any other medical intervention we can offer.”

Being present does not mean fixing something, it means providing unconditional love, caring, and support that are nonjudgmental and allow for a sense of accountability and thus trust:

“...just being present. Not fixing anything, just being there...”.

### **Parish Nurse Challenges**

The PNs also described some of the challenges they face. For example, isolation can be a problem because they may be practicing as the only one or one of a few in their churches:

“There is one other parish nurse.”

Therefore, their relationships with other PNs are very important.

Other challenges that the PNs described include the vast number of possible health problems, conditions, and treatments that exist and being unable to be an expert in all areas:

“I also think that there are so many areas that we touch upon in parish nursing that we don’t really have the time to spend on a very, very deep subject...”

They described often feeling that recommendations for health conditions may be outside of their scope of practice and thus they see themselves often in the role of facilitator by helping get a patient connected with the appropriate resources because they want to give their patients accurate information:

“...I could see where I would outsource that referral to the experts...”.

The PNs also expressed that their patients may not be treated justly in the healthcare setting despite the fact that they may have insurance and access to care:

“...people are not treated equitably. So women of color for example, have insurance, access to care, they go, but they still have high mortality rates in almost every category- infant mortality, diabetes, you name it. ..the professionals, they think they are giving them good care. So something’s missing in there,...they may not get what they need.”

In addition, they feel that their patients may have difficulty understanding and deciphering what is important from the vast amount of healthcare information they receive:

“Sometimes the volumes of information that parishioners receive from their doctor or their nurse or their expert is just- it’s so much information...”

They also describe challenges related to their patient’s status, needs, and barriers such as reading level, intellectual abilities, lack of insurance, and language barriers:

“It was given, but they can’t read it...”. “The intellectual ability of the person makes a huge difference-a huge difference in what they retain, and how often you have to go over the same thing over and over and over again.” “A lot of them are Haitian, and I don’t speak Spanish, so it’s challenging.” “...they don’t have insurance. So, I have to find a way to get them to the doctor in the first place.”

The PNs also described why a patient might not seek care from a PN. These include being unaware of having a health problem or at-risk condition:

“And programs, they don’t necessarily go to them because they don’t see a need to talk about those things.”

Another circumstance is being undocumented; in these cases patients may need time to get to the point of the trusting relationship.

“...I have a whole population that are undocumented and uninsured...But you know, when you get undocumented and stuff like that, they don’t they’re not comfortable (to) admit to anybody they’re not even supposed to be here.”

### **Parish Nurse Support Network**

Because of the PNs’ isolation, mentioned above, creating a support network and establishing relationships and connections with other PNs is imperative:

“..I think as we move forward and expand our program it’s great to have the ability to speak with parish nurses, be involved in the process. Things that I can not only take back to my parish, but also to help those other programs. If a PN has come upon a new resource or new method of care that can be effective in the PN setting she is able to share this with others. ...”

This network also allows for the dissemination of information among them:

“We don’t need to reinvent the wheel, if it’s some that already does that, we support that and we know where to send people.”

### **Parish Nurse Practice and Programming**

The PNs described those for whom they care in their role as a PN as well as those who attend their faith-based communities/churches who could be potential patients:

“...we’re kind of... a mixture, young, middle-aged, and elderly population...” Their description includes demographic information such as age, race, socioeconomic status, and most common disease processes that their patients experience. “...my church is primarily African American...”

The PNs described how their practice is funded. Some positions are paid but for the most part they are volunteering their time. They may seek funding from their church, donations, and/or grants and even support a lot of their practice with their own money. Because of limited funding, their ability to seek additional continuing education may be reduced:

“...a lot of faith community nurses are in an unpaid situation. So, we do not get money for anything. So anything that we essentially need is paid for out of pocket. So we do continued education for our own good, also for state licensure, but it still has to be affordable....you’ve already got people donating their time, ... poor on their resources.”

In addition, they describe their resources to include referral to programs (in the community, through hospital systems, other PN practices) that already exist if they cannot or do not provide it in their own practice:

“I’m not reinventing the wheel. I connect with all these different places and I search these places out...And then I connect-and these places...”

The PNs described in detail the programming that they offer to their patients in their practice. Health services include home visits, hospital/nursing home visits, office visits, and phone calls:

“...I do lots of visitations in homes, hospitals, nursing homes, and office visits.”

Health education was described as ranging from one-on-one teaching based on patient need to a formal program. Blood pressure screenings were described as a way PNs start a conversation about health that often leads to offering health education:

“Usually the people that have-are on my blood pressure list are diabetics also, so you get a chance for about three minutes, five minutes, to sort of discuss ‘How are you doing?’ ”

Less direct education was provided through health articles in the church bulletin/newsletter, health bulletin boards, and laying out pamphlets and health education materials in high traffic areas:

“In what we do is our bulletin board...utilizing the most simplistic, eye-catching attention for that sentiment for that month...”

Directed formal health education was described as education on general wellness, basic nutrition, activity, promoting getting physical check-ups, and foot care:

“We also do education, for example, kind of life issues planning.” Some also describe wellness fairs that may include lab screening (glucose), blood pressure checks, bone density screening, blood drives, and flu shot clinics. “Yes, we have community events, there was a health fair...”. “...we provide community resources like flu clinics and insurance discussions...”.

They have offered resources including health education materials in the church library, and bible studies incorporating self-management, counseling groups/support groups:

“We have a little section in the library on health issues...” “We have a chronic disease kind of self-management bible study group.”

In addition, health professionals who attend the church may talk to parishioners about health related to their specialty area.

“...one of the parishioners who helps our group is a registered dietitian,...so we have some talent within the parish. It was a great example of pulling in some talent...”

### **Diabetes Practice and Programming**

The PNs described patients in their faith-based settings with a diagnosis of diabetes:

“I’d say about twelve percent of our congregation have diabetes.” “At our church, I’d say a good ninety percent.” “...most of my females will be diabetic” “Most of them are Type 2”.

They also described that these numbers would be even higher if those who are pre-diabetics, at risk for developing diabetes, or unaware themselves of having diabetes were considered.

“But we are finding out that more and more people are discovering they have diabetes, so it’s like-it’s undiagnosed...” “I think for the large percentage they just don’t know that they’re diabetic, or in denial.”

The PNs also described the experiences they have had providing care for patients with diabetes. These included informal discussion when a patient reveals that he/she has received a diagnosis of diabetes and then discuss the diagnosis when he/she comes to a church dinner/coffee hour:

“But I do see that where during coffee hour, there’s more-more elderly will say to me, ‘Well, you know, I can’t really have a donut because I have diabetes.’ And then that is my opening to start talking to them about it.”

Or it may be to have his/her blood pressure checked.

“And very often, once they starting coming in for their blood pressure, I usually ask them if they have any other medications that they’re taking for anything. And very often, then they’ll say, ‘Well, yeah. I’m diabetic,’ or something like that. So, that’s about the only way I’m determining-you know, again, from people who are just presenting themselves for something else...”

The PNs also described misconceptions their patients have about diabetes.

“And talking to them, we learned how little education they had received about (diabetes)...except they couldn’t have sugar, and they did not realize that they could qualify for education through their insurance about what they could eat and how they could manage their own diet.”

The type of education done with patients who have diabetes was also described. This education can range from being very informal to a more formal program and include those who are at risk for diabetes as well as those who already have a diagnosis:

“...it’s more like inquiring from them....so kind of a roundabout way that I try to educate them.” “They’ve held health fairs, and we are planning, in our particular church, planning a health fair...And of course, the blood sugar screen...part of the health fair.”

Some do not currently provide care, education, or programming that is specific to patients with diabetes, because they are newer to the practice and have not yet been able to establish these programs or because they have started to practice in a new faith-based setting:

“We don’t have anything specifically directed towards diabetics formally available.” “I’ve been a parish nurse since...it was a year and a half,...so we’re kind of a new ministry.”

Informal education is described as fliers and signs discussing symptoms and warning signs of diabetes, newsletter, and one-on-one discussions about medications or insulin administration teaching:

“ ‘How’s your diabetes?’ That kind of informal conversation happens. Like never a focused class.”

The participants describe more formal programs differently as some have a medical professional other than the PN (physician, dietician, diabetes educator) presenting them:

“...we had four sessions with the diabetic educator.”

They also talked about foot health and complications like cardiovascular disease. They have included discussion groups and support groups:

“...but we did a one-month series on diabetes...”. “...I offered a diabetic program, education program, and a discussion group.” They held an entire health fair dedicated specifically to diabetes. “We did have a diabetes fair...”

### **Pregnancy Practice and Programming**

The PNs noted that women of childbearing age were present in their churches, creating an opportunity for education and counseling:

“...we have quite a few middle-age and young people, so there are childbearing age people in the congregation...”

They described that, to date, they have had little to no care interaction, programming or education around pregnancy:

“..in my home parish, I have not had the opportunity to work with any pregnant women.”

## **4.6 DISCUSSION**

By using a focus group approach, we explored parish experiences with educating members of their congregation with T1D and T2D especially AA women. Six themes emerged from the PN's discussion including: their role and approach and unique practice situate PNs perfectly to provide life altering care and education. They may be able to influence positive health related decision-making. This is especially true in AA communities which may experience either lack of insurance and/or access to care and lack of health equity.

Parish nurses face unique challenges due to the nature of their care. One important challenge mentioned is isolation, thus making the parish nurse support network extremely important.

Parish nurses are savvy at providing health education. They currently provide health education on multiple topics that they see fit for their patients. Many provide diabetes education in ways specific to their patient needs. However, they currently are not providing diabetes education related to pregnancy or PC. The PNs also discussed that to date the majority of

parishioners that they currently work are beyond the childbearing years. However, they acknowledge that women of childbearing age are present in their churches through regular church activities as well as outreach activities with the community. Furthermore, they note that PC for women with diabetes is an important topic, and that they would provide PC education if they had training and a tool to use. Considering that a range of childbearing age (13-45) women will be present in the churches, i.e. youth groups, youth choirs, church schools, vacation bible school; pre-marital counseling; mothers of children in church-based preschools; and women's ministries, different approaches to education for these groups should be considered. This also has implications for outreach, program development, and elements that would need to be included in the toolkit described by the PNs.

An article by Dyess, Chase, and Newlin (2010) reviewed the state of research for parish nursing. In this article the authors identify a content area as roles and activities of parish nurses. The authors discuss seven studies that include information about the role of the parish nurse. According to the review, all but one article describe the role of the parish nurse as similar to the results of this study. Some of the main role topic overlap includes: spiritual care, holistic care, health promotion and education activities, counseling, referring, and active listening. Confirming results of this study would be included as a strength. Additionally, there is no discussion related to the health education theme incorporating anything related to pregnancy. Furthermore, to our knowledge there is only one study that has been done utilizing parish nurses with women who have gestational diabetes. Therefore, this study is the first study to describe PNs experiences, understanding, knowledge, and confidence related to diabetes involvement with pregnancy and PC. An additional strength of the study is that the focus group methodology utilized distance

methods which allowed for a larger more diverse sample and was convenient for those who could not physically be present.

One of the main limitations is that the sample was obtained from contacts of a single parish nurse organization in Pittsburgh with subjects mainly from western Pennsylvania with fewer focus group participants from other locations. Therefore, the study findings may be more representative of PNs from the Pittsburgh area and may not necessarily be representative of parish nurses across the country. To counteract this possibility purposive sampling was utilized to maximize variation of study participants minimized this limitation. Furthermore, given the large sample pool of parish nurses in this organization, broad representation was anticipated. In addition, the cross-sectional nature of this study did not permit test-retest reliability on the quantitative measures. Additional data collection points would be preferred.

Parish nurses are uniquely situated not only because they practice in a community setting, putting them in closer proximity to the homes of clients, but also because of they are in a setting where patients may attend on a regular basis and share similar set of values due to their faith. This allows for a relationship that has many more dimensions, which develops a greater sense of trust compared to a traditional nurse-patient relationship. The PN provides holistic care including the physical, mental, and spiritual aspects of a person; incorporating faith into care, health promotion and prevention activities.

#### **4.7 IMPLICATIONS**

By exploring the parish experiences with educating members of their congregation with T1D and T2D (especially AA women) we can better understand their needs related to resources and

training. In our study of PNs, who are uniquely poised to deliver care to a vulnerable population of underserved women with DM, we begin to address a gap in the literature related to the lack of awareness and lack of available education programs regarding PC. In this sample, we found that PNs were unaware of PC because they had not received it in their formal training or never sought it out in continuing education programs (CEU). Because PNs are volunteer and have limited funding for CEU courses they may not have selected a program on PC. Therefore, future research could develop a more tailored program for PNs regarding PC which could make a significant impact of women with diabetes, especially those who have the potential to become pregnant.

