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Improving the postpartum care of women with a recent history of preeclampsia: a focus group study

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ABSTRACT

Objective: Women with prior preeclampsia are at increased risk of cardiovascular disease (CVD). This study investigated barriers and facilitators toward learning about this link and engaging in lifestyle modifications to reduce this risk. *Methods:* Four focus groups were held with 14 women within 6 months of a preeclamptic pregnancy. *Results:* Participants were unaware of the link between preeclampsia and CVD, suggested improvements to provider–patient communication, and discussed the benefits of social support and online tracking (weight, blood pressure) in making lifestyle modifications. *Conclusions:* Solutions offered may improve efforts to modify lifestyle and communication between providers and women about this link.

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Preeclampsia; population health; health services research; hypertension; maternal morbidity and mortality

Introduction

Preeclampsia is a hypertensive disorder of pregnancy that affects approximately 5% of all pregnancies (1). There is growing evidence that preeclampsia has long-term maternal consequences, with a three-fold increased risk of future hypertension and a two-fold increased risk of cardiovascular disease (CVD) (2). Pregnancy can be seen as a stress test that serves as an indicator of women who are at increased risk for CVD (3,4). Based on the association between a history of preeclampsia and future hypertension and CVD, the American Heart Association (AHA) updated its recommendations for women in 2011, adding history of preeclampsia to the list of previously established risk factors for CVD (such as active smoking, hypertension, or dyslipidemia) (5) and recommend lifestyle modification for women with this history. We previously demonstrated that women with a history of preeclampsia, on average 18 months postpartum, were generally unaware of the link between preeclampsia and future CVD; but once aware of the link, were interested in engaging in lifestyle modification to reduce this risk (6). The purpose of the present focus groups was to identify specific barriers to learning about the link between a history of preeclampsia and future CVD risk, and to identify barriers to implementing and

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sustaining recommended healthy lifestyle changes to reduce the risk. Regarding both of these aims, these focus groups also sought to solicit participants' ideas about how to overcome each barrier identified in women with a recent pregnancy complicated by preeclampsia.

Methods

We recruited women from 18 up to and including 50 years old, within 6 months of a live birth resulting from a pregnancy complicated by preeclampsia, by self-report, and currently residing in the United States. Women were invited to participate in a 90-min phone-based focus group, as it has been shown that face-to-face focus groups are difficult for postpartum women to attend (7) and based on our prior experience with a similar population (6). The use of phone-based focus groups also allowed us to recruit nationwide.

Recruitment was conducted through postings on Craigslist in 36 major US cities and through the Preeclampsia Foundation Website and Facebook page over a 2-week period. Pre-eligibility was determined through an online questionnaire administered through REDCap (Research Electronic Data Capture) version 6.5.9, a secure web-based research tool hosted at Brigham and Women's Hospital (8). Fifty-two women met the inclusion criteria on the REDCap questionnaire. The questionnaire also included a section with four focus group time slots from which women were asked to indicate if they were available: one weekday afternoon and three different weekday evenings during July and August, 2014. Thirty-three women met inclusion criteria and indicated availability for one or more of the focus group time slots and were scheduled accordingly. Of these 33 eligible women, 10 were not reachable by phone to confirm medical history and schedule the focus group, and 1 cancelled. The remaining 22 women were scheduled for a focus group of which 14 participated. Reasons for non-participation are unknown.

Demographic information obtained included age, race/ethnicity, state of residence, gravidity, parity, weight, height, number of weeks since the most recent delivery, number of children living at home, and ownership of an internet-enabled device (i.e., smartphone, tablet, computer). Data regarding access to health-care providers were obtained during the focus groups.

An interview guide outlined domains of interest, but allowed the facilitator latitude to explore other themes that emerged during the focus groups. The script was structured to target domains that the authors identified as important in examining barriers and facilitators about engaging in lifestyle modification to reduce future risk of CVD in women with a history of preeclampsia (7). Domains of interest included: knowledge of the link between preeclampsia and future cardiovascular risk, access to and type of current health-care provider, preferred ways to communicate the link between preeclampsia and future CVD by health-care providers, interest in an online community of other preeclampsia survivors, and motivators for lifestyle change (including tracking).

