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Making Decisions About Medication Use During Pregnancy: Implications for Communication Strategies

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Abstract

Objective—To explore women's perceptions of the risks and benefits associated with medication use during pregnancy and to better understand how women make decisions related to medication use in pregnancy.

Methods—We conducted online focus groups with 48 women who used medication during pregnancy or while planning a pregnancy, and 12 in-depth follow-up interviews with a subset of these women.

Results—We found that women were aware of general risks associated with medication use but were often unable to articulate specific negative outcomes. Women were concerned most about medications' impact on fetal development but were also concerned about how either continuing or discontinuing medication during pregnancy could affect their own health. Women indicated that if the risk of a given medication were unknown, they would not take that medication during pregnancy.

Conclusion—This formative research found that women face difficult decisions about medication use during pregnancy and need specific information to help them make decisions. Enhanced communication between patients and their providers regarding medication use would help address this need. We suggest that public health practitioners develop messages to (1) encourage, remind, and prompt women to proactively talk with their healthcare providers about the risks of taking, not taking, stopping, or altering the dosage of a medication while trying to become pregnant and/or while pregnant; and (2) encourage all women of childbearing age to ask their healthcare providers about medication use.

Keywords

Pregnancy; Preconception health; Medication; Chronic disease

Introduction

Medication use among pregnant women and its impact on maternal and fetal health is a growing public health concern. Although little information is available about the safety of many medications taken during pregnancy, certain medications, such as isotretinoin, are known to cause serious birth defects if taken during early pregnancy (Fisher et al. 2008). Other medications, when taken during pregnancy, have also been associated with birth defects and adverse pregnancy outcomes (Briggs et al. 2008). The use of any medication—prescription or over-the-counter (OTC)—during pregnancy is estimated at 94% (Mitchellet al. 2011). The average number of medications (both prescription and OTC) taken by pregnant women has increased 68% in the past three decades, from 2.5 in 1976–1978 to 4.2 in 2006–2008 (Mitchell et al. 2011). However, studies have shown that less than 10% of medications approved from 1980 to 2010 have sufficient data to determine fetal risks (Adam et al. 2011).

Despite the widespread use of medications during pregnancy in the United States, there is a dearth of studies on what women know about medication safety and risks during pregnancy and how they make decisions about such use. A few recent papers have examined various aspects of this topic with different audiences. A survey conducted with 61 pregnant women found that nearly 97% of them had used an OTC medication, vitamin, or herbal supplement during their current pregnancy, and the majority of respondents considered these substances to be “safe, but would talk to a healthcare professional before using” (Kline and Westberg 2011). Most of these respondents consulted healthcare professionals about drug information and recommendations, but a small percentage of respondents spoke with pharmacists or family and friends (Kline and Westberg 2011). In a study of obstetrician gynecologists (OB/GYN), 90% of the participants reported that all or many of their pregnant patients asked about the effects of prescription medication on the fetus (Morgan et al. 2010). A multidisciplinary commentary that discussed decision making about medication use during pregnancy showed that pregnant women depend on information not only from healthcare professionals but also from their families and partners (McDonald et al. 2011). These same commentators urged future researchers to employ qualitative methods to explore this topic in detail (McDonald et al. 2011). Further studies such as the present one are needed to explore in depth women’s attitudes, beliefs, and practices related to medication use during pregnancy. The purpose of this study was to conduct formative research with U.S. women of childbearing age to better understand their knowledge, awareness, decision-making processes, and access to information about medication use during pregnancy.

Methods

Focus Groups

In 2014–2015, we conducted six virtual focus groups with women across the United States who took medication during pregnancy or who were planning a pregnancy in the upcoming year and were currently taking prescription medication, and 12 in-depth follow-up interviews with select focus group members.

