Matern Child Health J (2017) 21 (Suppl 1):S81–S92
DOI 10.1007/s10995-017-2372-2

Understanding Perspectives of African American Medicaid-Insured Women on the Process of Perinatal Care: An Opportunity for Systems Improvement

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Published online: 30 September 2017

Abstract *Objectives* To address disparities in adverse birth outcomes, communities are challenged to improve the quality of health services and foster systems integration. The purpose of this study was to explore the perspectives of Medicaid-insured women about their experiences of perinatal care (PNC) across a continuum of clinical and community-based services. *Methods* Three focus groups (N = 21) were conducted and thematic analysis methods were used to identify basic and global themes about experiences of care. Women were recruited through a local Federal Healthy Start (HS) program in Michigan that targets services to African American women. *Results* Four basic themes were identified: (1) Pursuit of PNC; (2) Experiences of traditional PNC; (3) Enhanced prenatal and postnatal care; and (4) Women's health: A missed opportunity. Two global themes were also identified: (1) Communication with providers, and (2) Perceived socio-economic and racial bias. Many women experienced difficulties engaging in early care, getting more help, and understanding and communicating with their providers, with some reporting socio-economic and racial bias in care. Delays in PNC limited early access to HS and enhanced prenatal care (EPC) programs with little evidence of supportive transitions to primary care. Notably, women's narratives revealed few connections among clinical and community-based services. *Conclusions* The process of participating in PNC and community-based programs is challenging for women, especially for those with multiple health problems and living in difficult life circumstances. PNC, HS and other EPC programs could partner to streamline processes, improve the content and process of care, and enhance engagement in services.

Keywords Healthy start · Prenatal care · Perinatal system of care · Medicaid-insured pregnant women · African American pregnant women

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Significance

Although there is a well-established literature on the perspectives of Medicaid-insured, African American women about prenatal care and a growing literature on postpartum care; little is known about women's perceptions of the process of care across prenatal care (PNC) and community-based enhanced prenatal care and home visiting services. This study reveals the difficulties women experience in negotiating care, communicating with providers, getting help, and learning about their own health. Multiple opportunities exist for PNC, Healthy Start, Enhanced Prenatal Care and other programs to integrate services to improve the care experience, reduce disparities in care, and achieve population improvements.

Introduction

Federal Healthy Start (HS) programs target low-income women who are disproportionately exposed to physical, social, and psychological stress, are more likely to have chronic health problems, have fewer health literacy skills, and have barriers to care that make it difficult to use health services and navigate a confusing delivery system (Borders et al. 2015; Gavin et al. 2012). HS programs serve a high proportion of African American women who are at greater risk for pregnancy complications and underutilization of services that contribute to persistent disparities in birth outcomes (Behrman and Stith Butler 2007; Creanga et al. 2014a, 2014b). To address disparities and achieve population health improvements, HS programs are challenged to lead community efforts to increase access and utilization of resources, promote the quality of health services, improve women's health, and foster systems integration.

To address this charge, clinical and community-based health providers in a single Michigan county collaborated to develop, implement and evaluate a county level perinatal system of care for Medicaid-insured women, in the context of a federally-funded research demonstration project. Partners included the local HS program, state-sponsored Medicaid enhanced prenatal care (EPC) providers, local health systems, the county health department, a Federally Qualified Health Center (FQHC), a community mental health agency and others; all who deliver prenatal and interconception care to low-income families during the perinatal period.

During the development of a system of care, a county-level analysis of service utilization revealed many care improvement opportunities for Medicaid-insured, African American women. For example, only 58% of women initiated prenatal care (PNC) in the first trimester; 23% received inadequate/ intermediate PNC; and 24% had 3 or more prenatal emergency department (ED) visits. Although all Medicaid-insured women were eligible for the state-sponsored EPC program, 44% enrolled in the program, with 26% of women enrolled in the 1st trimester. About half of all women completed a postpartum visit, 16% used the ED in the 8 weeks post-birth; and 60% used the ED in the postnatal year (23% had 3 or more ED visits/year).

The inclusion of women's perceptions about their care is critical to care improvement activities. While there is a well-established literature on perceptions and barriers to PNC and a growing literature on postpartum and interconception care, little is known about the process of care across the perinatal period. The objective of this study was to explore the perceptions of Medicaid-insured women about the process of care during the perinatal period, defined broadly to include prenatal and the 12 months postpartum, across clinical and community sites.