Each focus group was led by one of two trained facilitators experienced in conducting focus groups. The size of each focus group was limited to a maximum of five participants, per published recommendations for phone-based focus groups (9). The focus groups were recorded and transcripts were transcribed verbatim (Babbletype, LLC). Participants received a \$30 gift card and were offered a link to The Preeclampsia Registry from the

Preeclampsia Foundation. The study was approved by the Brigham and Women's Hospital Institutional Review Board. Oral consent to participate in the study was obtained at the start of each focus group.

Focus group data analysis: Analysis of focus group data followed standard procedures for qualitative data analysis (10,11). Two of the coauthors (ES & SL) independently read and re-read the transcripts to identify representative themes that reflected the data. Themes were identified for coding based on: the repetition of specific words, phrases, and opinions; the use of language and general thought patterns; and topics that dominated the focus group discussions. When there were differences of opinion in the coding of representative themes, coders discussed differing opinions until a consensus was reached.

Results

Table 1 shows demographic characteristics of the 14 women who participated in the focus groups (participants) as well as the demographic characteristics of the 8 women who were scheduled, but did not call in (nonparticipants). Participants and nonparticipants appeared overall similar in demographic characteristics. The majority of women had access to a smartphone and/or a tablet.

Table 1. Demographic characteristics of women scheduled to participate in focus groups (participants ($n = 14$) and nonparticipants ($n = 8$)).

	Participants ($n = 14$)	Nonparticipants ($n = 8$)
Demographic characteristics mean (SD)		
Age (years)	31 (5)	33 (8)
Body Mass Index (kg/m^2)	28 (6)	34 (12)
Age of the baby (weeks)	12 (6)	13 (6)
Parity	2 (1)	2 (1)
Geographic distribution (n [%])*		
South	7 (50)	2 (33)
Northeast	5 (36)	1 (17)
Midwest	1 (7)	3 (50)
Pacific	1 (7)	0
West	0	0
Ethnicity (n [%])		
Hispanic	3 (21)	3 (38)
Not Hispanic	11 (78)	5 (72)
Race (n [%])[‡]		
White	12 (86)	6 (86)
Black	1 (7)	1 (14)
Mixed	1 (7)	0
Source of Recruitment (n [%])		
Facebook	9 (64)	4 (50)
Craigslist	3 (21)	4 (50)
Google	1 (7)	0
Referral	1 (7)	0
Access to internet-enabled devices (participants may have more than one device) (n [%])		
Smartphone or tablet	14 (100)	7 (88)
Smartphone	12 (86)	7 (88)
Tablet	10 (71)	4 (50)
Smartphone and tablet	8 (57)	4 (50)
Computer only	0	1 (13)

*Data not available for two nonparticipants; [‡]data not available for one nonparticipant; SD: standard deviation; %: percentage.

When asked about their health-care providers during the focus groups, all women had access to at least one type of health-care providers with 11 of them still being seen by the obstetrician who followed up the preeclamptic pregnancy.

Knowledge of the link between preeclampsia and CVD

A majority of the women (10/14) were unaware of the link between preeclampsia and CVD: “I’ve never heard of that [link] before. My doctor didn’t tell me that, so I’m not aware of that. This [focus group] is the first time I’m hearing that.” Another stated that providers “didn’t give me any information about what happens after preeclampsia. They told me that once I delivered my son that was the cure for preeclampsia. They didn’t give me any follow-up information on it.” Among the four women previously aware of the link, one had been told by her primary care provider (a nurse practitioner), one had learned from doing her own research, and the other two did not specify how they learned about the link.

Proposed solutions

Women expressed a desire to have materials available in their doctors’ offices to teach them about the link and how to modify their risk: “It would be helpful to have a pamphlet or a handout or something that has the basic facts and has resources that you can go to (...) Where can I find the blogs? (...) Where is great useful information?” Another participant commented that “In the doctors’ offices that I’ve gone to I’ve never seen [pamphlets] for preeclampsia. They’ve got one for birth control, some for selling products, breast cancer, but I’ve never seen them for preeclampsia.”