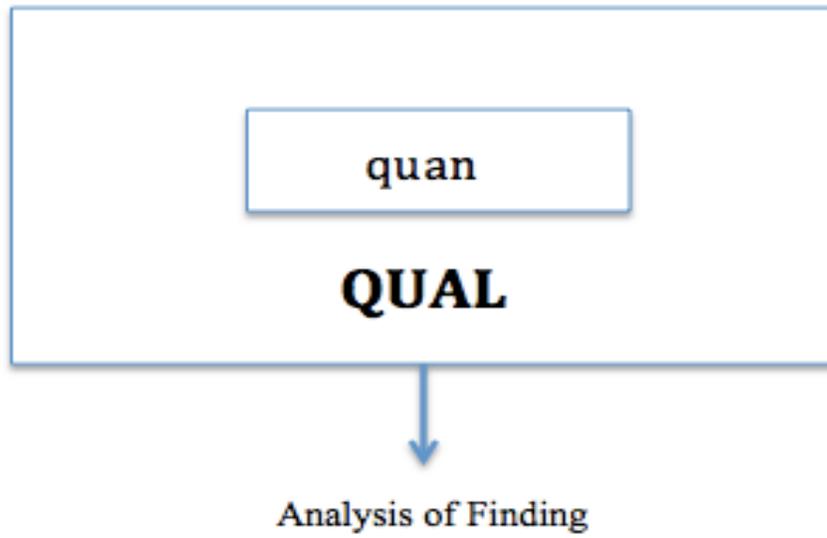
The results of this study supports the need for future development and testing of a prototype for a technology-based training, as well as a prototype E-health education resource for parish nurses to use with African American women with diabetes related to pregnancy and PC, both of which will be tailored from an already existing educational program and training component to be more culturally relevant for African American women. The PNs gave some very specific suggestions for the toolkit that they described. One of these points included that the toolkit include general information about PC in addition to specifics about diabetes and pregnancy. Other considerations might include education extending beyond the preconception period to when a woman becomes pregnant, post-partum and include information on lactation.

## 4.8 ACKNOWLEDGEMENTS

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Table 6: Focus Group Questions and Probes

<b>Focus Group Questions with probes</b>
<b>Opening Statement</b>
Tell me about your role or practice as a parish nurse?
a. Tell me about those you care for as a parish nurse?
1. What percent of your patients have T1D or T2D?
a. About what percent of these are female?
b. About what percent are within their childbearing years?
2. What do you teach your patients about diabetes?
3. Tell me about how you provide this education or programming?
4. How confident do you feel providing this education?
5. What more do you feel you need to know about diabetes to educate your patients?
6. What do you teach your patients about diabetes and pregnancy?
7. What do you know about preconception counseling?
8. Have you discussed preconception counseling to women with diabetes?
9. How might this information be helpful to have?
10. How confident do you feel providing preconception counseling?
11. What more do you feel you need to know about preconception counseling for women with diabetes in order to provide this education?
12. Have you ever gotten formal instruction about preconception counseling or pregnancy with diabetes? From where?
a. Would you benefit from further preconception counseling training?
i. If yes, what would an ideal training program look like?
b. Would your community benefit from further preconception counseling training?
i. If yes, what would an ideal tool or program to use with your patients look like?



**Figure 3.** Concurrent Embedded Design

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## **APPENDIX A**

### **SOCIODEMOGRAPHIC MEASURE**

Instrument Number:

0 4 1

Shade circles like this: ●  
Not like this: ○

Study ID: 1 8 0

### REPRODUCTIVE HEALTH PROGRAM FOR WOMEN WITH DIABETES SOCIODEMOGRAPHIC QUESTIONNAIRE

ID Number:

Administration Date:   /   /

(month) (day) (year)

(FOR STAFF USE ONLY)

Please use **BLACK** Pen Only!

**Instructions:** Please answer the following questions by filling in the circle that corresponds to your response.

**1. What is your age?**

- 1) < 25
- 2) 25 - 30
- 3) 31 - 40
- 4) 41 - 50
- 5) 51 - 60
- 6) > 60

**3. What is your race?**

- 1 Caucasian
- 2 Black or African American
- 3 Asian
- 4 Hispanic
- 5 Other, specify --o

\_\_\_\_\_

(for office use only)

**2. What is your gender?**

- 1 Male
- 2 Female

**4. What is your highest level of nursing education?**

- 1 Diploma
- 2 Associates
- 3 Bachelors
- 4 Masters
- 5 PhD /DNP
- 6 Other, specify --o

\_\_\_\_\_

(for office use only)



ID Number: \_\_\_\_\_  
(for internal use only)

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
(for internal use only)

Study ID: 

1	8	0
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**Instructions:** Please answer the following questions by writing in your response in the space provided.

5. In what year did you obtain your nursing license? 

--	--	--	--

6. In what year did you obtain your parish nurse certificate? 

--	--	--	--	--

7. How long have you practiced in the role of parish nurse?

- 1) Less than 1 year
- 2) 1 year to less than 3 years
- 3) 3 years to less than 6 years
- 4) 6 years to less than 10 years
- 5) 10 or more years

8. What are the three most prevalent aspects of your job as parish nurse?

- a. \_\_\_\_\_
- b. \_\_\_\_\_
- c. \_\_\_\_\_

(for office use only)


9. What do you feel are the top three medical conditions that your patients experience?

- a. \_\_\_\_\_
- b. \_\_\_\_\_
- c. \_\_\_\_\_

(for office use only)


ID Number: \_\_\_\_\_  
(for internal use only)

Date: \_\_\_ / \_\_\_ / \_\_\_  
(for internal use only)

Study ID: 1 8 0

We are interested in knowing about the people in your congregation. You may not know exact percentages, but, please give us your best guess . . . .

10. What percentage of your congregation are of the following races?

[ Keeping in mind that the percentage total cannot exceed 100%, enter the percentages in the boxes provided. ]

<input type="text"/>	<input type="text"/>	<input type="text"/>	%	a. Caucasian	
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	b. Black or African American	
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	c. Asian	
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	d. Hispanic	
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	e. Other; specify ----->	<input type="text"/> _____

(for office use only)

11. What percentage of your congregation are females?

%

12. What percentage of your female congregants are of child-bearing age? [ ages 13 - 45 ]

%

13. What percentage of your congregation do you believe to have diabetes?

[ "Diabetes" includes Type 1 Diabetes Mellitus, Type 2 Diabetes Mellitus, or Gestational Diabetes. ]

%

14. Estimate what percentage of your congregation falls into the following categories for a household gross annual income:

[ Keeping in mind that the percentage total cannot exceed 100%, enter the percentages in the boxes provided. ]

<input type="text"/>	<input type="text"/>	<input type="text"/>	%	a.) Below \$15,000
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	b.) \$15,000 - \$24,999
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	c.) \$25,000 - \$49,999
<input type="text"/>	<input type="text"/>	<input type="text"/>	%	d.) \$50,000 and above

## **APPENDIX B**

### **PC KNOWLEDGE MEASURE**

Instrument Number:

0 4 3

Mary M. Collins, Susan M. Swartz, Andrea Rodgers-Park, Patricia L. Schell and Denise Chertow-Pacheco. A self instructional program for diabetes education or preconception counseling for women with diabetes. The Diabetes Educator 2008; 32(4): 402-404.1

Study ID: 1 8 0

Shade circles like this:  
Not like this:



### REPRODUCTIVE HEALTH PROGRAM FOR WOMEN WITH DIABETES PRECONCEPTION COUNSELING KNOWLEDGE

ID Number:

10 digit ID number input boxes

Administration Date:

MM/DD/YYYY date input boxes

(month)

(day)

(year)

(FOR STAFF USE ONLY)

Please use **BLACK** Pen Only!

**Instructions:** Please indicate whether the following statements concerning women with diabetes are "True" or "False" by filling in the circle that corresponds to your response.

	True	False
	1	2
1. Up to two thirds of women with diabetes have unplanned pregnancies.	<input type="radio"/>	<input type="radio"/>
2. Risk of congenital malformations can be reduced if A1C values in early pregnancy are less than 3% above normal range.	<input type="radio"/>	<input type="radio"/>
3. The incidence of malformations in infants of mothers with diabetes has been 9%.	<input type="radio"/>	<input type="radio"/>
4. The goal of glycemic control is fasting glucose levels below 120 mg/dl (7 mmol/l).	<input type="radio"/>	<input type="radio"/>
5. Counseling to prevent complications of pregnancy should begin at the beginning of the first trimester.	<input type="radio"/>	<input type="radio"/>
6. Preconception counseling should include birth regulation methods.	<input type="radio"/>	<input type="radio"/>
7. Women contemplating pregnancy should be evaluated and treated for retinopathy, nephropathy, neuropathy, and cardiovascular disease.	<input type="radio"/>	<input type="radio"/>
8. Women with hyperlipidemia who are trying to conceive should be prescribed a statin to achieve normal lipid levels.	<input type="radio"/>	<input type="radio"/>
9. For T2D, oral antidiabetic agents should be discontinued before pregnancy and insulin prescribed.	<input type="radio"/>	<input type="radio"/>
10. Ace inhibitors should be stopped in women with diabetes who are contemplating pregnancy.	<input type="radio"/>	<input type="radio"/>



ID Number: \_\_\_\_\_  
(for internal use only)

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
(for internal use only)

Study ID: 1 8 0

	True 1	False 2
11. Increasing exercise tolerance is an important goal for women with diabetes who are contemplating pregnancy.	<input type="radio"/>	<input type="radio"/>
12. Proteinuria > 190 mg/24 hours increase the risk of hypertension in pregnancy.	<input type="radio"/>	<input type="radio"/>
13. Serum creatinine > 3 mg/dl or creatinine clearance < 50 ml/min could permanently worsen renal function during pregnancy in women with diabetes.	<input type="radio"/>	<input type="radio"/>
14. If a woman doesn't conceive in one year, an infertility referral is indicated.	<input type="radio"/>	<input type="radio"/>
15. A multidisciplinary team is crucial to providing preconception counseling.	<input type="radio"/>	<input type="radio"/>
16. All women of childbearing age should receive preconception counseling.	<input type="radio"/>	<input type="radio"/>
17. Preconception care for women with diabetes must include TSH and T4 test.	<input type="radio"/>	<input type="radio"/>
18. Psychological counseling for coping and stress skills are important components of preconception counseling.	<input type="radio"/>	<input type="radio"/>
19. During pregnancy, maternal insulin requirements increase 4-5 times the normal dose.	<input type="radio"/>	<input type="radio"/>
20. Diabetic retinopathy may accelerate during pregnancy.	<input type="radio"/>	<input type="radio"/>
21. Preconception counseling does not routinely include education in diabetes self-management skills.	<input type="radio"/>	<input type="radio"/>
22. Renal function may worsen transiently during pregnancy.	<input type="radio"/>	<input type="radio"/>
23. The "in-Depth" phase is the first phase of preconception counseling.	<input type="radio"/>	<input type="radio"/>
24. Preconception counseling should begin at puberty.	<input type="radio"/>	<input type="radio"/>
25. Pregnant women should not inject insulin in the abdomen.	<input type="radio"/>	<input type="radio"/>

<sup>1</sup> Gary M. Collier, Susan M. Barkin, Andrea Rodgers-Peck, Patricia L. Schulz and Charles Chertok-Prichard. A self-instructional program for diabetes education on preconception counseling for women with diabetes. *The Diabetes Educator*. 2003; 30(4): 482-486.

<sup>2</sup> American Diabetes Association. Position statement: preconception care of women with diabetes. *Diabetes Care*. 2004;27:1629-1635.

<sup>3</sup> Janel M. Herman WH, Becker MP et al. Diabetes and Pregnancy: factors associated with seeking preconception care. *Diabetes Care*. 1998;21:107-109.

<sup>4</sup> Janel M. Herman WH, Becker MP et al. "Pregnancy and Diabetes Interview Schedule" (PDI) (NIDDK/NIH P30 NR 03942-01C2). 1992. University of Michigan, Graduate School of Public Health.

## **APPENDIX C**

### **PC SELF-EFFICACY MEASURE**



*How confident are you that you could provide the following to female clients of childbearing age with diabetes . . . .*

<p><b>5. Information about diabetes and pregnancy (risks, complications, management)?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>6. Information on obtaining excellent glucose control prior to pregnancy?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>7. Information on testing for Rubella Antibodies?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>8. Information on the risks of smoking and alcohol in pregnancy?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>9. Information on identifying the time of conception?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>10. A pregnancy evaluation (pregnancy test)?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>
<p><b>11. A referral for (or provide) genetic counseling?</b></p> <p>Not at all Confident <span style="float: right;">Absolutely Confident</span></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><input type="radio"/> <input type="radio"/></p>





**APPENDIX D**

**FOCUS GROUP GUIDE**

Hello, my name is Jessica Devido and I am a current PhD student at the University of Pittsburgh School of Nursing. I would like to welcome you here today, and thank you for taking some time out of your busy day to spend with us.

The purpose of this research study is to better understand your role as a parish nurse and your current practice regarding diabetes education, particularly for women who have diabetes who have the potential to become pregnant. I want to get input from all of you, the experts, practicing parish nurses. For that reason we will be asking you to fill out three brief surveys (approximately min 20) and participate in a focus group discussion (approximately 1.5 hours).

If you are willing to participate, our questionnaires will ask about background (e.g. race, age, nursing degrees and years obtained, years since participates in the parish nurse certificate program, years spent practicing as a nurse/parish nurse, areas you feel you have specialized in), as well as your knowledge, experience, and confidence to provide diabetes education. In addition, you will be participating in a focus group, which is a directed discussion around a particular topic, the “focus” of the group. This is not a therapy group but rather an opportunity to gather information from you, the experts. Your knowledge, opinions, and perceptions will help us to understand your role as parish nurse as it relates to diabetes education. I encourage all of you as possible to share your points of view. Please note that the purpose of today is not to reach any one conclusion but gather ideas that are presented.

There are no foreseeable risks associated with this project, nor are there any direct benefits to you. Each participant will receive free parking, free diabetes education materials for her patients, and access to a continuing education program that will provide you with 4 free nursing CEU credits when completed as a token of our appreciation.