Methods

This study was conducted in collaboration with Strong Beginnings, a federal HS program that targets African American women for service. Strong Beginnings teams Community Health Workers (CHWs) with state-sponsored home visiting EPC nurses and social workers to provide enhanced prenatal and postnatal care. CHWs are located in EPC programs at either a health system, health department, or a federally qualified health center site and their clients receive PNC in multiple clinics or practices.

Focus group methodology was used to identify women's perceptions of care and guide the identification of care improvement opportunities. Historically, the SB program has partnered with other community-based stakeholders to conduct focus groups because they are a trusted provider for African American women and serve women at greater risk for adverse birth outcomes. A prior study determined that women who enroll in Strong Beginnings, when compared to other Medicaid-insured African American women in the county are more likely to be unmarried, living at a lower poverty level, and have a depression diagnosis or illicit drug use. When compared to women who enroll in EPC programs, Strong Beginnings participants are more likely to have a prior adverse birth outcomes, a history of mental health problems, depressive symptoms, or other behavioral health problems (Meghea et al. 2014).

CHWs recruited women who were pregnant or had delivered an infant in the last 12 months, were Medicaid-insured at the time of birth, 18 years or older, and spoke English. To standardize the conversation for inviting participants, Strong Beginnings created a one page flyer for the CHWs to discuss with their clients. The flyer described the purpose of the group as an opportunity to talk about accessing health and other services. CHWs provided information about the

study, consent procedures, reimbursement and child care options. Women were consented prior to the focus group. Transportation, child care, food, and a $50 reimbursement to compensate women's time were provided.

The groups were co-led by a Strong Beginnings facilitator, with group experience and focus group training, and a research facilitator. The groups were held in a neighborhood community mental health care setting, with available child care, where Strong Beginnings clients can access a variety of maternal and infant services (e.g. stress groups, individual interpersonal therapy), as well as, parenting education and support. Some women, but not all, who participated in the focus groups would have received services at the setting. Data were collected and transcribed verbatim, using professional stenographers.

Using a structured interview guide, women were asked to describe the current process of care and what they valued. Seven domains were explored: (1) process of getting insurance and PNC; (2) getting connected to and navigating other health/social resources; (3) using home visiting and care coordination; (4) staying in PNC; (5) getting care when sick; (6) going home: the first weeks; and (7) getting care and staying healthy post birth.

Data were analyzed using thematic analysis methods: generating initial codes, searching, reviewing, defining and naming subthemes, and identifying basic and global themes (Braun and Clarke 2006). Team members coded transcripts using line-by-line open coding; met to discuss similarities, differences, and refine coding; and discussed emerging themes. Data saturation was reached when no new codes or themes were identified. The first author and another investigator were responsible for re-coding, refining themes, and summarizing for review and discussion. The study was reviewed and determined exempt by the Michigan State University and Spectrum Health Institutional Review Boards.

Results

Twenty-one women participated in one of three focus groups. Ninety-one percent of women were African American. Most women were unemployed (91%) and single (86%), and between 20 and 34 years of age (67%). Twenty percent of women had less than 12th grade education, 29% had 12th grade/GED education, and half of women had more than a high school education. Eight different prenatal or primary care clinics/practices were identified as sites of PNC. Nineteen percent of women indicated that they had been hospitalized with a medical problem during pregnancy; 19% reported their infant was hospitalized in the neonatal intensive care unit. In examining Strong Beginnings program records, focus group participants were similar in most characteristics to women typically served in Strong Beginnings, although they were slightly older; more women had greater than a high school education (10% difference); and more women had an infant with an NICU experience (10% difference). Four basic themes, and 17 subthemes (in italics) were identified that captured women's perspectives about their care across the perinatal period; two overarching global themes were identified that were common in the basic themes (Table 1).

Basic Themes

The four basic themes included: (1) Pursuit of PNC; (2) Experiences of traditional PNC; (3) Enhanced prenatal and postnatal care; and (4) Women's health: a missed opportunity. Tables 2, 3, 4 and 5 include the themes and a representative sample of women's quotations.