Gap in communication of the link between preeclampsia and CVD

All women expressed that they currently had access to a health-care provider (nurse practitioner, primary care doctor, and/or obstetrician). Some had already returned to regular care with their primary care provider, while others continued to see and communicate with their obstetrician. Despite being connected to health-care providers, most women expressed that their providers did not communicate the link between preeclampsia and future CVD. One participant stated “there wasn’t a lot of information given as far as how I was going to recover from it. If I needed to continue to monitor my blood pressure regularly, if I needed to start some sort of exercise program or healthy eating to help prevent blood pressure issues in the future.” It was questioned as to whether there might be “a way when a woman gets diagnosed with preeclampsia to have the physician be aware and talk to the patient about [the link between preeclampsia and future CVD].”

Proposed solutions

Participants suggested several solutions to improve communication between women with recent preeclampsia and health-care providers about the link between preeclampsia and future CVD. These included encouraging obstetricians to contact patients’ primary-care providers directly: “I think that would be a good idea if obstetricians would send letters to primary care just letting them know that preeclampsia is associated with later risk of heart disease and then they would tell patients.” Women also suggested that their providers

needed more education about the link between preeclampsia and future CVD as well as greater formal education: “Maybe they need to have [education] as a requirement, some type of in-services about it. It would be good for the doctors . . . I think they need to be educated [about the link].”

Some women talked about the possibility of “their” educating their primary-care providers about the link between preeclampsia and future CVD, but expressed concerns about doing so: “I feel like when you go to your primary care or doctor and you tell them [about the link] . . . you don’t want to appear paranoid.” Women suggested that having a pamphlet for their provider would be helpful in this regard: “Have [a pamphlet about preeclampsia and CVD risk] at a regular doctor’s saying there’s a link with [CVD] so maybe [the patient] can show it to their doctor in case he doesn’t read what he’s putting out there in the waiting room.” Another women who knew about the link felt comfortable taking charge and telling their providers how they should be monitored for future CVD: “My OB at least didn’t know anything about that (. . .) I had to tell my doctor what tests I thought I needed and he went ahead and ordered them.” Some women were interested in learning more about how they could be proactive in ensuring their long-term issues related to preeclampsia were addressed by their health-care providers and suggested having a list of questions they could bring to their doctor “about blood work or what [blood pressure] range is normal (. . .) when you go for check-ups.”

Identifying barriers to implementing and sustaining lifestyle changes

Women expressed isolation as a major barrier to implementing and sustaining lifestyle changes. Such isolation included the challenges that can exist while trying to make lifestyle changes while the rest of the family is not on board, as well as the sense of isolation many women expressed in regards to being the only one they know that had gone through preeclampsia: “I’m the first person that I knew that had [preeclampsia]. Nobody knew what I was going through.”

Family support in lifestyle change

Women stressed the importance of having family on board with lifestyle change and the potential for sabotage if they were not: “. . . my problem is when I try to buy a low-fat food or anything that is healthy, [my husband’s] not on board really. So I buy junk in the house and it’s hard to stick to what you want to do when the person you live with still wants to eat [such foods] regularly, because if it’s in the house I’m going to eat it. If I see a box of Little Debbie’s in the cabinet, they’re looking at me. It’s hard.”

Proposed solutions

Women discussed the importance of involvement of family members to support them in lifestyle modifications. Most women were enthusiastic about the involvement of their spouse/partner, while others expressed interest in the involvement of their entire household: “I would say my husband . . . I think my kids also. Whoever basically lives in your household, because that’s who you’ll be eating with most of the time or cooking or preparing dinner or whatever meal.” One woman thought her sister would be the best person to involve. Of interest, participants mentioned that such involvement “could

influence the family maybe in a positive way” and “not only would these [lifestyle modifications] be benefiting me, but they’d be benefiting [my husband] as well. Yes. He’s never had preeclampsia, but I’m sure being healthy would prevent his risk of getting heart disease as well.”

Online community to provide support for lifestyle change

A common theme expressed was a sense of isolation following a pregnancy complicated by preeclampsia: “I’m the first person that I knew that had it. Nobody knew what I was going through. It was like, ‘what did you have? I never heard of that’.” Women expressed that decreasing isolation might decrease stress, which might in turn, lower blood pressure as well: “I know that in terms of blood pressure (...) there are a lot of ways that you can help reduce stress. Maybe that would just be achieved by nature of being part of a support network.”