Using a purposive sample, participants were recruited across the United States by a professional recruitment firm using their national panel. To participate, women had to be between the ages of 18 and 44, not currently pregnant, currently taking a medication, able to read and write in English, and to have access to the Internet so they could participate in the focus group. In addition to the main screener variables, recruiters strove for a diverse mix of geographic locations, including across U.S. states and from rural, suburban, and urban communities. To capture different experiences with medication during pregnancy, we segmented women into two groups: (1) those women planning to become pregnant in the next year (preconception) and (2) those women who had a child within the past year (postpartum). Within each of the two preconception or postpartum segmented groups, we further segmented women by medications commonly prescribed to women of reproductive age: prescription antidepressants (both groups), prescription asthma medications (both groups), prescription pain medications (planners), and a short-term medication[1] (recently pregnant) (see Table 1). We conducted one focus group with each audience segment, for a total of six groups. These groups were selected as proxies for different medication-use routines/schedules and to capture varying perceptions of risk. We used virtual focus groups, in part, because they offer participants more privacy and anonymity, which may be important when discussing topics some may perceive as sensitive, and because they allowed us to achieve a geographically diverse sample (Sweet 2001).

To conduct the virtual focus groups, iTracks, an online focus group vendor, provided a real-time, live chat platform. A trained moderator led each virtual group and used a semistructured moderator guide (see Table 2) to lead participants in an open discussion about the following: current medication use, how medication use changes during pregnancy, risk perceptions related to medication use during pregnancy, experiences with healthcare providers, and trusted sources and organizations for information about medication use during pregnancy. The group moderators posted questions and probes and allowed participants to type responses visible to the moderator and all other participants. A co-moderator observed each session via the internet and assisted with logistical issues. Each session lasted approximately 45–60 min, and transcripts were produced instantaneously. At the conclusion of each session, each participant received a $50 incentive in the form of a check administered by iTracks. All data collection was approved by RTI International's Institutional Review Board and the Office of Management and Budget.

[1]A short-term medication was defined as a medication, besides a vitamin, taken during pregnancy to treat a short-term sickness or to reduce pain or discomfort, such as acetaminophen, an allergy medication, cold medication, antibiotic, nausea pill.

Follow-up Interviews

To supplement the virtual focus groups, we conducted follow-up telephone interviews with a subset of participants to collect their narrative stories. The purpose of the follow-up interviews was to obtain a more in-depth perspective on the themes identified in the focus groups. We selected two participants from each focus group who provided a unique perspective or articulated an issue or theme that represented a major focus group finding and invited them to participate in a one-on-one telephone follow-up interview. All participants who were invited to these interviews consented and participated. Interviews took place approximately 2 weeks after the focus groups. Participants were asked about their sources of information about pregnancy and medications, any discussions they had had with their healthcare providers about current and future use of the medication, and concerns and decisions about taking medication while pregnant. The telephone interviews were taped, and note takers recorded responses. Each interview lasted approximately 20–30 min. At the conclusion of the interview, each participant received an additional $25 incentive.

Data Analysis

Focus group transcripts and notes from the interviews were independently reviewed and coded by two analysts in NVivo 10.0 (©QSR International Pty Ltd.) qualitative analysis software. Coders reviewed and coded interviews based on a predetermined coding structure using the major domains from the discussion guides (Krueger and Casey 2000). Coders also developed and assigned emergent codes for responses that did not fit the preexisting coding scheme. Using both the predetermined and emergent codes, we identified the key themes and determined the degree of consensus or discordance with a particular view. We ensured that the data were coded consistently and objectively by double-coding a sample of transcripts (n = 4) until acceptable coder agreement was received (>90%). After coding was completed, we produced coding reports and identified trends across the interviews and, when applicable, within the group segments.

Results

A total of 48 women from across the United States participated in six virtual focus groups, and 12 of these women participated in follow-up telephone interviews. Table 3 presents the participants' pregnancy status, medication use, and demographic characteristics. Our analysis indicated that participants had gaps in their knowledge about their medication use during pregnancy and that they were concerned about the health of their child, their own health, and the unknown risks of medications. In addition, our results identified participants' needs and preferred sources of information about medication use during pregnancy and determined how participants would use this information to make decisions.

Awareness of Risks

The majority of participants had a general awareness that risks were associated with taking medication during pregnancy and that their unborn child could experience some type of negative health outcome. However, most participants were unable to articulate a specific outcome that could occur from taking the medication they had used before or during pregnancy. Participants' perceptions of the safety of medications differed based on whether

the medication was prescribed or was available OTC. Several women believed that prescription medication was safer to take than OTC medication because they perceived that prescription medication received more physician oversight, had undergone more clinical trials, and included more specific directions. As one focus group participant who was planning a pregnancy and taking pain medication remarked, “Prescription meds are safer because they have specific instructions for you on how to use the product. Over the counter is a broad blanket statement for everyone”.