After our session today, the information will be compiled, analyzed and shared with you, the participants to ensure accuracy of the information we obtain for later use. The group will be digitally recorded. All responses are confidential, and results will be kept under lock and key. Your participation is voluntary, and you may withdraw from this project at any time. Permission to participate today gives me the permission to contact you later for future research. If you prefer not to be contacted later please let me know at the conclusion of our discussion.

First I would like to clarify the roles of the group participants. I will act as the facilitator and I will be asking the questions and then clarifying uncertain terms or ideas and verifying information that is presented. I will be non-judgmental so please try to be as honest as possible with your answers. Please keep in mind that I am not here to answer questions, you are the experts but I will field questions that arise back to the group and will provide a debrief at the conclusion of the discussion to allow for any additions as well as keep track of our time.

You might have noticed the woman who is sitting on the outside of our circle; she is going to act as the recorder today. During our discussion she will be taking notes and gathering information from the discussion based on your comments. She will not be interacting or participating in the group discussion but will help with the debriefing at the conclusion. If you need to use the restrooms during your time here today they are located ...

Finally, let's discuss your role as participants. I am asking today that you will openly discuss the questions that are posed to you; please know that everything you tell us is valuable.

Just to touch on some ground rules before we start our discussion: please speak one at a time and in a very loud and clear voice. Voice your disagreements when the speaker is finished and please respect the confidentiality of the group. With that being said the content that is discussed in this session today needs to remain private and personal. We will respect the

confidentiality of the group by keeping the names of the participants private; information presented will not be connected to an individual. In addition, the recorder's notes will be locked in a file cabinet and digital recordings will be destroyed after transcription. Finally, please know that you can leave at any time.

Before we move on, do you have any questions?

### Focus Group Questions

#### Opening Statement:

1. Tell me about your role or practice as a parish nurse.
  - a. Tell me about those you care for as a parish nurse.
  
1. What percent of your patients have T1D or T2D?
  - a. What percent of these are female within their childbearing years?
2. What do you teach your patients about diabetes?
3. How confident do you feel providing this education?
4. What more do you feel you need to know about diabetes to educate your patients?
5. What do you teach your patients about diabetes and pregnancy?
6. What do you know about preconception counseling?
7. Have you discussed preconception counseling to women with?
8. How might this information be helpful to have?
9. How confident do you feel providing preconception counseling?
10. What more do you feel you need to know about preconception counseling for women with diabetes in order to provide this education?
11. Have you ever gotten formal instruction about preconception counseling or pregnancy with diabetes? From where?
  - a. Would you benefit from further preconception counseling training?
    - i. If yes, what would an ideal training program look like?
  - b. Would your community benefit from further preconception counseling training?
    - i. If yes, what would an ideal training tool or program look like?

**APPENDIX E**

**IRB APPROVAL**



**University of Pittsburgh**  
*Institutional Review Board*

3500 Fifth Avenue  
Pittsburgh, PA 15213  
(412) 383-1480  
(412) 383-1508 (fax)  
<http://www.irb.pitt.edu>

**Memorandum**

To: Jessica Devido  
From: Sue Beers PhD, Vice Chair  
Date: 1/20/2012  
IRB#: [PRO11120315](#)  
Subject: Parish Nurses Providing Diabetes Education/ Preconception Counseling To African American Women: A Mixed-Method Design

---

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2).

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

**APPENDIX F**

**APPROVAL FROM DR. DENISE CHARRON-PROCHOWNIK FOR USE OF  
MEASURES**

Sent: Wednesday, April 02, 2014 5:44 PM

To: Devido, Jessica A

Yes you have my permission.  
Denise Charron-Prochownik

Denise Charron-Prochownik, PhD, RN, CPNP, FAAN  
Professor  
Nursing and Graduate School of Public Health  
Chairman  
Department of Health Promotion and Development  
School of Nursing  
440 Victoria Bldg  
University of Pittsburgh  
Pittsburgh, PA 15261  
412-624-6953  
412-624-8521 (fax)  
dcpro@pitt.edu

-----Original Message-----

From: Devido, Jessica A  
Sent: Wednesday, April 02, 2014 3:31 PM  
To: Charron-Prochownik, Denise  
Subject: Permission

Hello Dr. Charron-Prochownik,  
I am writing to request permission for use of your two measures, "Preconception Counseling Knowledge for Certified Diabetes Educators" "PC Self-Efficacy for CDEs" both of which are discussed in the following article in which you are the senior author:

Cothran, M., Sereika, S., Fischl, A., Schmitt, P., Charron-Prochownik, D. (2009). A self instructional program for diabetes educators on preconception counseling for women with diabetes. *Diabetes Educator*, 35(4), 652-656.

The measures were used to collect data from parish nurses related to their knowledge and teaching self-efficacy of diabetes and pregnancy and PC, the measures will be copied and administered to 50 parish nurses. They are in their original format with a modification for parish nurses as follows: The IRB at the Catholic Hospital that houses the parish nurse program office required changing the terminology "birth control methods" to "birth regulation methods" on the measures in order to uphold ethical and religious directives of the Catholic moral teaching.

These measures are fully referenced in any description of their use in the study including my dissertation titled: Exploring the Role of the Parish Nurse in Providing Diabetes Education and Preconception Counseling to African American Women Using a Community-Engaged Mixed-Methods Approach, that will be available on the University of Pittsburgh electronic dissertation website and manuscripts that are part of the dissertation and will be submitted for journal publication.

**APPENDIX G**

**PERMISSION FROM SAGE PUBLISHING FOR USE OF FIGURE**

**RE: Dissertation Document**

Binur, Michelle [Michelle.Binur@sagepub.com] on behalf of permissions (US) [permissions@sagepub.com]

Sent: Wednesday, April 02, 2014 6:53 PM

To: Devido, Jessica A

Dear Jessica,

Thank you for your request. You can consider this email as permission to reprint the material as detailed below in your upcoming dissertation. Please note that this permission does not cover any 3rd party material that may be found within the work. We do ask that you properly credit the original source, SAGE Publications. Please contact us for any further usage of the material.

Best regards,  
Michelle Binur

Rights Assistant  
SAGE Publications Inc.  
Michelle.Binur@sagepub.com

[www.sagepub.com](http://www.sagepub.com)

Los Angeles | London | New Delhi  
Singapore | Washington DC  
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-----Original Message-----

From: Devido, Jessica A [<mailto:jac40@pitt.edu>]

Sent: Wednesday, April 02, 2014 12:50 PM

To: permissions (US)

Subject: Dissertation Document

To whom it may concern,

I am a PhD student at the University of Pittsburgh School of Nursing. I am getting ready to defend my dissertation titled: Exploring the Role of the Parish Nurse in Providing Diabetes Education and Preconception Counseling to African American Women Using a Community-Engaged Mixed-Methods Approach. I am using a mixed-method concurrent embedded design using focus group methodology as the primary method and a quantitative descriptive design with 3 self-report measures (demographic, PC self-efficacy, and PC knowledge) as the secondary method and I cite/reference the description of this method from the book:

Creswell J. (2009). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches, 3rd edition. Thousand Oaks, CA: Sage.

I am writing to request permission to include the figure (10.3) that is used to describe this method found on page 210. With permission I will fully reference the figure.

**APPENDIX H**

**PERMISSION FROM AUTHOR DR. JOHN CRESWELL FOR USE OF FIGURE**

 Reply  Reply to All  Forward  Move  Delete  Junk | Close

## **FW: Permission Needed**

Candace Ristow [cristow2@unl.edu]

**Sent:** Friday, April 04, 2014 9:46 AM

**To:** [Devido, Jessica A](#)

Dear Jessica,

My sincerest apologies, here is a more complete response and preferred by Dr. Creswell. I hope this response is helpful and assures you of Dr. Creswell's permission, as well.

You have Dr. Creswell's permission to use the material from one of Professor John W. Creswell's books, but you do need to go to SAGE Publications (sage pub.com) for permission. They hold the copyright to Dr. Creswell's books.

Thank you.

Candy Ristow

Executive Assistant to Professor Creswell University of Nebraska-Lincoln

Email: cristow2@unl.edu

---

**APPENDIX I**

**PRELIMINARY STUDY MANUSCRIPT**

**Characteristics of Young Women With Diabetes who Initiate Communication Regarding  
Preconception Counseling With Health Care Providers**

**Cover Letter to Journal Editor**

April 18, 2014

Dear Editors and Reviewers,

Please consider the attached manuscript, “Characteristics of Young Women With Diabetes who Initiate Communication Regarding Preconception Counseling With Health Care Providers” for publication in the Journal of Diabetes Educators. examine the relationship between internal characteristics (age, race, religiosity), external characteristics (sexual activity status, social support, type of routine health care provider [HCP]) and intention to communicate and actual communication with health care providers about preconception counseling (PC) among adolescent females with diabetes.

Jessica Devido is serving as the first and corresponding author. Please feel free to contact her with any questions that may arise.

Regards,

Jessica Devido, PhD(c), MSN, CPNP, RN

University of Pittsburgh School of Nursing

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University of Pittsburgh School of Nursing

Email: [dcpro@pitt.edu](mailto:dcpro@pitt.edu)

**Characteristics of Young Women With Diabetes who Initiate Communication Regarding  
Preconception Counseling With Health Care Providers**

Running head: CHARACTERISTICS OF YOUNG

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Health Promotion and Development

University of Pittsburgh School of Nursing

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Denise Charron-Prochownik, PhD, RN, CPNP, FAAN, Professor and Department Chair, Health  
Promotion and Development

University of Pittsburgh School of Nursing and School of Public Health

Pittsburgh, PA

## **Abstract**

**Purpose:** To examine the relationship between internal characteristics (age, race, religiosity), external characteristics (sexual activity status, social support, type of routine health care provider [HCP]) and intention to communicate and actual communication with health care providers about preconception counseling (PC) among adolescent females with diabetes.

**Background:** The strongest predictor for women to seek preconception care and plan their pregnancy was having been told by a health care provider to seek PC when planning a pregnancy, thus raising their awareness. However, a gap exists related to the characteristics of young women who initiate communication with their HCPs about PC.

**Methods:** A secondary data analysis examined baseline data of 110 female adolescents (92% Type 1 Diabetes [T1D]) who participated in a PC intervention study called READY-Girls. Participants came from two study sites. Statistical analysis included descriptive statistics and multiple regression.

**Results:** Subjects' ages ranged from 13.28 to 19.95 years, 81.8% were Caucasian, 80% had never been sexually active, 58% had perceived low to moderate amounts of social support, and the pediatrician was reported as the HCP most frequently used. Only race and religiosity had an interaction effect with actual communication ( $p=.046$ ,  $B=2.706$ ). AAs who reported that religion had a moderate to large impact on their decision whether or not to engage in sexual activity had initiated more actual communication with a HCP when compared to Whites.

**Conclusions/Implications:** Race and religiosity appeared to correlate to adolescent girls with diabetes initiating communication regarding PC with HCP. Therefore, these characteristics should be considered when providing PC. Religious beliefs were associated with increased communication between teen and provider among AAs. Therefore, we need to educate the HCP

to empower young women to initiate communication about PC to their HCP. Further research with a larger more diverse sample is warranted to confirm these results.

## Introduction

Diabetes poses a major risk for maternal as well as fetal complication (Kitzmilller, 1996). Preconception counseling (PC) decreases these risks and ideally begins at puberty (American Diabetes Association [ADA], 2011). The simple act of providing preconception counseling has a huge impact; however, HCPs do consistently provide it. Seventy percent of women with diabetes report not having had preconception counseling prior to pregnancy, and less than 40% of certified diabetes educators are providing preconception counseling (Michel, 2006). There is great need to empower female adolescents to initiate preconception counseling communication with their HCPs. Little evidence is available regarding communication among adolescent females with diabetes and their health care provider, particularly around preconception counseling.

## Communication

The strongest predictor for female patients with diabetes to seek preconception care and plan their pregnancy is to receive advice to seek preconception counseling. In turn, their awareness is raised by a health care provider (Janz et al., 1995). In order to raise awareness there must be communication between the health care provider and the patient. To ensure uptake of interventions to provide effective preconception counseling we must know who is likely to have communication with their provider and even more importantly those who are less likely to have communication with their healthcare provider. Targeting these individuals will increase the likelihood of communication and ultimately preconception counseling. However, there are few data that provide insight on predictors of communication or even intention to communicate.

Patient-centered communication, which is a style of communication between a health care provider and patient, includes the role of partnership between provider and patient, empathy,

interpersonal sensitivity, and an exchange of mutual information. It has been found to be particularly effective with adolescents with T1D since there is an increased sensitivity to authoritarian treatment and desire to have a more adult role in their health care (Croom et al., 2011). High levels of patient-centered communication are associated with greater perceptions of control and competence related to diabetes care on both the part of the teen and their parents. Patient-centered communication is also related, indirectly, to adherence and metabolic control when perceptions of the adolescent's competence for their care are included (Croom et al., 2011).