Proposed solutions

Women were very positive about the possibility of an online community to help decrease their sense of isolation and provide support for healthy lifestyle change: “... the most important aspect to me about an online forum is that you can get on there and see other people who have gone through the same thing and ease your mind.” Women expressed that an online community had the advantage of providing a readily accessible community that is “right there (...) and easy to access.”

In addition, women felt that the community would help educate themselves and each other. Women also expressed their desire to help others through an online community: “... you’ve been through something like that, you want to tell everybody else and you want to help people.”

The importance of maintaining privacy through anonymity and the creation of a private online community was a central issue for most women: “What I liked about [the online community] was that I’m anonymous on there. I could say whatever I wanted or ask for advice without feeling like (...) my friends can see that I posted on here.” There was however concern that online community interactions could be negative: “The only concern that I would have is sometimes not everyone is so positive or supportive.” For this reason, women favored having a moderator for the online community and that “... it’s important to keep [the forum] moderated (...) because everybody’s situation is different and your situation might negatively impact somebody else.”

Tracking as a motivator for lifestyle change

Women viewed tracking of weight and/or blood pressure as an important motivator for lifestyle change: “I think (...) a good idea that would be more motivating is if you definitely tracked your weight” and “I would find it interesting to monitor the blood pressure and the weight.” Some women felt that they would need encouragement to stick with tracking: “I don’t have anyone to tell me ‘hey, how’s that going’ or ‘let me see what you’ve eaten or anything’. I don’t have anyone to encourage me.” Others expressed that the potential for personal health benefit would be sufficient motivation: “... the education alone of how you can prevent the really bad things happening to you or to your child,

would be motive enough for me to [track].” Some women expressed that they would want rewards to incentivize them to track behaviors: “I think that incentive program would be a nice perk to add.” The rewards mentioned ranged from online badges to gift cards for 10-min massages, healthy food, or workout equipment.

Discussion

This study demonstrated a lack of knowledge of the link between preeclampsia and future CVD in women with recent preeclampsia in the early postpartum period, within 6 months of delivery. This study extends the findings reported by our group (6) and others (12) documenting the lack of knowledge of the link between preeclampsia and future CVD in women with such a history who were further postpartum (on average 11 months (12) and 18 months postpartum (6)). One possibility raised by the prior studies (6,12) is that women were informed about the link during hospitalization for delivery or at the usual postpartum visit and may have forgotten about the link when questioned more than a year after delivery. However, the current study supports that women with preeclampsia do not learn about their future risk in this earlier time period. Furthermore, this paper provides several solutions toward educating women with a history of recent preeclampsia about their increased CVD risk and providing motivation and support for engaging in healthy lifestyles to reduce this risk.

In the present study, women were uniformly interested in learning more about the link between preeclampsia and CVD and identified several barriers that they had experienced toward increasing their awareness. Lack of having a health-care provider was explored as a potential barrier; however, all of the women identified a health-care provider to whom they had access. Despite having health-care providers, a prominent barrier was their perception that these providers were not knowledgeable about, or at times, not even aware of the link between preeclampsia and CVD. These perceptions are supported by studies demonstrating a lack of providers’ knowledge about the link between preeclampsia and future CVD (13,14). In a study comparing obstetricians to internists, obstetricians were more aware of the link and less likely to recommend preventive measures to decrease CVD risk, while internists were less likely to be aware of the link, but more likely to recommend preventive measures (13). The optimal timing for communication of the link between preeclampsia and future CVD is not known, but it is of interest that women in both the early postpartum period, as demonstrated here, as well as those more than a year postpartum were similarly unaware of the link (6).

To overcome the lack of knowledge about the link, women suggested that providers receive more education either in medical school courses, through continuing education, and/or through brochures to be shared with patients. Women also discussed the need for their obstetrical provider to communicate their preeclampsia diagnosis and its potential sequelae to their primary provider. This could be a potential solution to the gap in communication between obstetricians and primary-care providers which has been identified (15,16).

