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# Exploring Knowledge and Attitudes Related to Pregnancy and Preconception Health in Women with Chronic Medical Conditions

## Cynthia H. Chuang

Division of General Internal Medicine, Penn State College of Medicine, 600 Centerview Drive, A210, Hershey, PA 17033, USA

Department of Public Health Sciences, Penn State College of Medicine, Hershey, PA, USA

### Diana L. Velott

Department of Public Health Sciences, Penn State College of Medicine, Hershey, PA, USA

## Carol S. Weisman

Department of Public Health Sciences, Penn State College of Medicine, Hershey, PA, USA Department of Obstetrics & Gynecology, Penn State College of Medicine, Hershey, PA, USA Cynthia H. Chuang: cchuang@psu.edu

### **Abstract**

Women with chronic medical conditions are at increased risk for pregnancy-related complications, yet little research has addressed how women with diabetes, hypertension, and obesity perceive their pregnancy-associated risks or make reproductive health decisions. Focus groups were conducted with 72 non-pregnant women stratified by chronic condition (diabetes, hypertension, obesity) and by previous live birth. Participants discussed their intention for future pregnancy, preconception health optimization, perceived risk of adverse pregnancy outcomes, and contraceptive beliefs. Four major themes were identified, with some variation across medical conditions and parity: (1) Knowledge about pregnancy risks related to chronic medical conditions was limited; (2) Pregnancy intentions were affected by diabetes and hypertension, (3) Knowledge about optimizing preconception health was limited; and (4) Lack of control over ability to avoid unintended pregnancy, including limited knowledge about how medical conditions might affect contraceptive choices. Women with diabetes and hypertension, but not obesity, were generally aware of increased risk for pregnancy complications, and often expressed less intention for future pregnancy as a result. However, diabetic and hypertensive women had little knowledge about the specific complications they were at risk for, even among those who had previously experienced pregnancy complications. Neither chronic condition nor perceived risk ensured intent to engage in preconception health promotion. We observed knowledge deficits about pregnancy-related risks in women with diabetes, hypertension, and obesity, as well as lack of intent to engage in preconception health promotion and pregnancy planning. These findings have important implications for the development of preconception care for women with chronic medical conditions.

# Keywords

Chronic medical conditions; Preconception care; Pregnancy; Pregnancy intention

## Introduction

While unintended pregnancy is a major public health issue for all reproductive age women in the US [1], women with chronic medical conditions are of particular concern due to significantly increased risk for pregnancy-related morbidity and adverse pregnancy outcomes [2]. A few studies have suggested that women with chronic conditions are at increased risk for unintended pregnancy [3–5], which may be the result of lower rates of contraceptive use in women with chronic medical conditions [6,7]. Little is known about whether women with chronic medical conditions understand their pregnancy-related risks, how these conditions influence intent for pregnancy, and how chronic conditions influence pregnancy avoidance and/or pregnancy planning behaviors.

Our objective was to explore pregnancy and preconception health knowledge and attitudes in the context of specific chronic maternal diseases. While there are many chronic medical conditions that affect women of reproductive age, we chose to study diabetes, hypertension, and obesity due to their increasing prevalence and known associations with adverse pregnancy outcomes. Diabetes increases the risk of major congenital malformations, pregnancy-induced hypertension, and spontaneous abortions [8,9]. Hypertension increases maternal risk for preeclampsia and eclampsia, cerebral hemorrhage, and renal failure; fetal risks include preterm birth, intrauterine growth restriction, placental abruption, and stillbirth [10]. Obesity increases maternal risk of gestational diabetes, pregnancy-induced hypertension, thromboembolic disorders, and cesarean section; infants of obese mothers are at risk for macrosomia, birth trauma, and congenital anomalies [11–13].