In a qualitative study by Beresford et al. (2003), adolescents with chronic conditions such as diabetes reported that the duration and frequency of visits with their health care provider, perceived attitudes of their health care provider towards adolescents, communication skills of both the adolescent and the health care provider, and presence of others in the exam room (parents/medical students) impact the openness and effectiveness of communication between themselves and the health care provider. Age of the adolescent is also a factor; younger adolescents are more likely to be sensitive to issues of status and reporting that their parents oftentimes had more interaction and communication with the health care provider than themselves. Loes Van Staa (2001) also found that despite adolescents with chronic diseases wanting to be involved as partners regarding healthcare communication, they are often bystanders because their participation was not sought or encouraged while parents filled in the gaps for the health care provider. Older adolescents report having concerns about loss of privacy as an issue of communication with a health care provider (Beresford et al., 2003).

The provider's perspective is equally important in the communication relationship. Provider training is important in communication specific to adolescents. Sixteen percent of

doctors, nurses, and dietitians who provide diabetic services report having never received training on communication skills with adolescents, and 47% had not received any additional training since graduating. Additionally, they felt less confident about addressing psychosocial issues than medical issues during patient interactions (Hambly et al., 2009).

### Diabetes and Pregnancy and Preconception Counseling

Diabetes causes perinatal complications (e.g., congenital anomalies, spontaneous abortions, prematurity) (Combs et al., 1991; Coustan, et al., 1997; Elixhauser et al., 1993; Hemachandra et al.,1995; Kitzmiller, 1991,1996; York et al., 1999). The majority of early perinatal complications are due to maternal hyperglycemia prior to the seventh week of pregnancy resulting from unplanned pregnancies (Kitzmiller, 1996; Miller et al., 1981; Mills et al., 1979). Most problems can be prevented with glycemic control (Kitzmiller, 1991,1996; Nankervis et al., 1998; Schroeder et al., 2000), which can be achieved through preconception counseling. Studies have shown a reduction in the incidence of congenital abnormalities from 9% to 2% with preconception counseling (Kitzmiller, 1996; Nankervis et al., 1998; Schroeder et al., 2000).

A comprehensive, three phase computer-based preconception counseling program (READY-Girls parent study) was developed to increase the awareness and knowledge of reproductive health issues with adolescents with diabetes. The program centered on enhancement of positive attitudes, self-efficacy, communication skills and intentions in performing health-promoting reproductive behaviors. This study utilized a mental models approach to decision-making, which allows the characterization of more personal beliefs and understanding of key concepts in the target population of girls with a different type of diabetes and a younger age range, and compared that understanding with the expert model. This allowed

the intervention to be targeted more appropriately to the specific needs and characteristics of the individual girls. The mental models approach allows for a broader incorporation of elements from the Expanded Health Belief Model, which was the foundation of the prototype intervention. The approach included the following steps: first is a formal analysis of the problem, the analysis then identifies qualitative relationships between factors, organizing them into an influence diagram which represents the factors as nodes with causal links connecting where appropriate, in turn the probability that a given action (sexual behavior, with or without a condom, oral contraceptives, etc.) will occur.

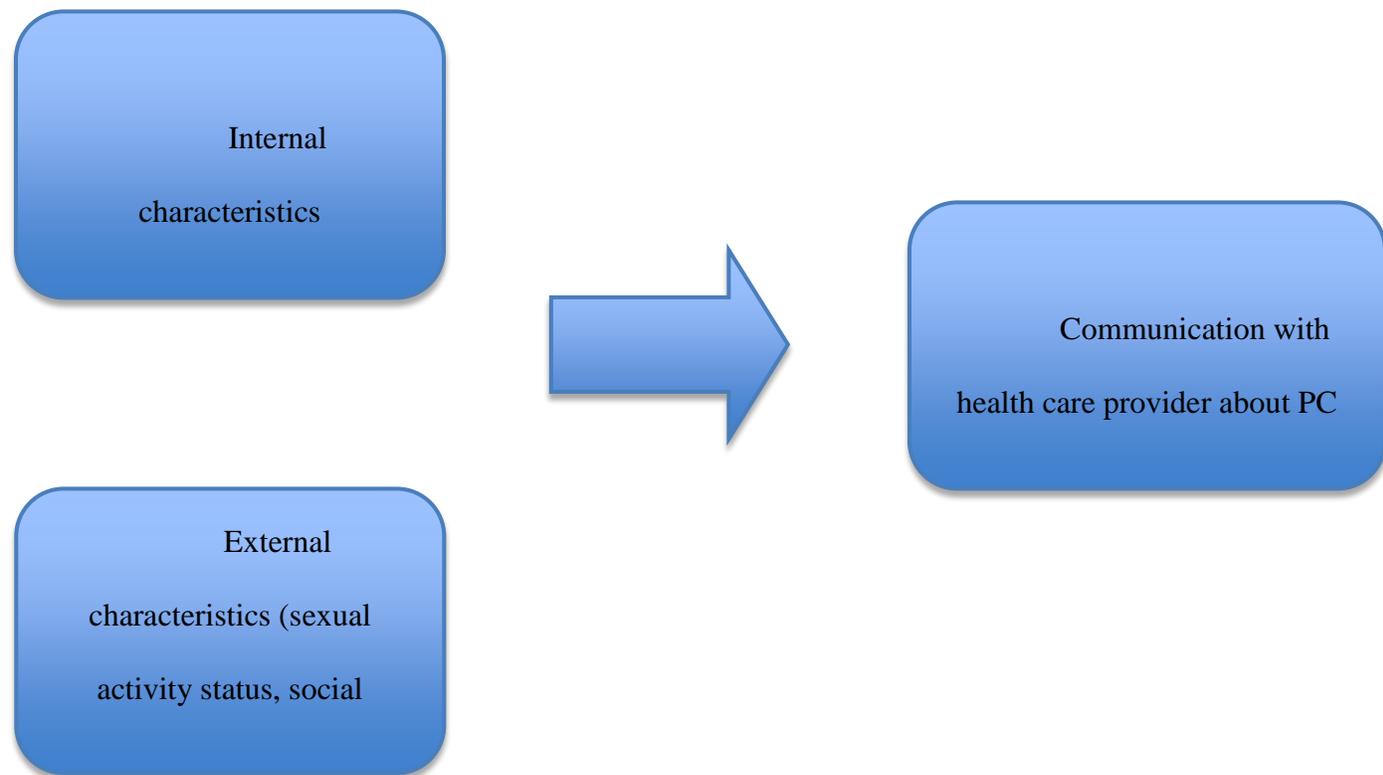
### **Purpose**

The purpose of this secondary data analysis was to examine the relationship between internal characteristics (race, age, religiosity), external characteristics (sexual activity status, social support, and type of routine health care provider) and intention to communicate and actual communication about PC with health care providers among adolescent females with diabetes (see figure 1).

**Specific Aim 1:** Examine the relationship between internal characteristics (race, age, religiosity) and intention to communicate and actual communication about PC with health care providers.

**Specific Aim 2:** Examine the relationships between external characteristics (sexual activity status, social support, and type of routine health care provider) and intention to communicate and actual communication about PC with health care providers.

Figure 1



## Methods

### *Design*

A secondary data analysis of a cross-sectional correlation design study was performed using baseline data obtained from a multisite two-phase intervention study conducted from August 1, 2005, to May 31, 2010. In the first phase of the parent study, subjects participated in a mixed method mental model evaluation of the existing READY-Girls program. The mental models approach includes an influence diagram covering the relevant topics that were developed, in collaboration with the expert panel: the model defines relevant factors about diabetes and pregnancy, with special attention to the need for benefits of preconception counseling. The model is based in part on the expert model that served as the foundation for an earlier adolescent

sexuality and sexually transmitted disease intervention. The aims of the parent study included (1) revision of the intervention, and (2) evaluation of the revised intervention. Baseline data for the following variables were used for the secondary data analysis: age, race, religion as measures of internal characteristics and sexual activity status, social support, and type of routine health care provider as measures of external characteristics.

### *Sample*

In the parent study participants were recruited from 3 diabetes clinics one in southwestern Pennsylvania, one in eastern Missouri and another in Michigan. For the purpose of this study we will be studying only subjects from the Pennsylvania and Missouri sites. Participants were enrolled if they were between the ages of 13 and <20 years, diagnosed with type 1 or type 2 diabetes for at least one year, and fluent in English. Participants were excluded if they: (1) had a history of another chronic illness or mental retardation, (2) were currently pregnant, (3) or had participated in the mental model interview. The resulting sample size was 115 adolescent females.

### *Measures*

Data on sociodemographic and health variables were collected from the subject during a baseline assessment; these data included age, race, religion, living arrangement, and education. Sociodemographic variables of interest for this analysis were age, race, and religion. Outcome measures were included for cognitive outcomes, psychosocial outcomes, behavioral outcomes, and biological outcomes. For cognitive outcomes knowledge, attitudes, motivational cues, decision-making skills, initiating discussion skills were measured. For psychosocial outcomes social support, self-esteem, stressors, and religiosity were measured. For behavioral outcomes intention was measured and for biological outcomes metabolic control was measured. A single

investigator-developed questionnaire was self-administered to collect the measures. Psychometric properties of all the measures were reanalyzed using pooled data. Overall, the measures appear to remain valid and reliable, meeting minimum criteria for internal consistency (Cronbach's alpha >0.70).

### *Data Analysis*

Data analysis was conducted using IBM SPSS (version 21, International Business Machines, Corp., Armonk, NY). Prior to a descriptive analysis of all baseline variables, data were cleaned. Descriptive analysis of the baseline variables of interest from the READY Girls study was performed to assess data accuracy and describe sample characteristics. From an initial sample of 115 participants, missing data were isolated for 12 respondents; five of these subjects were missing 43.8-62.5% of their data related to the variables of this secondary analysis. The five cases with high amounts of missing data were deleted following investigation into missingness. The missing data were found to be missing at random. Participants who had missing data were found to be slightly younger than participants with no missing data. The reduced sample (n=110) was evaluated to ensure that it was representative of the larger sample after the deletion of cases with more than 40% missing data. A correlation matrix was completed in order to create a predictive model for imputation of missing data for the remaining seven subjects of the original 12 found to have missing data. Assumption checking was performed and no assumptions were found to be violated. Descriptive statistics were computed based on grouping variables (internal characteristics: age, race, religion and external characteristics: sexual activity status, social support, and type of routine health care provider

Binary logistic regression modeling was used to assess the independent effects of internal characteristics: age, race, religion; and external characteristics: sexual activity status, social

support, and type of routine health care provider on actual discussion with a health care provider about preconception counseling. Linear regression modeling was used to assess the independent effects of internal characteristics: age, race, religion and external characteristics: sexual activity status, social support, and type of routine health care provider on intention to discuss preconception counseling with a health care provider. The saturated/full multivariate model for both outcome variables included the main effects for age, race, religion, sexual activity status, social support, and type of routine health care provider.

Variables with p-values found to be .25 or less, which included race, use of a general provider or nurse practitioner, use of a pediatrician, and how someone's religion would impact their decision regarding sexual activity, were first chosen to be included in multivariate logistic regression. Then backward logistic regression was used to permit the assessment of the best model fit. When both were found to yield insignificant results, all variables were placed back in the model for multivariate logistic regression followed by backward logistic regression for all models. Again, when both methods were found to yield insignificant results variables whose p levels were found to be .25 or less were first placed back in the model bivariately with their cross products to explore nonadditivity by looking at interactions of the variables. Significance was obtained at this level and will be discussed further in the results section. The variable which looked at the degree to which someone's religion impacted their decision to engage in sexual activity was a three level variable with responses being a lot, somewhat, or not at all. The somewhat and a lot category were collapsed into one making it a bivariate variable, and the model was assessed again with the significance increasing slightly.

Variables whose p levels were found to be .25 or less (based on single predictor models), which included race, sexual activity status, level of social support, and use of a general provider

or nurse practitioner, were first chosen to be included in multiple linear regression. Then backward logistic regression was used to identify a more parsimonious model. When both were found to yield insignificant results, all variables were placed back in the model for multiple logistic regression followed by backward logistic regression for all models.

## **Results**

The sample (n=110) ranged in age from 13.28 to 19.95 (M=16.18, SD=1.64) years. Respondents were 100% female and Caucasian, accounting for 81.8% of the sample. Ninety-two percent of the sample reported having T1D. Eighty percent of the sample reported never participating in sexual activity. Fifty-eight percent of the sample reported having perceived low to moderate amounts of social support. Subjects self-reported their religion as follows: 59% Protestant, 30% Catholic, and 11% other. Twenty-two percent reported that their religion impacted their decision to participate in sexual activity a lot, and 12% reported that their religion would impact a lot what they chose to use to prevent a pregnancy. Thirty-five percent reported utilizing a health center and/or endocrinologist as their health care provider, 24% a private doctor, 18% a general practitioner or nurse practitioner, and 55% a pediatrician.

### *Actual Communication*

After performing univariate logistic regression, no predictors were statistically significant, in predicting actual discussion with a health care provider. In regards to actual communication, sexual activity status (p=.071) and race (p=.153) showed the most promise (see Table 1). No predictors were statistically significant through multivariate logistic regression. When variables whose p levels were found to be .25 or less were placed back in the model bivariate with their cross products to explore nonadditivity by looking at interactions of the

variables, significance was obtained, with race being significant and race by religion having impact on their decision to engage in sexual activity also being significant (see Table 3). It was found that for those individuals who were White there was no difference in actual communication levels between their religion having somewhat/a lot of impact on their decision to engage in sexual activity vs. not at all. But, for African American there was significant difference ( $p= 0.46$ ) in actual communication between those whose religion having somewhat/a lot of impact on their decision to engage in sexual activity vs. not at all (see figure 2).