Some women were also open to initiating the conversation with their providers or even to educating their providers themselves. However, it is important to note that there was a wide range of comfort among women toward initiating a conversation about the link between preeclampsia and future CVD, if their provider did not. Some women reported

being very comfortable in the role of educating their providers and felt that having material such as a brochure to bring to the provider's office would ease initiation of the conversation. Others felt uncomfortable and expressed that they would be viewed as challenging if they did so. Several focus group studies have reported that patients felt they could experience negative consequences if they discussed their own knowledge/expertise of their medical condition with their providers (17–19). For example, in a focus group study of diabetic patients, who had received a high level of diabetes education, participants felt that they would experience negative consequences and be viewed as difficult if they were to share their own knowledge of their condition with their provider (18). The range of women's comfort levels in initiating this conversation should be kept in mind by providers so that they are aware of the importance of their role in initiating the discussion.

The availability of brochures explaining the link between preeclampsia and future CVD may be an important facilitator for women to prompt this conversation with their health-care providers. Such a brochure, available online at www.preeclampsia.org, has been created by the Preeclampsia Foundation, but may not be sufficiently well publicized. It has been proposed that as greater access to medical information and more resources become available, especially via the internet, this may result in a change to the patient-provider relationship whereby patients become more of a partner with their providers (20).

Given the AHA, American Stroke Association, and American College of Obstetricians and Gynecologists recommendations for healthy lifestyle for women with prior preeclampsia (1,5,21), we sought to identify barriers and facilitators to following a healthy lifestyle in recently postpartum women. Lack of social support has been identified as one of the major barriers to lifestyle modifications in postpartum women (22–24). In the present study, many women felt isolated by their experience following their preeclamptic pregnancy. Isolation was also a theme expressed in our earlier focus groups of women who were further postpartum (6). One solution to this isolation, expressed by participants in the present study, is the importance of family member involvement in lifestyle changes. Women most commonly identified their spouse or partner as the most important person to be involved. They noted that not only would their involvement provide important support, but that, without their positive involvement, family members might sabotage their efforts to follow a healthy lifestyle. Women also mentioned that potential health benefits to family members were additional motivators to pursue lifestyle changes.

Beyond family involvement, women also expressed a desire for an online community of women who had been through similar experiences to whom they could turn to for support. The idea of support from other women who experienced preeclampsia was also expressed in another focus group study (25). The importance of privacy for such a community was emphasized. In addition, women were interested in having a moderator who would ensure that the information being posted was medically correct and generally positive. Women expressed that an online community could allow them to help other women with similar experiences, which is reported by others as a common reason for participating in an online community (26,27). Of interest, in a focus group study of women with polycystic ovarian syndrome in the United Kingdom, women expressed that participation in an online community empowered them to talk to their providers about their condition (28). Whether an online community would help enable women with

recent preeclampsia to feel more comfortable talking to their providers about future CVD risk remains unknown. It is important to note that access to an online community would not be difficult for women who participated in our focus groups as they all had access to the internet via smartphone and/or tablet, as do a majority of women of child bearing age in the United States (29).

Most women felt that having the opportunity to track behavior change was an important motivator for improving their lifestyle. Although some women felt that just knowing that they were improving their health and that of their family would be sufficient motivation to track, others expressed the need for reinforcement with, for example, online medals and awards, as well as actual rewards such as coupons. It is important to note that a wide range of motivators may be needed to reach different women with recent preeclampsia.

There are limitations to this study. We identified family support as being an important factor lifestyle change for women with prior preeclampsia; however, relationship status data were not collected. In addition, diagnosis of preeclampsia was gathered via self-report.

These focus groups demonstrate that women, in their first months' postpartum, are generally unaware of the link between preeclampsia and future CVD but want to be educated about this risk. Participants were motivated to make lifestyle modifications to help decrease this risk, and proposed several solutions to existing barriers to improve communication with their health-care providers. A major motivator was that their family might benefit from their efforts to make lifestyle changes. They also expressed the desire to receive support from family members in implementing and maintaining lifestyle modifications and through an online community, which could serve to reduce feelings of isolation following a preeclamptic pregnancy. As all women had access to the internet through mobile devices, online tracking was mentioned positively. Social support was considered an important solution to identified barriers, suggesting that when health-care providers counsel women, they inquire as to whether women feel they receive adequate support. If not, providers could encourage women to seek support in their households and communities, through online community forums and/or online support groups. Results of this focus group study can help inform efforts to enable women with prior preeclampsia and providers to improve postpartum health care and adopt healthy lifestyles with a goal of reducing future CVD.

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