The Pursuit of PNC

Some women reported that *recognizing and acknowledging the pregnancy* was a first step towards PNC (Table 2). Most women purchased pregnancy tests to confirm their

Table 1 List of focus group themes and subthemes

Themes and sub-themes
Basic themes
1. Pursuit of PNC
1.1. Recognizing and acknowledging pregnancy
1.2. Making it work
1.3. Getting there
2. Experiences of traditional PNC
2.1. Wasting time
2.2. Leaving with nothing
2.3. Knowing me and caring
3. Enhanced prenatal and postnatal care
3.1. Acknowledging the need for help
3.2. Letting caregivers in
3.3. Engaging in mental health care
3.4. Community health workers, someone like me
4. Women's health: a missed opportunity
4.1. Skipping the postpartum visit
4.2. Going to the ED in the perinatal period
4.3. Not knowing about contraception
Global themes
5. Communication with providers
5.1. Is anyone listening?
5.2. It's confusing
6. Perceived socioeconomic and racial bias
6.1. Being dismissed
6.2. Put on a face and keep going

PNC prenatal care

Table 2 Basic theme 1: Pursuit of PNC

Sub-theme 1.1. Recognizing and acknowledging pregnancy

i. "Well, it was like I had my period for the first half of my pregnancy, and I didn't even know I was pregnant until after I stopped having them, and I wasn't like the only one. My friend's sister had her period throughout her whole pregnancy"
ii. "I was seeing an OB-GYN every 6 months…had issues with fibroids. I was going in because I was supposed to be having my tubes removed because I was having too many fibroids causing heavy periods. I missed a period, got sick, nauseous and found out I was pregnant. I cried on the way, cried when I got there, I cried on the way home"
iii. "I was getting sick, was in a clinic and found out I was pregnant. I had no doctor, my whole 9 months, I had pregnant pills, went to a doctor at 7 months; my baby was fine. It's just, I immediately like right away—it actually took me a few weeks to feel anything. I didn't feel anything, because it wasn't planned"

Sub-theme 1.2. Making it work

i. "I think that with the Welfare, you have to have predetermination, and I didn't do something right. I went to the doctor's office, and they couldn't see me because I didn't know how to get on Medicaid until I got there. Then I had to reschedule and wait for them to get like the verification that I had it"
ii. "It takes a long time because sometime they don't even let you schedule your appointments until like you're on Medicaid or something…so now you went like these weeks without prenatal care, but they tell you like hurry up. It's important that you get this care, whatever, but they're not approving you for it"
iii. "If you say, well, I don't have Medicaid, you need to talk to DHS about getting signed up for it. So make an appointment with DHS. DHS wants you to prove you pregnant, so you have to still go to a clinic just to get the help. They're not going to take a home pregnancy test or a phone call either. The paperwork is what you need"
iv. "It's like, we can't make them [Medicaid] speed up the process, you know. All we can do is just wait until everything goes through, mean, I just think that they can improve the process"
v. "The only reason I did—I got in [accepted for Medicaid] is because my CHW was on my case. She was just e-mailing like, you know, hey, what's the hold up"

Sub-theme 1.3. Getting there

i. "[The cab driver was] pulling over and taking a cigarette break with me in the car, was going to sell tickets for his other job, and stuff like that is unprofessional, you know?"
ii. "I'm saying you are about to run out of gas. Stopping to get gas. Conversations you know and trying to holler at you [to get date] is really unprofessional."
iii. "Too many personal questions, want to walk you inside, one of those jobs"
iv. "Don't anybody come, having the wrong address and be mixing it up, picking-up me and picking-up another person, and 45 min late, I was always late and it would hard for them to see me because I'm high risk, the worst experience"
v. "I have one cab driver, he was very nice, he always came on time—sometimes"

PNC prenatal care

pregnancy; others indicated their pregnancy was unexpected, and it took time to acknowledge the pregnancy, delaying PNC. Many women had preexisting health problems that made it hard to distinguish pregnancy symptoms, and some women had their pregnancy confirmed in the ED or in a doctor's visit for a health problem.