Concerns About Fetal Development

Overall, participants were most concerned about whether their medication use during pregnancy would harm fetal development. When probed further, they described two categories of possible harm: (1) an immediate impact in utero that could cause prematurity, miscarriage, or a birth defect; or (2) a longer-term effect that would not be recognized until the child was older, such as asthma or a developmental disability.

In thinking about these possible adverse effects on their child, participants described guilt, fear, and anxiety. As one interview participant who was planning a pregnancy and taking an antidepressant said,

> My concern is just the effects on the child. That is my greatest fear. Every time I take medication that comes to mind. I don’t know if I am just being paranoid…I am always concerned, though. In the long run, will there be a side effect? I am the one who will be taking care of a child with a problem, and it would be a long, lifetime struggle.

In addition to an overall sense of harm to the fetus from medication use during pregnancy, some participants were concerned that their fetus might experience side effects from a medication they were taking that were similar to the ones they experienced themselves. For example, two participants who took steroid medications had concerns that their fetuses would experience side effects such as rapid heart rate or overdevelopment of muscles. Additionally, a focus group participant who was planning a pregnancy and taking asthma medication said, “Well, I get sleeplessness from the medicine, so I guess my baby would too*”*.

Other participants were concerned that exposure to the medication could increase the risks of their child having the same health condition as them. For example, one participant worried that taking an antidepressant would affect her child’s mood in the future.

Concerns About Maternal Health

Although the most widely described concern about medication use during pregnancy was harm to the child, participants also recognized the importance of maternal health. On one hand, the women talked about risks as a result of taking medication, such as not being able to conceive, not having a safe pregnancy, or experiencing side effects during pregnancy. Alternately, a few participants mentioned the risks to the woman and fetus if the woman were *not* properly medicated, such as having uncontrolled symptoms like mood swings or extreme stress, without prescription antidepressants, or not being able to breathe well

without asthma medication. As one interview participant who had taken an antidepressant during pregnancy noted, *"*I was concerned about my baby, but you have to be okay in order for your baby to be okay".

Concerns About Unknown Risks of Medication Use

Overwhelmingly, all participants in this study indicated that if a given medication had unknown risks, they would not take the medication during pregnancy. Many participants made comments such as "better safe than sorry," "err on the side of caution," and "if there's a potential for risk, why even mess with it?" Although most women said they simply would not take a medication with unknown risk to the fetus, a few women said that they would do their own research to try to learn as much as possible about risks and side effects, suggesting that they would not rely entirely on their doctor's advice to make their decision. As one focus group participant who was planning a pregnancy and taking asthma medication said, "f there's no risk information, then I don't take the medication. It's not worth risking the little one. I'd value my doctor's opinion, but I don't want to cause life-long damage to the baby."

Information Needs

Overall, participants said they wanted as much detailed information as possible about potential adverse effects of medication taken during pregnancy. Pregnant women and women planning a pregnancy wanted detailed information regarding potential negative outcomes associated with medication use during pregnancy. Some participants wanted specific information about potential adverse effects, including long-term side effects to both themselves and their child, and information about risks to the fetus during each trimester. Several participants shared that they had received conflicting information from providers, causing some women frustration and requiring others to seek out additional information. As one focus group participant who was planning a pregnancy and taking an antidepressant said,

> Yes, my primary doctor told me that I could take my medication throughout my 1st pregnancy while the nurse practitioner in the same office told me to stop taking immediately after finding out I was pregnant. I did some research and took both opinions into consideration and decided to error [sic] on the safe side and not take it.

Further, participants across several focus groups commented that they wished they had received the same information about medication risks from all of their providers. They indicated that this consistency would enhance the trustworthiness of the information they received. As one pain medication focus group participant who was planning a pregnancy stated, "All doctors should be giving out the same information that is accurate as possible. I want to trust information*"*. In contrast, one antidepressant focus group participant who was planning a pregnancy thought that all the information received about taking medication during pregnancy was *"*geared toward the worst possible scenarios". This participant said, "There should also be a statement saying there may be good reasons for someone to take medication while pregnant… instead they just make everyone super paranoid."