#### *Intention to Communicate about PC*

Additionally, no variables were found to be statistical significance to predict intention to communicate with a health care provider after univariate linear regression was performed. For intention to communicate again, race ( $p= 0.111$ ) showed the most promise; additionally use of a general practitioner or nurse practitioner showed promise ( $p= 0.117$ ) (see Table 2). Finally, no predictors were statistically significant through multivariate linear regression.

Table 1. Univariate Logistic Regression for Actual Communication with a Health Care Provider

Predictor	OR	95% CI for OR	Wald Chi-Square, p-value
<b>Race</b>			
White (-0)	1.0		
Black	0.444	(0.164, 1.205)	2.541, 0.111
<b>Age</b>			
Age	1.084	(0.842, 1.395)	0.388, 0.533
<b>Sexual Activity Status</b>			
No (-0)	1.0		
Yes	0.694	(0.259, 1.859)	0.527, 0.468
<b>Social Support</b>			
Low-Mod (-0)	1.0		
High	0.933	(0.412, 2.111)	0.028, 0.868
<b>Use of a Private Doctor</b>			
Yes	0.953	(0.367, 2.478)	0.010, 0.922
No (-0)	1.0		
<b>Use of a Health Center or Endocrinologist</b>			
Yes	0.892	(0.381, 2.092)	0.069, 0.793
No (-0)	1.0		
<b>Use of a General Practitioner or nurse practitioner</b>			
Yes	2.833	(0.770, 10.430)	2.453, 0.117
No (-0)	1.0		
<b>Use of a Pediatrician</b>			
No	1.687	(0.742, 3.837)	1.558, 0.212
Yes (-0)	1.0		
<b>Religion</b>			
Protestant (-0)	1.0		0.895, 0.639
Catholic	1.101	(0.433, 2.803)	.041, 0.839
Other	0.578	(0.163, 2.051)	0.719, 0.396
<b>Religion having an impact on sexual activity status</b>			
			2.98, 0.226

Not at all (-0)	1.0		
Somewhat	2.0	(0.806, 4.966)	2.232, 0.135
A lot	2.267	(0.696, 7.383)	1.845, 0.174
Religion having impact on choice of birth control			1.383, .501
Not at all (-0)	1.0		
Somewhat	1.266	(.536, 2.990)	.289, .591
A lot	2.571	(.508, 13.008)	1.304, .254



Table 2. Univariate Linear Regression for Intention to Communicate with a Health Care provider

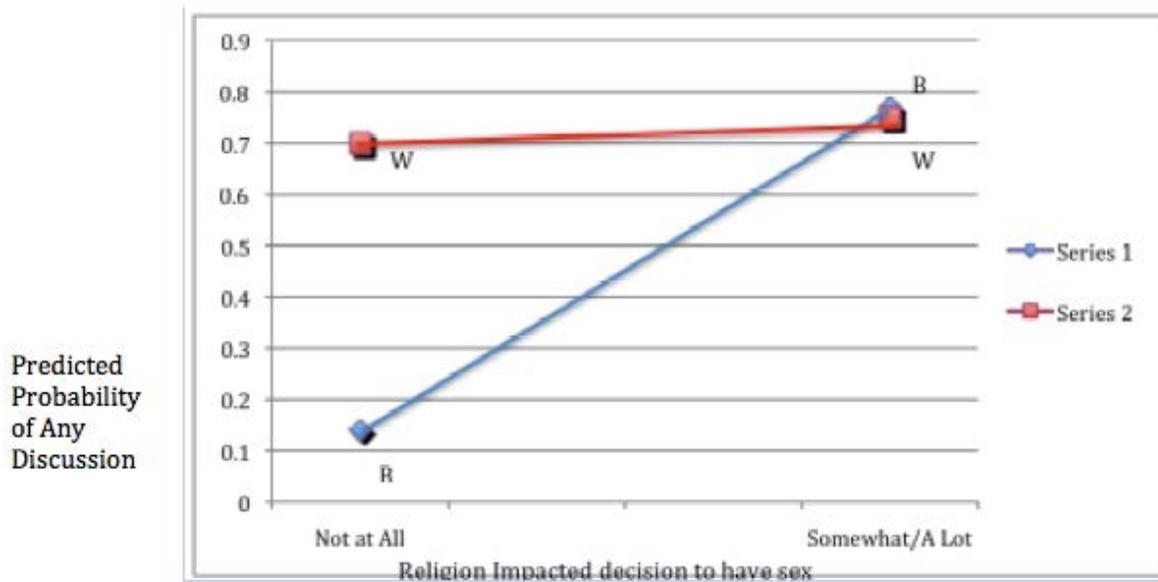
Predictor	b	95% CI for b	t value
<b>Race</b>			
White (-0)	1.00		
Black	1.37	(-0.360, 2.272)	1.439, 0.153
<b>Age</b>			
	0.015	(-0.289, 0.337)	0.154, 0.878
<b>Sexual Activity Status</b>			
No (-0)	1.00		
Yes	0.173	(-0.103, 2.421)	1.821, 0.071
<b>Social Support</b>			
Low-Mod (-0)	1.00		
High	0.121	(-0.368, 1.670)	1.267, 0.208
<b>Use of a Private Doctor</b>			
Yes	0.015	(-1.109, 1.303)	0.160, 0.874
No (-0)	1.00		
<b>Use of a Health Center or Endocrinologist</b>			
Yes	0.004	(-1.057, 1.098)	0.038, 0.970
No (-0)	1.00		
<b>Use of a General Practitioner or nurse practitioner</b>			
Yes	0.120	(-0.486, 2.152)	1.252, 0.213
No (-0)	1.00		
<b>Use of a Pediatrician</b>			
No	-0.088	(-1.498, 0.552)	-0.915, 0.362
Yes (-0)	1.00		
<b>Religion</b>			
Protestant (-0)	1.00		
Catholic	-0.017	(-1.253, 1.053)	-0.172, 0.864
Other	0.035	(-1.394, 1.996)	0.352, 0.752
<b>Religion having an impact on sexual activity status</b>			
Not at all (-0)	1.00		
Somewhat	0.458	(-0.694, 1.611)	0.788, 0.432

A lot	0.216	(-1.213, 1.645)	0.299, 0.765
Religion having impact on choice of birth control			
Not at all (=0)	1.0		
Somewhat	0.328	(-0.765, 1.421)	0.596, 0.553
A lot	0.112	(-1.612, 1.835)	0.128, 0.898

Table 3. Multiple Logistic Regression for Actual Communication

	Beta	p-value	Wald
Race (W=0, B=1)	-2.625	0.022	5.258
Impact of religion on sexual activity decision making (0=Not at all)	0.289	0.553	0.351
Race (W=0) by Impact of religion on (Not at all =0) sexual activity decision making	2.706	0.046	3.985

Figure 2. Impact of Religion on Decision to Participate in sexual Activity by Race



## **Discussion**

This study's original premise was to look for predictors of actual communication and intention to communicate using internal characteristics: age, race, religion and external characteristics: sexual activity status, social support, and type of routine health care provider. In addition, examining possible interaction between predictors must also be examined as the interaction's presence may affect the regression coefficients and p values for the main effects. After statistical analysis and modeling were conducted it was discovered that the interaction of race and religion having impact on decisions related to sexual activity significantly predict actual communication. For African American teens there was significant difference in actual communication between those whose religion had either somewhat of or a great impact on their decision to engage in sexual activity versus not at all.

Keeping the influence of religion in consideration, providers should be aware of this relationship when providing preconception counseling to African American teens. For this reason the church makes an ideal arena for preconception counseling. Studies have shown a positive relationship between health outcomes and participation in faith-based communities (Koenig et al., 2001; Newlin et al., 2008). Pivotal members of faith-based communities who could provide preconception counseling and diabetes education to its members are parish nurses. Parish nursing, also known as faith community nursing, is an example of health practice rooted in the faith community, which bridges the gap between community, religion, and health.

Parish nursing plays a critical role in providing education, health promotion, and disease prevention based on a holistic care model (King et al., 2009). A primary focus of the model includes prevention management of chronic disease at the community level (McGinnis et al.,

2008). Parish nurses perceive chronic disease, particularly diabetes, as an important health issue for their patients (King et al., 2009; McGinnis et al., 2008). Parish nurses are effective in providing health related education and interventions as evidenced by positive patient outcomes as they relate to diabetes, obesity, and chronic disease (Garber et al., 2008; White et al., 2006). Clients' perceptions of the role of parish nursing and care included being useful, meaningful, and effective (Wallace et al., 2002). With proper training parish nurses can play a significant role in providing preconception counseling in the African American community.

### **Limitations**

The main limitation of this study is that it is a secondary data analysis and the original aims of the study, which dictate the methods, differ from those of the secondary analysis. The sample was not diverse and therefore the results may have been influenced by a largely Caucasian sample. Taking these two factors into consideration a larger, more diverse study is warranted to confirm results. In addition, the sample size was rather small which also would influence the results of the analysis by potentially inflating them.

### **Practical and Research Implications**

The health care industry must build on the strengths of good relationships that currently exist between providers and their clients. One such relationship is that of the parish nurse and their clients. Focusing on this relationship, communication between the health care provider and the client related to preconception counseling warrants further investigation. Once this component is understood an intervention can be considered. To ensure easy access and broad dissemination parish nurses can play a pivotal role in guiding the delivery of PC information. Keeping this in mind, this research has the potential to change the way PC is delivered to AA

women with diabetes, which in turn can impact the pregnancy outcomes of women and their future children.

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**APPENDIX J**

**FEASIBILITY STUDY POSTER**



# Using Parish Nurses to Deliver Diabetes Education/ Preconception Counseling to African American Women: A Mixed-Method Feasibility Study

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## Abstract

This mixed-methods feasibility study explored the experiences and knowledge of parish nurses regarding diabetes education and preconception counseling (PC). The qualitative phase explored the experiences of parish nurses providing DM education/PC to women, specifically African American women, with type 1 and type 2 diabetes using focus groups. A discussion with six nurses was recorded, transcribed, and analyzed for themes. Preliminary results show that parish nurses were not aware of PC, but felt that it was important, and would provide it to their female patients with diabetes if they had a resource to do so. Quantitative results showed that knowledge about PC was low (mean = 59%, range = 40-84%), and these nurses had only a moderate level of self-efficacy (mean = 59.4, range = 27-144).

## Background

Parish nurses can play a significant role in AA faith-based communities. Parish nurses are effective in providing community-based health-related education and interventions as evidenced by positive outcomes for patients with diabetes, obesity, and chronic disease. AA women have higher risks for developing diabetes and its complications, especially related to pregnancy. PC has been shown to reduce risks of perinatal complications in women with diabetes. Yet most AA women do not receive PC due to lack of health insurance access. Currently, there is no systematic delivery of DM education/PC at the community level for underserved women. Parish nurses can meet this need and impact this disparity.

## Purpose

To explore the experiences and knowledge of parish nurses regarding diabetes education and preconception counseling (PC) to African American (AA) women with diabetes.

## Methods

Parish nurses who had a nursing license and practiced in a faith-base setting in the Pittsburgh area were invited to participate. The qualitative phase explored the experiences of parish nurses providing DM education/PC to women with Type 1 and Type 2 diabetes using focus groups. A discussion with six nurses was recorded, date were transcribed, and analyzed for themes by the primary investigator and an expert in focus group methodology. Then, the nurses completed measures on demographic characteristics, knowledge and self-efficacy related to diabetes and PC. Preconception Counseling Knowledge for Certified Diabetes Educators<sup>®</sup> consisted of 25 true-false questions scored as percent correct. PC Self-Efficacy for CODES<sup>®</sup> a validated measure consists of seven-item Likert-type scaled items, where 0 was labeled "not at all confident" and 10 was labeled "absolutely confident." Possible score range was from 0-170. Higher score indicated greater self-efficacy.

## Sample

Six female parish nurses with different religious affiliations were recruited from a Parish Nurse and Health Ministry program in the greater Pittsburgh area. They were 33, 36, African American, with a mean age of 64.8 yrs (range = 51-78 yrs), had been an RN for an average of 37.2 years (range = 5-50 yrs), and a parish nurse for an average of 9.5 years (range = 1-20 yrs).

## Quantitative Results

Knowledge score was low with a mean = 59%, range = 40-84% (n=6). Self-efficacy score was moderate with a mean = 99.4, range = 27-144 (n=5).