We explore whether women with diabetes, hypertension, and obesity have been exposed to risk messages/ counseling about pregnancy-related risks, and whether risk perception influences desire for future pregnancy. We also explore whether women with previous live births would be more likely to be aware of their pregnancy-related risks, due to previous experience with pregnancy-related complications, need for high-risk obstetric care, or counseling received during previous pregnancies. Greater understanding of these concepts will lead to better informed strategies by researchers, policy makers, and clinicians to assist women to optimize preconception health and reduce unintended pregnancies.

## **Methods**

## **Participants**

In Spring 2008, we recruited women ages 18–45 with diabetes, hypertension, or obesity through advertisements (newspaper, radio, internet), flyers posted in community settings and clinical sites at the Penn State Hershey Medical Center, and a volunteer research database of people with diabetes. Recruitment materials invited women to participate in focus groups to discuss their feelings about general health and pregnancy as it related to their medical conditions. Women who responded were screened by phone for eligibility. Eligibility criteria included a self-reported diagnosis of non-pregnancy related diabetes, non-pregnancy related hypertension, or obesity (defined as body mass index of 30 kg/m² or greater using self-reported height and weight). Since our focus was on preconception and interconception health risks, women who were currently pregnant, had a hysterectomy, or had tubal sterilization were not eligible. Women who met eligibility criteria and agreed to participate were scheduled for a focus group discussion. Informed written consent was obtained before

the focus group sessions and each woman was compensated for her participation. This study was approved by the Penn State University School of Medicine's Institutional Review Board (Hershey, PA, USA).

#### **Procedures**

We conducted 12 focus groups with a total of 72 participants. Groups were stratified by chronic medical condition (diabetes, hypertension, and obesity). Each chronic condition group was further stratified by whether or not women had a previous live birth (nulliparous vs. parous). Due to the distribution of eligible women recruited, we had four groups of diabetic women (2 parous, 2 nulliparous), three groups of hypertensive women (2 parous, 1 mixed parity), and five groups of obese women (3 parous, 2 nulliparous). There was one woman who had one previous pregnancy that did not result in a live birth; she was included in a nulliparous group.

The focus group guide is outlined in Table 1. Discussion topics included future pregnancy intention (plans for future pregnancy, role of chronic medical conditions); preconception health optimization; perceived risk of pregnancy-related complications; and contraception in the context of chronic medical conditions.

The focus groups were conducted by trained facilitators from the Penn State Survey Research Center. The groups were held in conference rooms at either a hotel or a campus location. Prior to each session participants completed a brief, anonymous self-administered questionnaire regarding demographic data and basic medical information. Groups were facilitated by a female moderator, who had extensive moderating experience and was not involved with the design of the study. The moderator introduced discussion topics as presented in the focus group guide (Table 1), occasionally using probes to keep the discussion on topic or to request elaboration of certain ideas. A trained observer was also present as a note taker. All sessions were audio and videotaped; audiotapes were transcribed by a professional transcription service.

## **Data Analysis**

Frequencies for demographic and medical history data reported on the brief questionnaire are presented. Two members of the research team independently analyzed each transcript, using a modified grounded theory approach to identify themes related to the topics discussed [14]. Grounded theory is a systematic approach to qualitative analysis emphasizing concept and theory formation that are grounded in empirical observations in the data. The videotapes were reviewed to clarify speakers and non-verbal expressions. The investigators then jointly decided on the major themes, for which there was full agreement. Illustrative examples of the themes were selected. The NVivo8 software package for qualitative data (QSR International, Melbourne, Australia) was used to categorize the responses into the appropriate themes.

## Results

Characteristics of the 72 focus group participants are shown in Table 2. Of participants with at least one previous birth, 51% had at least one previous pregnancy complication (defined as gestational diabetes among non-diabetics, pregnancy-associated hypertension among non-hypertensives, low birthweight, preterm birth, or birth defect/birth disorder).

As outlined in Table 3, four major themes were identified in the analysis: (1) Knowledge about pregnancy risks related to chronic medical conditions was limited; (2) Pregnancy intentions were affected by diabetes and hypertension, (3) Knowledge about optimizing preconception health was limited; and (4) Lack of control over avoiding pregnancies,

including limited knowledge about how medical conditions might limit contraceptive choices.