Sources of Information

The most trusted source of information on medication use during pregnancy for participants was their OB/GYN. When specifically asked whom they contacted when they had questions about medication use during pregnancy, participants gave responses such as, according to one antidepressant focus group participant who was postpartum, *"*I always talked to my OB/GYN. She always made me feel I was doing the right thing". Many participants mentioned that they also consulted at least one other provider, usually a specialist (e.g., psychiatrist, pulmonologist) related to their health condition.

In addition to receiving information from healthcare providers, some participants cited friends and relatives as being resources for assessing the credibility of information they had obtained elsewhere. One participant specifically mentioned getting information from friends who had pain when they were pregnant. This participant said she planned to consult them on how they had decided to manage their pain because she felt they would *"*give honest answers as far as alternative methods and what they did with their doctor". Although written by strangers, online blogs and social networking sites were also influential. One participant mentioned that she and other pregnant women had met online and created a social media platform page for their babies, who had similar due dates; through this online connection, the women shared their experiences of being on the same medication during pregnancy. Other participants mentioned consulting additional information sources, such as online websites (e.g., WebMD, MayoClinic, Google) and health magazines. One focus group participant who had taken asthma medication during pregnancy said, "I check for recent and accurate information. I make sure that the source has a good reputation."

Decision Making

Overall, participants agreed that women must be proactive in their discussions with healthcare providers. In many cases, women said that they were the ones to initiate discussions with the providers about medication use during pregnancy and that they were left to educate themselves about the risks and benefits of the medications. Whereas some participants said they took information to their doctors that they found from other sources and then let their doctors decide whether they should take the medications, other participants mentioned relying on second opinions or trusting their intuition or "gut feelings" to make a decision. One asthma medication interview participant who was postpartum said,

> Now I look things up myself. I know that there are people out there who have gone through the same thing. There always has to be something out there that you can research on the topic. Pulling that evidence helps make my decision more firm.

Although women trusted their OB/GYN and viewed them as good resources, they believed that making the final difficult decisions was ultimately up to themselves. One interview participant who was planning a pregnancy and taking an antidepressant said,

> I should probably research some myself. It's important to always be your own advocate. Ultimately, it will be me and my partner's decision after receiving information from the doctors and [doing] research on my own. He knows me when I'm not on my medications.

An antidepressant focus group participant who was planning a pregnancy stated, “I will get as many opinions as I can plus research this myself. Then my husband and I can make the decision together.”

Discussion

Although current literature indicates that the majority of women have used at least one medication during pregnancy (Baraka et al. 2013; Bercaw et al. 2010; Lupattelli et al. 2014; Thorpe et al. 2013; Twigg et al. 2016; Zhu et al. 2010), many women have concerns about medication use (Mashayekhi et al. 2009; Nordeng et al. 2010; Twigg et al. 2016). They often feel that they have not received adequate information or counseling on the safety of their medications from their healthcare providers (Pashley and O’Donoghue 2009; Santucci et al. 2010). This formative research fills an important knowledge gap in understanding what women know about medication safety generally and how they make decisions about medication use during pregnancy. Our focus groups showed how women make decisions about medication use during pregnancy given their awareness about medication risks, their individual medical circumstances, and the sources of information that are available to them. For most women, their primary concern was the health of the child: both during pregnancy and after birth, including potential long-term adverse effects. Women also recognized that taking medications during pregnancy could affect their ability to conceive and have a healthy pregnancy in the future. In general, women did not mention outright specific risks to themselves from taking their specific medications, possibly because they had been taking the medication for a period of time to manage a chronic condition and had not experienced any side effects of concern or because they view their own medication use as having an overall positive effect on their own health.

Our findings suggest that although women may have a general understanding that fetal risks could be associated with medication use during pregnancy, they want more detailed and specific information about such risks and adverse effects specific to their own health condition or medication. These findings are consistent with previous research indicating that women often feel that they have not received adequate teratogenic risk counseling from their healthcare providers (Pashley and O’Donoghue 2009; Santucci et al. 2010). Despite their use of medication to maintain their own health, none of the women stated that they would be willing to take a medication with unknown fetal risks during pregnancy. At the same time, most of the medications these women were taking have unknown teratogenic risks, underscoring the fact that they may not be fully informed about the unknown or potential risks associated with their own medications.