## Qualitative Results

Themes	Responses
Lack of awareness of PC among the parish nurses	<ul style="list-style-type: none"> <li>I heard it because you told me it before that I had not.</li> <li>You hear all this publicity on smoking and all the things that could happen if you smoke. They should do that with diabetes. To say, if you're going to have a child, do you know this, this and that? Because who wants to have a child that's not healthy and especially who has diabetes or problems?</li> <li>I had no idea what you're saying about these parents bringing their children who are diagnosed because - I never knew that.</li> <li>It's really something that - that's the reason I came here today because it doesn't happen. And for the growing diabetes, particularly type 2, which people still think there the benign diabetes, like it's not going to cause any harm because it's only type 2.</li> <li>It's awareness to get parish nurses aware I think that this is an issue.</li> <li>I think I don't know about it, there there's a lot of people that don't know about it, and there's a really interesting piece about the nurse who said, "I heard it because you told me it before that I had not." I never knew that - they already guess what's happening? We just need to be concerned.</li> </ul>
Lack of formal training on PC either from RN education or parish nurse training	<ul style="list-style-type: none"> <li>I think I got it in nursing school, a little bit.</li> <li>Not preconception. But I was as a diabetes educator.</li> </ul>
Currently not providing PC to their female patients or underserving age who	<ul style="list-style-type: none"> <li>Not through the church. I used to work for WNC, we received PC to their female patients.</li> <li>Nothing one-on-one. But, like for diabetic orders, you might have a woman where you might focus on the family, and they include something</li> </ul>

## Qualitative Results (Cont.)

Themes	Responses
Recognize the importance of providing PC and diabetes education to any patient or underserving age with diabetes	<ul style="list-style-type: none"> <li>We've just have to put the information out there. I think.</li> <li>Most women would not their preconception counseling was very useful.</li> <li>I think as nurses, we have a responsibility to be - we know what people need, so we have that responsibility to give that information. We have that creative way we can. So I don't know - that's why I think nurses and especially parish nurses take that on because we care.</li> </ul>
Willing to provide PC to their female patients with diabetes if they had the training to do so	<ul style="list-style-type: none"> <li>So, yeah, anything - these kind of programs, that you can just hand to the people, and they can get that information and they can do it. My knowledge is not to be up on all these things today that you just can't.</li> <li>If they offer continuing education credits, everybody will do it. Oh my gosh.</li> </ul>
Acknowledge that education about PC (therapeutic goals) and be multimedial in nature	<ul style="list-style-type: none"> <li>You know where it really needs to start? In Junior High, where you - yeah, you can start there to get the kids in the / yeah, but it's not going to apply to the parents. So, at that point, but for there to be information that they can use, you know -</li> </ul>

## Conclusions

Six themes emerged from the data regarding lack of PC and diabetes awareness and formal training, not providing PC to women with diabetes, the need to provide PC and the resources to do so. Parish nurses lacked both knowledge and self-efficacy as it related to PC and diabetes. Understanding the role and experiences of parish nurses regarding diabetes education and providing PC to women, will help to plan future studies to tailor training and interventions for both nurses and women that could impact maternal and fetal outcomes and reduce disparities among African American women with diabetes.

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**APPENDIX K**

**FULL QUALITATIVE RESULTS PAPER**

**Delivering Diabetes Education/ Preconception Counseling To African American  
Women: The Experience of the Parish Nurse**

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**Abstract**

**Purpose:** To explore the experiences of parish nurses (PNs) in providing diabetes education and preconception counseling (PC) to women (especially African American [AA] women) with Type 1 Diabetes (T1D) and Type 2 Diabetes (T2D) and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes; and to describe parish nurses' knowledge and teaching self-efficacy regarding diabetes, pregnancy and PC.

**Design:** This study of parish nurses used a mixed-method concurrent embedded design with one data collection phase and utilized qualitative data for the primary method and quantitative data for the secondary method. This paper reports on the qualitative phase, which used focus groups. Forty-eight PNs who were contacts of a western Pennsylvania Parish Nurse and Health Ministry program participated in one of eleven focus groups.

**Methods:** Focus group methodology was utilized to elicit experiences and attitudes and capture discussions with participants joining from both onsite and "distance" (conference call, webex) venues. The focus groups were digitally recorded and transcribed, and analyzed. Qualitative content analysis was used to identify common themes across the focus groups. A representative set of themes describing the data was identified.

**Findings:** Seventeen qualitative themes emerged from the PNs: 1) parish nurse role, 2) parish nurse approach, 3) parish nurse challenges, 4) parish nurse support network 5) parish nurse practice and programming, 6) diabetes practice and programming, 7) diabetes and pregnancy and PC practice and programming, 8) awareness of PC, 9) experience providing PC, 10) formal training on PC, 11) importance and usefulness of providing PC and diabetes education, 12) willingness to provide PC, 13) acknowledgment of early PC (teenage girls), 14) confidence to provide PC, 15) need for parish nurse PC training, 16) recommendations for parish nurse PC training, and 17) recommendations for PC tool for patients.

**Conclusions:** Parish nurses are uniquely situated not only because they exist in a community setting, putting them in closer proximity to the homes of a client, but also because of they are in a setting where patients may attend on a regular basis and share similar set of values due to their faith. This allows for a relationship that has many more layers, which develops a greater sense of trust compared to a traditional nurse-patient relationship. The PN provides holistic care including the physical, mental, and spiritual aspects of a person; incorporating faith into care, health promotion and prevention activities.

**Keywords: Parish Nurse, Community Nursing, Minority Health and Health Disparities, Diabetes, Preconception Counseling**

Parish nurses practice in a faith-based setting and focus on health promotion and disease prevention education as their primary role. They practice from a more holistic prospective, incorporating an individual's spiritual health, (McDermott & Burke, 1993; Tuck & Wallace, 2000, 2001; Chase-Ziolek & Iris, 2002; King & Tessaro, 2009). Parish nurses have had success with patient outcomes related to chronic diseases (diabetes and obesity) (Garber Mendelson et al., 2008; White, Dreschsel, & Johnson, 2006), and thus parish nurses could play a pivotal role in providing education and health promotion at the community level for underserved populations (McGinnis & Zoske, 2008; Wallace, Tuck, Boland, & Witucki, 2002); such as underserved women in AA communities, particularly those that are childbearing and have diabetes. AA communities have had success with faith-based programs (Hye-cheon et al., 2008; Peterson & Cheng, 2011). Given that AA women have a strong connection to their faith-based communities (Drayton-Brooks & White, 2004; Newlin et al., 2008), the parish nurse could fulfill a need in this underserved and vulnerable population.

Low-income AA women have limited access to health care (Williams, 2005) and could greatly benefit from services delivered in their communities (Owens, Kieffer, & Chowdhury, 2006). African American women have greater disease burden (Williams, 2005). More specifically, AA women, in comparison to Non-Hispanic White women, have at least two to four times greater likelihood of developing T2D (Beckles & Thompson-Reid, 2001) and are more vulnerable to developing diabetes complications (Holcomb, Mostello, & Leguizamon, 2001). Compared to Caucasian women, African American women have higher rates of neonatal and infant death, higher risks of negative pregnancy outcomes, higher rates of maternal mortality (Harper, Dugan, Espeland, Martinez-Borges, & Mcquellon, 2007), and the highest rate of unintended pregnancies (Finer & Zolna, 2014), moreover, women with T1D or T2D who have

unplanned pregnancies have a two to threefold increase in rates of major congenital anomalies among their infants (American Diabetes Association [ADA], 2004; Kitzmiller et al., 1991).

PC can help prevent pregnancy related complications due to diabetes mellitus (DM). By carefully planning pregnancies complicated by diabetes and maintaining normal blood glucose levels, risks of reproductive complications can be reduced from 10% to 2% (ADA, 2004, 2011). However, women, especially AA women, are not receiving PC (Janz, Herman, Becker, Charron-Prochownik, 1995). To correct this disparity and better understand how to best deliver diabetes education and PC to AA women, the role of the parish nurse will be examined in providing diabetes education and PC to women with diabetes in this study.

## **Methods**

The overall study used a mixed-method concurrent embedded design with one phase that collected simultaneously both qualitative and quantitative data (see Figure 1). The primary method (qualitative) was the focus and thus guided the study, while the secondary method (quantitative) provided support for the primary data. Due to the secondary nature of the quantitative method, it was embedded within the qualitative method (Creswell, 2009). This paper describes the qualitative focus group data that explored parish experiences with educating and providing PC to women of childbearing age with T1D and T2D, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women. A qualitative approach provides detail-rich data that allows for a fuller description of knowledge and experiences (i.e. parish nurses understanding, and knowledge of PC) that cannot be derived from other methods (Sandelowski, 2000).

In addition, the structure of a focus group allows for openness and disclosure by participants about the topic (Krueger, 1994; Wilkinson, 1998). This methodology facilitates the

ability to obtain an in-depth understanding of the participants lived (Wilkinson, 1998). The goal of research utilizing focus group data includes understanding the complex mix of attitudes, knowledge, and past experiences of the participants (Morgan & Krueger, 1998). As a tool it is effective tool for exploring attitudes, beliefs, and the development of interventions (Carey & Smith, 1994; Denning & Verschelden, 1993).

### **Sample and Setting**

Parish nurses were recruited for both the qualitative and quantitative methods if they: 1) had a nursing license LPN, RN, or advanced degree (MSN, DNP, PhD); 2) practiced in a faith community setting; and 3) functioned as a PN (certification not required). All questionnaires were in English; therefore, only English-speaking participants were recruited.

Eleven focus groups (including one feasibility focus group) with two to eight individuals were conducted. Forty-eight PN participants (including 6 in feasibility focus group) participated in the study. In order to facilitate maximum participation the location of focus groups were determined by convenience of the PNs (Wilkinson, 1998). This also included “distance” focus groups that were teleconference-based or webex format. This allowed for individuals whose location and/or schedule precluded them from joining physically to participate and also for a more geographically diverse sample to be engaged (Cooper et. al, 2003; Hurwarth, 2004). When the “distance” format was used, the researchers limited the group to no more than five participants in order to allow for greater in-depth discussion. Size limitation is consistent with evidence suggesting that focus groups utilizing teleconference allow for the most meaningful interactions when kept small (Krueger, 2009).

Five of the focus groups were conducted with participants onsite. Four of these were conducted at the Parish Nurse and Health Ministry Program office and one took place at a church

of the participant's convenience in northern, PA. Two of the focus groups had a mix of both participants on-site (Parish Nurse and Health Ministry Program office) as well as via conference call. The four final focus groups utilized a "distance" webex format with PNs from Florida, Ohio, New York, and Arizona. Focus groups were conducted until saturation was reached in the data analysis and no new information was collected (Baum, 1998).

### **Data Collection**

The principal investigator (PI) conducted all focus groups using a structured focus group guide that was developed and utilized to elicit and refocus the group discussion of PNs' experiences with educating and providing PC to women of childbearing age with T1D and T2D, especially AA women, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes (see Table 1). However, the participants ultimately guided the discussion (i.e., concepts/new ideas brought up by the participants were investigated) (Krueger, 2009). There was no time limit to the focus groups, which generally last about 60 minutes. All focus groups were doubly digitally recorded, transferred to a secure computer, transcribed verbatim, and reviewed for accuracy. Additionally, when possible notes were taken in order to capture observations about the participants as well as to provide back up to the digital recorders (Krueger, 1994). The focus groups were conducted between the dates of August 7, 2012 and September 4, 2013.

### **Analysis**

Qualitative content analysis, an accessible and theoretically flexible approach, was used (Sandelowski, 2000). An inductive approach was utilized in order to identify themes that are strongly linked to the data and not driven by a particular theory or theoretical interest area (Braun & Clarke, 2006). Analysis began after the first focus group was conducted and transcribed.

ATLAS.ti (7.1.7), a qualitative database program, was used to facilitate the maintenance and organization of the data. The process of collecting, coding, and analyzing data occurred simultaneously and began with review by both the PI (J.A.D) and an experienced qualitative and focus group researcher (M.A.T).

The PI developed initial codes in naturally occurring units of meaning in the text occurring in the discussion. Coding was based on: the repetition of specific words, phrases, and opinions; the use of language and general thought patterns, and topics generated during the focus group discussion. The PI shared the codebook and uncoded transcripts with (M.A.T), who independently coded the same transcripts. Each interview was reviewed and discussed and consensus on the coded transcripts was reached through discussion. The code list and definitions evolved and were refined with the coding process of each interview. When necessary new codes were created. This review process reduces bias and promotes consistency in the analysis of the data (Morgan ed., 1993; Krueger, 1994). Through constant comparison, codes were applied to text where relevant.

The data were then looked at from a broader level of themes emerging from the codes. In some instances several codes comprised a theme, where in others a single code might represent a theme (Braun & Clarke, 2006). A set of representative themes, agreed upon by the PI and expert, were derived from the data.

## **Findings**

Forty-eight PN's participated in the 11 focus groups. The researchers identified the following seventeen themes related to parish experiences with providing diabetes education and PC to women (especially to AA women) T1D and T2D, and understanding of diabetes as it relates to pregnancy and pregnancy outcomes: 1) parish nurse role, 2) parish nurse approach, 3)

parish nurse challenges, 4) parish nurse support network 5) parish nurse practice and programming, 6) diabetes practice and programming, 7) diabetes and pregnancy and PC practice and programming, 8) awareness of PC, 9) experience providing PC, 10) formal training on PC, 11) importance and usefulness of providing PC and diabetes education, 12) willingness to provide PC, 13) acknowledgment of early PC (teenage girls), 14) confidence to provide PC, 15) need for parish nurse PC training, 16) recommendations for parish nurse PC training, and 17) recommendations for PC tool for patients, 15) recommendations for parish nurse PC training, and 16) recommendations for PC tool for patients.

### **Parish Nurse Role**

PNs describe their role to include that of a facilitator, advisor, and educator. They describe how they directly and indirectly care for patients, as their fellow parishioners may come to them seeking advice, guidance, or clarification about a health concern of a friend/peer or family member who does not attend the church. “...they have daughters and they have grandchildren,..and they often talk about their concerns about their children and grandchildren. So that’s a way of getting information.” There may actually be a trickle down effect as younger women in the church may seek advice from a “wise woman” (older woman who may or may not be a relative or peer in the same age group) in the church. “..they also feel comfortable among their peers-an older, wise woman or another young mother who’s been there done that. And if the parish nurse can connect with that network of wise women with information, sending information to filter down...”