## Knowledge About Pregnancy Risks Related to Chronic Medical Conditions was Limited

Nulliparous women with diabetes were aware of increased pregnancy-related risk, but did not know what the specific risks were to either the mother or the baby. Parous women with diabetes knew they were at risk of having larger babies and newborn blood glucose abnormalities. Women were concerned about fetal exposure to diabetic medication during pregnancy and many expressed concern that their children would be at risk for diabetes. Only one woman expressed concern for risk of heart complications because she remembered receiving fetal cardiac testing during her pregnancy. There was no other mention of risk for fetal anomalies.

While many women with hypertension were aware that they could experience maternal complications (e.g. pregnancy-induced hypertension/preeclampsia, need to be on bedrest, stroke, and uterine bleeding) during pregnancy, the women could not name specific risks to the fetus/baby. It was often expressed that hypertension causes direct risk to the mother only. When asked whether their doctors had informed them of potential risks to their babies, women responded no.

While many hypertensive women with children described having had preeclampsia, preterm births, and low birthweight babies, none of the women directly attributed these complications to their chronic hypertension or discussed a link between hypertension and these previous complications. A few hypertensive women expressed denial about their pregnancy-related risks, as with this hypertensive woman with two children:

My husband was so worried and my doctor was so worried, I was either just stupid or just sleep deprived or whatever because I was never worried. I wasn't worried. I read the Internet stuff and it didn't faze me. It was like yes, whatever.

Once pregnant, many hypertensive women with children reported being scared, largely due to the messages their doctors conveyed about potential complications.

Feelings were mixed among the obese women as to whether their weight increased pregnancy-related risks. Women with children were generally more aware and concerned about potential risks, specifically for gestational diabetes, having big babies, and Cesarean sections. However, many women denied overweight being a significant factor:

...I was overweight with my first two pregnancies and didn't think anything about it. I got pregnant easily. I had very normal pregnancies. I had preeclampsia and I knew obviously the significance of that stuff, but you know skinny people have preeclampsia too.

Several obese women who have had children did recall that their doctors were concerned about their health risks, but the women largely considered the doctors' concerns to be overly cautious and perhaps due to fear of litigation.

Nulliparous obese women were more likely to deny the risks of obesity to be significant with pregnancy. They frequently cited the belief that normal weight women were just as likely to have pregnancy complications.

...there are women who are 120 pounds who have the same problem that your sister had [referring to a woman who's "grossly overweight" sister had gestational diabetes]. Like they get it too so what is the difference between them getting diabetes and someone who weighs 400 pounds?

While some nulliparous women did state concerns about pregnancy complications, those concerns were limited to losing mobility during pregnancy with additional weight gain.

## **Pregnancy Intentions were Affected by Diabetes and Hypertension**

During discussions of influences on pregnancy intention, women primarily focused on traditionally described determinants of pregnancy intentions, such as satisfaction with current number of children, financial concerns, ideal family size, relationship stability, and school/career goals. Obesity was not identified as a factor that influenced intentions for future pregnancy. However, many hypertensive and diabetic women expressed increased ambivalence or decreased intent for future pregnancy because of the risks posed by their conditions:

[I have had] high blood pressure for so many years and you know other complications that I had with my second pregnancy. It would be tough to go through that again.

Diabetes affected another woman's desire for having a child, not because of the pregnancy-related risks, but due to concern about her ability to take care of a child when she is already burdened with taking care of herself:

I know for me the ability to care for children was a concern for me... just getting up and dealing with diabetes for 35 years in a row is just exhausting and I just could not imagine having to get up in the morning and have somebody else to have to take care of on top of myself.

Some of these fears were tempered by confidence that advances in medical care and technology would ensure healthy outcomes. Some women also expressed the belief that the health risks were only to the mother and not to the baby; women would therefore be willing to take the risk to their own health. In general, women with children were more cautious about considering future pregnancies in light of their medical conditions.