Despite the participants’ not citing specific concerns about medication use, they wanted to understand the risks and benefits, especially the long-term effects of medication use and potential negative outcomes. In fact, these women wanted as much information as possible, indicating that they are ready and willing to be actively involved in making decisions about medication use. Although they would like to receive more information on the potential harms of medications from their healthcare providers, they also acknowledged that women generally need to be proactive in having these types of conversations with their healthcare providers and conduct their own research. Furthermore, although women cited their

OB/GYN as their most trusted source of information, they also turned to other healthcare providers, relatives, friends, and online sources such as blogs and social media to help them make decisions about medication use during pregnancy. This trend, suggesting that women can be reached with information they may want and need through multiple sources, further underscores the need for a multipronged approach to this problem.

Implications for Practice

Based on the information we have gained through focus groups with women of childbearing age who have used prescription medication prior to conception and during pregnancy, we have some suggestions for public health practitioners to address these women's informational needs.

Develop Educational Materials About the Safety of Taking Prescription and OTC Medications

Women want more information about the safety of medication during pregnancy. Our findings indicate that women lack knowledge about specific effects of their medication on a developing fetus. We suggest that public health practitioners develop messages about the risk of medications that summarize what is known, in plain language, about the risks to the fetus if the medication is taken. In addition, for medications that are taken for chronic conditions (e.g., depression or asthma), the risks of *not* taking the medication could also be clearly communicated. Talking with their healthcare provider is one important way to receive this information. However, our research indicates that women also want to be able to get such information from other trusted sources outside of a medical setting and in advance of medical appointments with their healthcare providers. A recent Centers for Disease Control and Prevention (CDC) study highlighted the inadequate evidence base and inconsistent guidance provided by many web-based sources (i.e., "safe lists" for medications in pregnancy) and the need for more evidence-based information (Peters et al. 2013). Professional organizations could partner with one another to create educational content (e.g., messages, graphics) that is seen as reputable, accessible through social media or mobile devices, and relevant to women who are planning to become or are already pregnant.

Because our findings indicate that some women believe that taking a prescription medication is less risky than taking OTC medication, educational content could be created to explain that unknown risks exist for all types of medications, including prescription, OTC, herbal, and dietary products.

Improve Communication with Women and Their Healthcare Providers to Promote Better Understanding About Medication use While Trying to Become Pregnant and/or While Pregnant

Our findings showed that participants agreed that women must be proactive in their discussions with healthcare providers and that they often had to initiate discussions with providers about medication use. Currently, resources are available that could serve as a model for improving patientprovider communication. For example, the Agency for Healthcare Research and Quality (AHRQ) campaign entitled "Questions Are the Answer," promotes patient and family engagement in health care. The site contains a brochure called

"Be More Involved in Your Health Care" (https://tinyurl.com/kn6pj2w) and a tool called "Question Builder" (http://www.ahrq.gov/apps/qb/), which allows patients to create a list of questions they can take to their next medical appointment; these resources could be adapted to the subject of medications and pregnancy. Before, Between, and Beyond Pregnancy offers a web-based platform for patients and healthcare providers that could be further disseminated (https://beforeandbeyond.org/toolkit/at-risk-unsure/medication-use).

Strengths and Limitations

This study was conducted with a purposive sample of women who took medication during pregnancy or who were planning a pregnancy in the upcoming year and were taking prescription medication. Because the main purposive sampling criteria included pregnancy status and medication use, the sample was limited in terms of racial/ethnic diversity and inclusion of rural communities, and did not include women who may not be planning a pregnancy. Furthermore, our research was conducted using online focus groups, which may lack the richness and detail of face-to-face focus groups. However, using online focus groups also gave women the chance to discuss sensitive topics without possible embarrassment inherent in being physically present in a larger group. We also conducted individual telephone interviews to delve deeper into topics that were raised during the focus groups but not discussed in detail. Finally, note that because of an intentional study design choice, all women in our focus groups were currently or recently taking medication for a chronic or acute condition. Although we chose to focus on women who could discuss their personal experiences with medication use, to achieve our study's purpose, we realize that these particular women may be more aware of medication-related health and safety issues than women who do not regularly take medication. In addition, future studies could include other groups of women such as women who previously considered medication use and decided against it and women who never considered medication use. Nonetheless, we believe that the sample's perspectives provide important information as public health practitioners look to develop communication and educational materials to help women have safer and healthier pregnancies.