In addition, the PNs describe how a patient may reveal a diagnosis or health concern to them. This includes health status in general, diabetes, and pregnancy. They express that a diagnosis or health concern like diabetes often is not revealed to the PN until the patient is

experiencing a problem that he/she would like advice or help with. “..most of my contact with those who have diabetes have come because of, some other issue, and diabetes has come up...” With this being said the PN may be unaware of a patients’ diagnosis until the patient is experiencing a problem or is in crisis. “I think going back to the issue; it’s looking for opportunities to bring up these subjects because only in crisis do people come to us about the subject.” “They reach out when they start to go under.” This may be related to lack of knowledge or education about a health condition on the part of the patient as well as unhealthy lifestyles. “I know a lot of it is an unhealthy lifestyle. And they don’t know. They don’t understand. You know? They continue eating the Doritos, continue drinking the Pepsi.”

The PNs also describe their role as a member of the congregation and their relationship with their patients as being different than the standard nurse patient relationship and includes a spiritual component to their healing, strong sense of trust and connection, and comfort with the setting. They provide more holistic comprehensive care. “...you are in a place that they feel comfortable at, that instead of walking into a walk-in clinic or into some strange health fair and talking to a random person, you feel that there’s a little link there...they feel comfortable..”

### **Parish Nurse Approach**

PNs describe their approach as being more complete because their care includes the body, mind, and spiritual health. “I think it’s more complete.” “...once the connection is made and once the person is heard, it just opens the door for all kinds of healing.” They described time and how it does not dictate the care that they give which allows it to be more complete and allows for healing. “I think a huge part of that is also that we have time, because we plan our own time...I was always limited in homecare and the push was for numbers, it’s not that way in parish nursing, because you’re time is how much time you want to spend with that person, which allows

a lot more to happen, I think.” Patients feel more comfortable talking to them because of their role. “But a lot of people didn’t know me and yet trusted, almost anything I say, trust anything I say just because that’s the mindset of the faith community.” The patients are in a familiar comfortable setting so it allows the establishment of trust between the PN and patient. “...there was immediate trust..I think its because its in the faith community setting...” They see themselves in a very supportive role. “I recently had one of youngsters who came down with juvenile diabetes and her parents were devastated. And so, they confided that to me in church, and basically, that’s what I did, you know, gave them spiritual and supportive assistance...” They build trust with their patients and the community in order to make change in their patients’ lives. “Building up relationships of trust in the community...But just building up trust relationships with people that live right next door and then, I noticed this almost right away when I was identified as a nurse.”

Parish nurses discussed their internal philosophies of how God works through them by using them as tool to help their patients, being in the right place at the right time. “Well, our specialty is linking faith and health. The parish nurse integrates spirituality into her practice. “So, all the other things, all of the medical things, and the referrals, and all of that, anybody can do that. The parish nurse is the one who remembers that the spirituality piece is the important piece we focus on, because that's so often missed in our health care today.” They may incorporate the mind, body, and spirit. “...it’s a curriculum that integrates mind, body, spirit,...”. They also discussed the use of motivational interviewing to help their patients discover how they approach and think through health related situations. “...I certainly do see my role as someone who walk alongside them as they go through this but many other issues related to health and wholeness and their faith journey.” “...I see a strong role for me as a health minister to kind of

help her assess what the effectiveness of all these are...Where she can turn so she's not overwhelmed and neglected and not having what she needs." They try to incorporate alternative medical therapies with an integrative approach. "And they feel so safe in the parish you know. It's the perfect place for the future of healthcare and integration into the community of faith and because there's trust there. So you can integrate faith with healthcare." These therapies could be free or low cost and should be integrated with medical interventions that are being prescribed by their medical providers. Doing this bridges a gap in healthcare. "And they feel so safe in the parish you know. It's a perfect place for the future of healthcare and integration in the community of faith and because there's trust there. So you can integrate faith with healthcare." "...we are bridging the gap. Integrative medicine is I think coming forward."

They also discussed how their holistic approach is different from the general nursing practice. The PNs describe this process as a more complete caring that incorporates the idea of spiritual caring and support, the link of faith to health. "...It's just all about education of body and spirit and combining what we can to provide a wonderful educational opportunities for our congregation." This approach includes the concept of being present and active listening, being with someone and supporting them through prayer and being present with them in a physical nature provide peace and comfort for both patient and nurse. "I believe so strongly that, you know, when you have that connection with someone who is non-judgmental, who's caring, who's offering unconditional love, just being a presence, I think that just serves the person so much better than any other medical intervention we can offer." Being present does not mean fixing something it means providing unconditional love, caring, and support that is nonjudgmental and allows for a sense of accountability and thus trust. "...just being present. Not fixing anything, just being there...".

## **Parish Nurse Challenges**

The PNs also described some of the challenges they face. For example, isolation can be a problem because they may be practicing as the only one or one of a few in their churches. “There is one other parish nurse.” Therefore, their relationships with other PNs are very important.

Other challenges that the PNs described include the vast amount of possible health problems, conditions, and treatments that exist and being unable to be an expert in all areas. “I also think that there are so many areas that we touch upon in parish nursing that we don’t really have the time to spend on a very, very deep subject...” They described often feeling that recommendations for health conditions may be outside of their scope of practice and thus they see themselves often in the role of facilitator by helping get a patient connected with the appropriate resources because they want to give their patients accurate information. “...I could see where I would outsource that referral to the experts...”

The PNs also expressed that their patients may not be treated equitably in the healthcare setting despite the fact that they may have insurance and access to care. “...people are not treated equitably. So women of color for example, have insurance, access to care, they go, but they still have high mortality rates in almost every category-infant mortality, diabetes, you name it. ...the professionals, they think they are giving them good care. So something’s missing in there,...they may not get what they need.” In addition, they feel that their patients may have difficulty understanding and deciphering what is important from the vast amount of healthcare information they receive. “Sometimes the volumes of information that parishioners receive from their doctor or their nurse or their expert is just- it’s so much information...”

They also describe challenges related to their patient's status, needs, and barriers such as reading level, intellectual abilities, lack of insurance, and language barriers. "It was given, but they can't read it...". "The intellectual ability of the person makes a huge difference-a huge difference in what they retain, and how often you have to go over the same thing over and over and over again." "A lot of them are Haitian, and I don't speak Spanish, so its challenging." "...they don't have insurance. So, I have to find a way to get them to the doctor in the first place."

The PNs also described why a patient might not seek care from a PN. These include being unaware of having a health problem or at-risk condition. "And programs, they don't necessarily go to them because they don't see a need to talk about those things." Also, being undocumented; in these cases patients may need time to get to the point of the trusting relationship. "...I have a whole population that are undocumented and uninsured...But you know, when you get undocumented and stuff like that, they don't-they're not comfortable (to) admit to anybody they're not even supposed to be here."

### **Parish Nurse Support Network**

Because of the PN's isolation, mentioned above, creating a support network and establishing relationships and connections with other PNs is imperative. "...I think as we move forward and expand our program it's great to have the ability to speak with parish nurses be involved in the process. Things that I can not only take back to my parish, but also to help those other programs. If a PN has come upon a new resource or new method of care that can be effective in the PN setting she is able to share this with others. ...". This network also allows for the dissemination of information among them. "We don't need to reinvent the wheel, if it's some that already does that, we support that and we know where to send people."

## **Parish Nurse Practice and Programming**

The PNs described those they care for in their role as a PN as well as those who attend their faith-based communities/churches that could be potential patients. "...we're kind of... a mixture, young, middle-aged, and elderly population..." Their description includes demographic information such as age, race, socioeconomic status, and most common disease processes that their patients experience. "...my church is primarily African American..."

The PNs described how their practice is funded. Some positions are paid but for the most part they are volunteering their time. They may seek funding from their church, donations, and/or grants and even support a lot of their practice with their own money. Because of limited funding, their ability to seek additional continuing education may be reduced. "...a lot of faith community nurses are in an unpaid situation. So, we do not get money for anything. So anything that we essentially need is paid for out of pocket. So we do continued education for our own good, also for state licensure, but it still has to be affordable....you've already got people donating their time, ... poor on their resources." In addition, they describe their resources to include referral to programs (in the community, through hospital systems, other PN practices) that already exist if they cannot or do not provide it in their own practice. "I'm not reinventing the wheel. I connect with all these different places and I search these places out...And then I connect-and these places..."

The PNs described in detail the programming that they conduct and offer to their patients in their practice. These included any health services, education, or resources that they provided to their patients. Health services include home visits, hospital/nursing home visits, office visits, and phone calls. "...I do lots of visitations in homes, hospitals, nursing homes, and office visits." Health education was described as ranging from one-on-one education that was directed by a

patient need to a formal program. Blood pressure screenings were described as a way PNs often start a conversation about health that often leads to offering health education. “Usually the people that have-are on my blood pressure list are diabetics also, so you get a chance for about three minutes, five minutes, to sort of discuss “How are you doing?”

Less direct education was provided through health articles in the church bulletin/newsletter, health bulletin boards, and laying out pamphlets and health education materials in high traffic areas. “In what we do is our bulletin board...utilizing the most simplistic, eye-catching attention for that sentiment for that month...” Directed formal health education was described as education on general wellness, basic nutrition, activity, promoting getting physical check-ups, and foot care. “We also do education, for example, kind of life issues planning.” Some also describe wellness fairs that may include lab screening (glucose), blood pressure checks, bone density screening, blood drives, and flu shot clinics. “Yes, we have community events there was a health fair...”. “...we provide community resources like flu clinics and insurance discussions...”.

They have offered resources including health education materials in the church library, bible studies incorporating self-management, counseling groups/support groups. “We have a little section in the library on health issues...” “We have a chronic disease kind of self-management bible study group.” In addition, health professionals who attend the church may talk to parishioners about health related to their specialty area. “...one of the parishioners who helps our group is a registered dietitian,...so we have some talent within the parish. It was a great example of pulling in some talent...”.

### **Diabetes Practice and Programming**

The PNs described patients in their faith-based settings with a diagnosis of diabetes. “I’d say about twelve percent of our congregation have diabetes.” “At our church, I’d say a good ninety percent.” “...most of my females will be diabetic” “Most of them are Type 2”. They also described that these numbers would be even higher if you considered those who are pre-diabetics, at risk for developing diabetes, or unaware themselves of having diabetes. “But we are finding out that more and more people are discovering they have diabetes, so it’s like-it’s undiagnosed...” “I think for the large percentage they just don’t know that they’re diabetic, or in denial.”

The PNs also described the experiences they have had providing care for patients with diabetes. These included informal discussion when a patient reveals that he/she has received a diagnosis of diabetes and then discuss the diagnosis when he/she comes to a church dinner/coffee hour, “But I do see that where during coffee hour, there’s more-more elderly will say to me, “Well, you know, I can’t really have a donut because I have diabetes.” And then that is my opening to start talking to them about it.” or to have his/her blood pressure checked. “And very often, once they starting coming in for their blood pressure, I usually ask them if they have any other medications that they’re taking for anything. And very often, then they’ll say, “Well, yeah. I’m diabetic,” or something like that. So, that’s about the only way I’m determining-you know, again, from people who are just presenting themselves for something else...” The PNs also described misconceptions their patients have about diabetes. “And talking to them, we learned how little education they had received about (diabetes)...except they couldn’t have sugar, and they did not realize that they could qualify for education through their insurance about what they could eat and how they could manage their own diet.”

The type of education done with patients who have diabetes was also described. This education can range from being very informal to a formal program and include those who are at risk for diabetes as well as those who already have a diagnosis. "...it's more like inquiring from them....so kind of a roundabout way that I try to educate them." "They've held health fairs, and we are planning, in our particular church, planning a health fair...And of course, the blood sugar screen...part of the health fair." Some do not currently provide care, education, or programming that is specific to patients with diabetes, because they are a newer PN and have not yet been able to establish these programs or because they have started to practice at a new faith-based setting. "We don't have anything specifically directed towards diabetics formally available." "I've been a parish nurse since...it was a year and a half,...so we're kind of a new ministry.

Informal education is described as fliers and signs discussing symptoms and warning signs of diabetes, newsletter, and one-on-one discussions about medications or insulin administration teaching. " 'How's your diabetes?' That kind of informal conversation happens. Like never a focused class." The participants describe those programs that are more formal differently as some have a medical professional other than the PN (physician, dietician, diabetes educator) presenting them. "...we had 4 sessions with the diabetic educator." They also talked about foot health and complications like cardiovascular disease. They've included discussion groups and support groups, "...but we did a one-month series on diabetes...". "...I offered a diabetic program, education program, and a discussion group." They held an entire health fair dedicated specifically to diabetes. "We did have a diabetes fair..."

### **Diabetes and Pregnancy and PC Practice and Programming**

The PNs noted that women of childbearing age were present in their churches and therefore an opportunity for education and counseling, "...we have quite a few middle-age and

young people, so there are childbearing age people in the congregation...” They described that, to date, they have had little to no care interaction, programming or education around pregnancy. “..in my home parish, I have not had the opportunity to work with any pregnant women.” More specifically, they have had little to no experience with caring for women with diabetes who are pregnant and have not done any education or programming related to pregnancy and diabetes. “...in my congregation, we have a lot of young females who are of childbearing age, and to be honest with you, I didn’t even consider the diabetes question because in looking at them, they are health. But, again, that doesn’t mean anything.”