In a few individuals, the complications experienced with previous pregnancies actually increased desire for pregnancy because they wanted to experience a "normal pregnancy." A couple of women who had delivered by Caesarean section felt cheated because they did not get to experience vaginal birth. Another woman with a very preterm birth felt shortchanged because she didn't experience carrying pregnancy full term. One hypertensive woman who had a previous stillbirth described this sentiment:

[My son] was at  $31\frac{1}{2}$  weeks and the preeclampsia hit me... From the time it hit me until the time he died it was about 3 days. So yes... I still have that fear, but...I need to prove that I can... So I would love to have another.

## Knowledge About Preconception Health Optimization was Limited

Women of all chronic conditions and pregnancy experience reported smoking cessation and moderation of alcohol consumption to be important prior to pregnancy. The importance of folic acid supplementation in the preconception period was mentioned in a few groups; these comments did not appear clustered by maternal condition. Several women described themselves as healthy, and therefore would not need to do anything. Specific knowledge and attitudes about appropriate preconception health optimization with regard to their chronic conditions varied widely, depending on the specific chronic condition.

Diabetic women had the most accurate, specific, and consistent knowledge about appropriate management of their condition prior to pregnancy. Most diabetic women recognized the importance of preconception glycemic control; several women believed

insulin pumps should be used in preparation for pregnancy. In spite of that knowledge, diabetic women acknowledged that preconception glycemic optimization was difficult:

So I mean yes, I would have loved to have planned it, but you know for me it would have been like trying to plan the rain... Because it is hard to control diabetes every day all the time and so you know to have to plan for pregnancy on top of that, I was not thinking of that at all. Yes it would be ideal. I guess ideally someone would have excellent blood sugars before they conceived and they would have thought about it thoroughly, but that just wasn't my experience at all.

A diabetic woman who currently desires pregnancy stated:

I'm kind of already being a little more attentive to trying to check my sugars more often so that I can keep my A1C lower. I mean you know it is like we may have our plans, but we all know how that goes...

Several diabetic women had discussions with their doctors regarding planning for pregnancy, and generally seemed welcoming to preconception planning.

I think it is really great when you have a physician that they bring it [pregnancy planning] up. As in, "Are you thinking about children?" or "I could do these things to assist you" and some and so on. It is a lot easier when they bring it up versus when you have to bring it up.

Women with hypertension and obesity had little knowledge about how to properly manage their chronic conditions before pregnancy. Fearing the harmful effects of antihypertensive medication during pregnancy, several stated they would stop their medications prior to trying to conceive. While obese women generally agreed that losing weight before pregnancy would be ideal, the reasons were mostly to avoid the discomfort of excess weight during pregnancy. No hypertensive or obese women mentioned seeing their health care provider as a part of preconception planning.

While many obese women wanted to lose weight before a future pregnancy, they expressed hostility toward their doctors regarding weight loss counseling. One obese woman said:

You mean I shouldn't be sitting on my couch and stuffing my face with Oreos all afternoon? I mean it is... insulting to have [doctors] be like... I don't understand why this is not working for you,... you obviously are not doing it correctly.

Whether weight loss counseling was well received often seemed to be influenced by the perceived weight of the doctor. However, how the doctor's size influenced the acceptability of the weight loss advice varied among the women:

They are sitting there and trying to tell me about being overweight. How the hell do they know what it is like to be in my shoes? They don't and then it is like they are pandering to me... You come and tell me about how you lost a hundred pounds and kept it off, then I will be willing to listen to you and until then, I still know more than they do.

[My gynecologist] is kind of on the chunkier side so she never really gets into weight or whatever. You know I think it is kind of like the under the table we both know that weight is an issue, but we are not going to talk about it thing... Then this 2<sup>nd</sup> pregnancy... I saw...the skinniest petite-est little doctor that they have in the practice. So she is all of a size 2...She said to me oh you know you are heavier. You really should only gain 15 to 20 pounds. That really stuck in my head this time...