Despite these limitations, our study is a much-needed exploration of women's perceptions related to the risks and benefits associated with medication use during pregnancy and how they make medication decisions before and during pregnancy. Given the frequent use of medications during pregnancy, we must identify ways that healthcare providers and public health practitioners can adequately address women's informational needs. Our findings suggest that women are generally aware that risks may be associated with medication use during pregnancy but do not have adequate information about the risks associated with their specific medication. Developing educational materials in plain language and creating widespread campaign messages and tools are strategies we have identified to help women make decisions about medication use during the preconception and pregnancy periods.

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Significance

Medication use among pregnant women and its impact on maternal and fetal health is a growing public health concern. Some medications are known to cause serious birth defects if taken during early pregnancy; however, information about the safety of most medications during pregnancy is limited. This formative research study fills an important knowledge gap in understanding what women know about medication safety and how they make decisions about medication use during pregnancy.

Table 1

Segmentation of virtual focus groups

Segment	Group number	Medication use	Number of participants
Women planning to become pregnant in the next year who	1	Currently take prescription pain medication for chronic pain	9
	2	Currently take a prescription antidepressant	8
	3	Currently take a prescription asthma medication	8
Women who had a child within the past year who…	4	Took a short-term medication during pregnancy	8
	5	Took a prescription antidepressant during pregnancy	8
	6	Took a prescription asthma medication during pregnancy	7
Total			48

Table 2

Example focus group moderator topics and questions

Segment	Focus group topic	Example of question
Women planning to become pregnant in the next year who currently take prescription pain medication for chronic pain	Current medication use	What are the biggest benefits you get from taking your medication used to treat pain, in general?
		What are the downsides, if any, to taking your medication, in general?
	Changes to medication use during pregnancy	Have you thought about if or how your medication use would change during pregnancy?
		When do you think would be the best time to start thinking about your medication use (whether it would change or not) related to planning a pregnancy?
	Sources of information about medication use before and during pregnancy	Besides your doctor(s), where else did you look for guidance about medication use while planning a pregnancy?
		How do you decide what information you can trust?
	Reactions to message about medication use	What are your initial reactions to this message?
		Is there anything that is confusing or difficult to understand? If so, what?

Table 3

Characteristics of virtual focus group participants and follow-up interviewees

Characteristic	Focus group participants (n = 48)	Follow-up interviewees (n = 12)
Pregnancy status		
Planning a pregnancy	52% (25)	50% (6)
Recently pregnant	48% (23)	50% (6)
Medication use		
Pain medication	19% (9)	17% (2)
Depression medication	33% (16)	33% (4)
Asthma medication	31% (15)	33% (4)
Short-term medication	17% (8)	17% (2)
Age		
18–24	10% (5)	0% (0)
25–34	60% (29)	67% (8)
35–44	30% (14)	33% (4)
Race/ethnicity		
White	54% (26)	58% (7)
African American	17% (8)	25% (3)
Asian	25% (12)	8% (1)
Native Hawaiian or Other Pacific Islander	2% (1)	8% (1)
Hispanic or Latina	2% (1)	0% (0)
Education		
High school graduate	9% (4)	0% (0)
College 1–4 years	81% (39)	92% (11)
Master's or professional degree	10% (5)	8% (1)
Income[a]		
<$30,000	10% (5)	17% (2)
$30,000–$75,000	52% (25)	58% (7)
More than $75,000	35% (17)	25% (3)
Geographic distribution		
Midwest	31% (15)	42% (5)
Northeast	17% (8)	17% (2)
South	42% (20)	33% (4)
West	10% (5)	8% (1)

[a]Totals may not add to 100% due to missing values