### **Awareness of PC**

Prior to participation in this study most PNs reported that they were unaware of PC for women with diabetes. “I heard it because you told me it. Before that, I had not.” “It’s really something that – that’s the reason I came here today, because it doesn’t happen. And for the growing diabetes, particularly type 2, which people still think that’s the benign diabetes, like it’s not going to cause any harm because it’s only type 2.” “ It’s awareness. To get parish nurses aware, I think, that this is an issue.” They expressed that they were familiar with the idea of preconception care unrelated to diabetes, but had never heard of PC for women with diabetes. “Not that expression. Not like that.” “I’ve heard the term, I don’t know specifics.”

### **Experience providing PC**

Most PNs expressed that they were not currently providing formal diabetes education regarding pregnancy or PC to their patients with diabetes, and the majority had never provided it. “I have not taught anything about diabetes and pregnancy.”

### **Formal training on PC**

Parish nurses reported having receiving very little to no education in their nursing training or PN training related to PC and had never received any PC education specific to women with diabetes. “As far as preconception before you got pregnant, I don’t remember anything even in nursing teaching that these are issues...”

### **Importance and usefulness of providing PC and diabetes education**

Despite never having had any training on PC or experience providing it, they feel that PC is an important topic and that it is beneficial for themselves as well as the childbearing women with diabetes in their community. “Most women would find that preconception counseling was very useful”, “I think as nurses, we have a responsibility to be – we know what people need. They don’t know what they need, but we do. So we have that responsibility to try and get that information out there, in whatever creative way we can. So I don’t know – that’s why, I think, nurses and especially parish nurses take that on. Because we care.” In addition, they believe that the church is a good arena for PC/DM education. “We could definitely use a program like that in our church.” “I think that would be helpful to me because I have a mixed population in my church right now and I think it’s important for people to know....”

### **Willingness to provide PC**

The PNs felt that having awareness, knowledge, and confidence regarding PC would be a benefit for themselves as well as childbearing women with diabetes they will encounter and their community. “I think it would be a huge help in providing that information (PC) and in awareness even for the whole congregation really to know that you know as diabetes is happening, particularly T2D in a younger childbearing population, there are risks that people just are not aware of, you know, because you aren’t being educated....” “I want to know everything. I can’t

help people if I don't know (in reference to PC).” "...a community nurse could really promote this (PC), especially with our Hispanic community and all the young girls that I'm seeing here.”

### **Acknowledgment of early PC (teenage girls)**

The PNs expressed that PC education needs to be introduced early, in the teenage years, in order to raise awareness among childbearing women with diabetes prior to a pregnancy. “You know where it really needs to start? In junior high, where you -Yeah, you can start there to get the idea in their head, but it's not going to apply to them at that point. But for there to be information that they can use, you know.” “...I think that this type of education almost has to start at puberty, with females and males. And knowing how you need to take care of your body and all the things leading up to the possibility... they need to know that this is the time they have to be preparing for their pregnancy. It's not even six months before and that brings in the whole concept of whole health.”

### **Confidence to provide PC**

Currently, the PNs felt that their confidence to provide any education to childbearing women with diabetes was low. “I feel fairly confident about that (diabetes). Pregnancy, though, is another issue. I don't feel confident about it.” “...so I don't have much confidence when it comes to women who are either in their childbearing years or they're already pregnant...”

### **Need for parish nurse PC training**

The PNs expressed an interest in receiving an education program to increase their awareness, knowledge, and teaching self-confidence related to PC and diabetes. “Just knowing that there is something available that if I needed it where I could go to find it or where I could direct a person to find it. So I think it would be excellent to have in our toolbox.” “...they (PNs) have to be trained where they have a confidence level, I mean to just explain something on a

sheet of paper that they don't understand the rationale behind, it isn't gonna give them confidence..." "...I would need more specifics as what a woman would have to know on the preconception level, what a woman needs to know how to take care of herself before she even conceives."

### **Recommendations for parish nurse PC training**

The PNs recommended the following training components including: 1) learning the basics of diabetes and pregnancy and PC to obtain baseline knowledge and understanding. "...a baseline class (related to PC)..." 2) They felt that have a multidisciplinary approach with insight from different medical professionals who have expertise related to diabetes and pregnancy and PC would be helpful. "...well its gotta be multidisciplinary too. A physician speaking, a dietician,". 3) They would like case studies "...to have someone there who is willing to share their life story, their difficulties...being pregnant with diabetes." 4) An algorithm to follow, a fact sheet, and a list of resources to access including where to refer their patients. "I would want to know the resources in the community..." "...like a checklist,..a factsheet..." "...I like the algorithm type of thing because then we could go down and say okay here go here and then go here ...as an interview counselor..." 5) They felt the strategy should include technology, be interactive, and be on-line. "...I like online..." "...flexible..like continuing education..." They also expressed that a seminar, webinar, or a symposium would be helpful. This program would need to be inexpensive with their limited funding. "Some of these nurses, you know, as far as continuing ed budget they have little to no money with that." 6) It was also discussed that doing training with other groups/members in church who may have interaction with or be influential in the lives of childbearing women would be an additional way to increase awareness about the topic. "...there are people in the congregation to whom people go, not necessarily the parish

nurse, but they may also feel comfortable among their peers-an older wiser woman or another young mother who's been there, done that. And if the parish nurse can connect with, that network of wise women with information to filter down...but there's room for those other women to whom people might go.”

### **Recommendations for PC tool for patients**

The PNs provide recommendations for a teaching program or education tool for PC to be used in their practice. 1) “We would love to have a toolkit that you put together with a fact sheet, web references...” 2) They expressed that it needs to give positive messages rather than negative consequences. “A more positivistic approach...rather than consequence related.” 3) It needs to incorporate faith and how one looks at her faith in making health related decisions. “I think it would be terrific to have a tool that would also bring in that faith piece, you know, ...”. 4) They felt it needs to start broader with self-care and being a good steward of your body and to include preconception in general for all women who are childbearing and then narrow down to diabetes. “You start out with self-care.”

They described a resource as a toolkit and suggested the following: 1) phases of readiness for pregnancy, 2) information from experts, 3) positive stories of women who had successful pregnancies with diabetes, 4) pictures to accommodate those with a lower reading level, discussion and pictures of pregnancy as it evolves and how this may be occurring before a woman even knows she is pregnant, “I need pictures in my group, because my group doesn't read to well.” 5) fact sheet with highlights for a take home, 6) and web references.

They had interest in a technology-based interactive component that would include a DVD, CD, or utilizes the web like an APP or social media. “I just think that the whole generation is kind of tech savvy so I would think that it would be an interactive type thing. Whether it would

be on the computer or whatever.” “...like an app...” By doing this, a person who needed it, would have the flexibility to use it when she had the time, was in her own home, and had privacy. “..something more interactive, like on the computer, like a software program they could do at home...or online...”

In addition, they suggested one-on-one discussion time with the PN as well as group time (pre-marital counseling) with their peers and partners or family members to have support. “I just feel...more ...face-to-face contact is by far the most important part of education.” This group time could even be a collaboration of multiple churches. “...collaborating among different programs would be-and to offer within a given area.” One suggestion was that there should be something specific for a partner or family member on how to support the woman with diabetes. “...but the other person I would include...is the father of the baby or the family, because its hard to stay on a diet or do one thing when you’re the only person doing it, but it you’re in the family...You need to have everybody on board.”

## **Discussion**

By using a qualitative focus group approach, we explored the role of the parish nurse and their experiences with educating and providing PC to women of childbearing age with T1D and T2D, and their understanding of diabetes as it relates to pregnancy and pregnancy outcomes, especially for AA women. Seventeen themes emerged from their discussion that included: their role and approach and unique practice situate PNs perfectly to provide life altering care and education. They may be able to influence positive health related decision-making. This is especially true in AA communities which may experience either lack of insurance and/or access to care and lack of health equity.

Parish nurses face unique challenges due to the nature of their care. One important challenge mentioned is isolation, thus making the parish nurse support network extremely important.

Parish nurses are savvy at providing health education. They currently provide health education on multiple topics that they see fit for their patients. Many provide diabetes education in ways specific to their patient needs.

However, they currently are not providing diabetes education related to pregnancy or PC. The majority of parish nurses have not provided this education because they were unaware of the topic and its importance and because they have had little to no education to prepare them to be confident to provide education in this area. They do however, feel that this topic is important and timely and that parish nurses can and should be providing this education to women who need it.

In order for parish nurses to have the confidence and knowledge base to provide this education they need an education program for themselves. A train-the-trainer, teach-the-teacher program is needed to prepare them for such a role. They would like a training program that is multifaceted incorporating different learning styles and needs with visual and audio information.

An ideal toolkit to provide to their patients includes a faith-based self-care general preconception program with specific information about diabetes. This program needs to incorporate the needs of the women it will serve.

An article by Dyess, Chase, & Newlin (2010) reviewed the state of research for parish nursing. In this article the authors identify a content area as roles and activities of parish nurses. The authors discuss seven studies that include information about the role of the parish nurse. According to the review, all but one article describe the role of the parish nurse similarly to the

results of this study. Some of the main role topic overlap includes: spiritual care, holistic care, health promotion and education activities, counseling, referring, and active listening. Therefore, confirming results of this study would be included as a strength. An additional strength of the study would include the focus group methodology utilizing “distance” method which allowed for a larger more diverse sample and was convenient for those who could not physically be present.

One of the main limitations is that the sample was obtained from contacts of a single parish nurse organization in Pittsburgh with subjects mainly from western Pennsylvania with fewer focus group participants from other locations. Therefore, the study findings may be more related to the experience of the participants from the Pittsburgh and surrounding area and not necessarily be representative of parish nurses across the country. To counteract this possibility purposive sampling was utilized to maximize variation of study participants minimized this limitation. Furthermore, given the large sample pool of parish nurses in this organization, broad representation was anticipated. In addition, the cross-sectional nature of this study did not permit test-retest reliability on the quantitative measures. Additional data collection points would be preferred.

Parish nurses are uniquely situated not only because they exist in a community setting, putting them in closer proximity to the homes of a client, but also because of they are in a setting where patients may attend on a regular basis and share similar set of values due to their faith. This allows for a relationship that has many more layers, which develops a greater sense of trust compared to a traditional nurse-patient relationship. The PN provides holistic care including the physical, mental, and spiritual aspects of a person; incorporating faith into care, health promotion and prevention activities.

## **Implications**

By exploring the experiences and understanding needs for resources and training of PN's who are uniquely poised to deliver care to a vulnerable population of underserved women with DM this study is filling a significant gap in the literature. This program of research can potentially make a significant impact on the pregnancy outcomes of women with diabetes.

The results of this work point to the need for future development and testing of a prototype for a technology-based training, as well as a prototype E-health education resource for parish nurses to use with African American women with diabetes, both of which will be tailored from an already existing educational program and training component to be more culturally relevant for African American women.

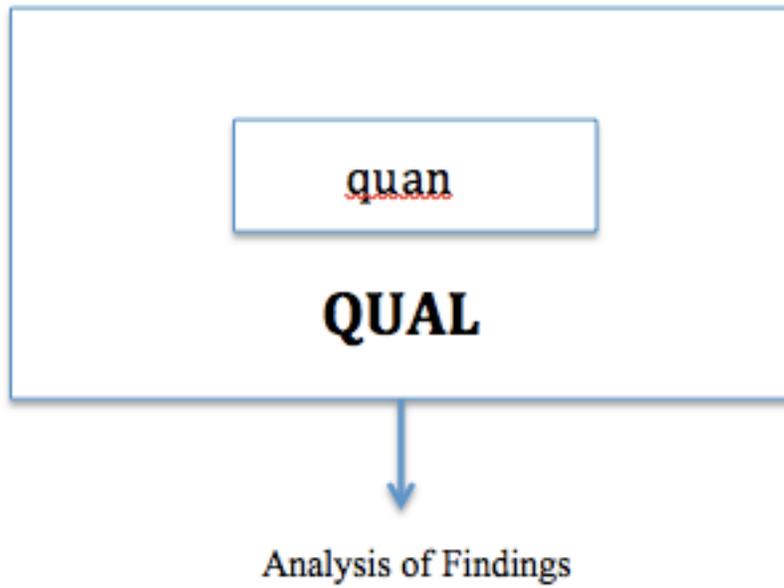
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Table 1

<b>Focus Group Questions with probes</b>	
<b>Opening Statement</b>	
Tell me about your role or practice as a parish nurse?	
a.	Tell me about those you care for as a parish nurse?
1.	What percent of your patients have T1D or T2D?
a.	About what percent of these are female?
b.	About what percent are within their childbearing years?
2.	What do you teach your patients about diabetes?
3.	Tell me about how you provide this education or programming?
4.	How confident do you feel providing this education?
5.	What more do you feel you need to know about diabetes to educate your patients?
6.	What do you teach your patients about diabetes and pregnancy?
7.	What do you know about preconception counseling?
8.	Have you discussed preconception counseling to women with diabetes?
9.	How might this information be helpful to have?
10.	How confident do you feel providing preconception counseling?
11.	What more do you feel you need to know about preconception counseling for women with diabetes in order to provide this education?
12.	Have you ever gotten formal instruction about preconception counseling or pregnancy with diabetes? From where?
a.	Would you benefit from further preconception counseling training?
i.	If yes, what would an ideal training program look like?
b.	Would your community benefit from further preconception counseling training?
i.	If yes, what would an ideal tool or program to use with your patients look like?

Figure 1 Concurrent Embedded Design



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