# Pregnancy Avoidance: Lack of Control and Minimal Contraceptive Knowledge

Regardless of previous pregnancy experience or type of chronic condition, many women expressed the belief that avoiding pregnancy was largely not in their own control, but controlled externally, by fate or divine intervention:

Diabetic woman #1: I met a lot of people who have had what they call an accident, but I mean I would think that is kind of fate, but I believe in that kind of stuff...

Diabetic woman #2: I think it is personal choice what means of protection you are using, but if you become pregnant it is more of God's will.

Diabetic woman #1: Yes, I agree with that too... Yes, I think God can override that stuff.

I kind of look at the people that say oh we are only going to have two kids and they are going to be spaced 2½ years apart... I look at them and I think you know the best way to make God laugh is to make a plan.

For all chronic conditions and parity experiences, women were unaware that their birth control options were potentially limited by their condition. The overwhelming response in most groups when asked whether they thought certain types of birth control may be less safe for them was either that there was no safety issues or that they never really thought about it. A few hypertensive women suggested that they may have been taken off the pill because of their blood pressure, but most of the hypertensive women did not know about any connection between birth control pills and blood pressure. Obese women were concerned about weight gain as a side effect of hormonal methods.

## **Discussion**

Using focus group methodology, we found that distinct chronic medical conditions had different influences on pregnancy intention among reproductive age women. Specifically, diabetic and hypertensive women were generally aware of increased risk for pregnancy-related complications and often expressed decreased intention for future pregnancy due to that risk. These findings support the idea that perceived risk of pregnancy complications can influence pregnancy intentions. Conversely, obese women generally did not perceive increased risk, and obesity did not influence their pregnancy intentions. However, the diabetic and hypertensive women had little knowledge about what specific pregnancy complications they were at risk for, even in women who had previously experienced pregnancy complications.

While higher perceived risk of pregnancy-related complications may result in decreased intent for pregnancy, it is less clear whether it results in behavior patterns, such as contraceptive use and adherence. It is also unclear whether women who intend pregnancy would be more likely to plan future pregnancies or engage in preconception health optimization. For example, diabetic women mostly agreed that tight glycemic control before pregnancy was important. But this knowledge was tempered by the reality that this would be difficult to achieve. Several diabetic women stated they would carefully control their diabetes prior to a future pregnancy, but admittedly did not do so prior to previous pregnancies. These contradictions between intention for behavior change and actual behavior pose a dilemma for preconception intervention development [15].

In terms of pregnancy avoidance, the women in our study generally did not recognize that their birth control options could potentially be limited by their chronic conditions [16]. Furthermore, many women reported lack of control over their ability to avoid pregnancy. Unintended pregnancy was not viewed as a result of inadequate contraceptive use, but rather

a decision made by fate or God. A woman's perceived lack of control over her ability to avoid pregnancy is an additional barrier to contraceptive use and compliance. Further research will need to investigate how such attitudes can be approached and addressed in family planning messages.

There are several limitations of this study. The focus group methodology and small sample size limit generalizability to all women with the targeted chronic conditions. Further, this study included women with only three chronic conditions and could not include all chronic conditions that affect pregnancy risk. Most importantly, our sample is highly educated (93% had at least some college), which means that even the limited knowledge levels observed with respect to pregnancy risk could be overestimated.

Our findings suggest that having a chronic medical condition influences how women think about future pregnancy; however knowledge and attitudes about pregnancy varies by specific medical condition. We observed significant knowledge and awareness deficits as well as a lack of behavioral intent to engage in preconception health promotion. Women are not fully aware of potential reproductive health and pregnancy-related risks of their chronic condition, which may lead to uninformed decisions about future pregnancy, pregnancy avoidance, and preconception planning. Current clinical practice and research aimed at preconception health promotion in reproductive age women with chronic conditions should address these gaps in knowledge to achieve the goal of avoiding unintended pregnancy and adverse pregnancy outcomes.

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#### Table 1

## Focus group guide

#### Questions

Future pregnancy intention

- 1 We would like to know if you are thinking about having any/more children in the future?
- 2 What factors are important to you in thinking about whether or not you want to have any/more children?
- 3 Does having diabetes/having hypertension/being overweight factor into your decision about having children in the future?

## Preconception health optimization

- 1 Some people think pregnancies should be planned and some people think that pregnancy happens when it happens. What do you think?
- What do you mean when you say you are planning a future pregnancy? Does planning pregnancy mean changing any of your behaviors?

Risk perception of adverse pregnancy outcomes

- 1 Do you think that diabetes/hypertension/being overweight makes you any more or less likely to have a difficult pregnancy?
- 2 Do you think diabetes/hypertension/being overweight makes you any more or less likely to have a baby with a complication?

#### Contraceptive use

- 1 Does having diabetes/hypertension/being overweight affect your decision about what type of birth control to sue?
- 2 Do you think certain types of birth control are less safe or less effective because you are diabetic/hypertensive/overweight?

Table 2

Characteristics of focus group participants, N = 72

Characteristic	% (N)
Chronic medical condition	
Diabetes	22.2 (16)
Hypertension	22.2 (16)
Obesity	56.6 (40)
Age-median (range), in years	34 (20–45)
Marital status	
Married	57.7 (41)
Never married	35.2 (25)
Separated/divorced	7.0 (5)
Race/ethnicity	
White	73.2 (52)
Black	15.5 (11)
Multiple races/ethnicities	4.2 (3)
Other	7.0 (5)
Annual household income	
Less than \$15,000	6.1 (4)
\$15,000–\$29,999	19.7 (13)
\$30,000–\$44,999	18.2 (12)
\$45,000–\$64,999	19.7 (13)
\$65,000 or more	36.4 (24)
Education	
Less than high school graduate	0 (0)
High school graduate or equivalent	7.1 (5)
Some college	44.3 (31)
College graduate	48.6 (34)
Body mass index—median (range), in kg/m <sup>2</sup>	36 (17–60)
Previous live births	70.8 (51)
History of any pregnancy complication $a$	51.0 (26/51)
1. Previous pregnancy complication	33.3 (17/51)
2. Previous pregnancy complication	13.7 (7/51)
3. Previous pregnancy complication	3.9 (2/51)

 $<sup>^{</sup>a}$ Pregnancy complications are defined as gestational diabetes (among non-diabetics), pregnancy-associated hypertension (among non-hypertensives), low birthweight, preterm birth, or birth defect/disorder

 Table 3

 Themes identified from focus groups of diabetic, hypertensive, and obese women

Themes	Diabetes	Hypertension	Obesity
Knowledge about pregnancy risks related to chronic medical conditions was limited	Nulliparous women unaware of specific risks of maternal diabetes	Poor knowledge about potential adverse infant outcomes	Variable knowledge about pregnancy-related risks
	Parous women aware of increased risk of larger babies, little knowledge about other risks	Lack of perceived association between chronic hypertension and previous birth complications	Doctors messages during pregnancy about potential complications viewed as being overly cautious
		Scared by doctors' messages during pregnancy about potential complications	
Pregnancy intentions were affected by diabetes and hypertension	Decreased desire for pregnancy	Decreased desire for pregnancy	Little/no influence on desire for pregnancy
Knowledge about preconception health optimization was limited	Preconception glycemic control is difficult, but understood to be important	Concerned about safety of antihypertensive medications if were to become pregnant	Variable knowledge about pregnancy-related risks of obesity
	Would welcome preconception planning with doctors	Would welcome preconception planning with doctors	Hostility toward doctors regarding weight loss counseling
Lack of control over avoiding unintended pregnancy and minimal contraceptive knowledge	Unintended pregnancies are not acci	dents, but planned by god or fate	
	No or minimal knowledge about cor	atraceptive safety with regard to the chronic	e medical conditions