Women knew they should get and many wanted early PNC, but getting care was a burdensome process of *making it work*. To get a provider, they had to get Medicaid; to get Medicaid they needed pregnancy confirmation from a provider; they needed to choose a health plan and a PNC provider; and they needed a PNC appointment, a process that caused delays. Women felt powerless to get early PNC, even when some reported that they had a prior high-risk pregnancy to the person scheduling appointments. One woman with barriers was told by her provider, "Why did you wait so long"? Another woman indicated that the Strong Beginnings CHW was helpful in directing her to PNC. While all Medicaid-insured women in Michigan can get help from Strong Beginnings or EPC to enroll in PNC, most women did not know about the assistance before PNC was initiated. For most women, PNC and additional resources were delayed until the second trimester.

Once they had an appointment, *Getting there* was the most common and stressful barrier to PNC participation. Transportation vouchers are available through health plans; but many women delayed picking a plan and many plans require 3–7 day notice for transportation help. Further, taxis were unreliable and the drivers' behavior was stressful: pulling over to take a cigarette break; selling tickets for another job; stopping to get gas; hollering at you (trying to get a date); and asking personal questions. If women arrived late for PNC, many indicated they were either rescheduled or told to wait until they could fit them in. Women felt PNC staff disregarded taxi problems and felt blamed for something they had no control over.

Experience of Traditional PNC

Most women described the first PNC visit as "paperwork" that left them frustrated, especially if they have been a prior patient at the practice. PNC visits were characterized as

Table 3 Basic theme 2: Experiences of PNC

Sub-theme 2.1. Wasting time
i. "They telling me, oh, I'm sorry, they behind, you have to wait. So if you keep checking with the time, they'll say, we'll get to you when we get to you. But if you come in late, though, they all don't want to hear your excuse, they just tell you to reschedule"
ii. "Paperwork—Too much, too much, too many, too many questions"
iii. "I'm telling you, ma'am, my number is still the same, everything is still the same. I'm just here, you know, to follow up with the ·appointment. [They say] Ma'am, I need you to fill this out or I can't see you. Look, you taking too much time going over the same stuff. And then they come in the room and ask you the same stuff. So what did you have me fill all these papers out for, ask me anyway? You are wasting time"
iv. "It was kind of a waste of time, to sit there all that time, and then, you know, be rushed out; pretty much I didn't get anything accomplished with that. You know, I guess it's okay to know that your baby is doing fine or whatever"
Sub-theme 2.2. Leaving getting nothing
i. "You just get weighed. Other than that, paperwork and questions, and it's over"
ii. "Because then I come in looking and asking, and you shoot me down and make me feel like I didn't get nothing out of you"
iii. "Discuss that with me, let me know what I am going to experience, let me know what I am going to go through, don't let me have to Google it"
iv. "She just came in and it's like she is so used to it and you are just another pregnancy, so she doesn't see you for an individual. She just does her thing and leaves"
v. "Come in and sit down, make me feel like you are listening to me, instead of just coming in and acting like you are just another pregnancy"
vi. "Yeah, some of the visits felt more, you know, valuable then, knowing what was going on. Then you are back to going for no reason all the time"
vii. "You need to be knowing more, when I went to go see my doctor, they didn't tell me a lot of stuff about being pregnant. All I know is from my family members"
Sub-theme 2.3. Knowing me and caring
i. "Prenatal care, it helps you feel a little bit safer, comfortable about what you're going through. Sometimes we get nervous. You don't know"
ii. "I'm excited about going [PNC], yeah…I really don't have no problem with my visits. My doctor—I could say, I could call there right now and be like, you know, something is wrong, and they will squeeze me in"
iii. "So if we go in, see, they can tell you, oh, you got this, you got that. Yeah, that's good you came to the doctors, they can tell you, prevent it from getting any worse"
iv. "She takes time with me. Our visits are not rushed. She is always smiling and willing to answer. Yeah, I have a great experience with her"

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doing more paperwork, waiting to see a provider, getting hurried through a quick exam, followed by waiting, again, for transportation—a process some described as *wasting time (*Table 3*)*. Women described PNC as quick check-ups for medical problems, could not describe the content of PNC, and many were unsatisfied with their care. Most indicated the provider was not in the room long enough, they didn't get enough information, sometimes did not get questions answered, and often ended up feeling like they were *leaving with nothing*.

Women wanted to actively engage and participate in their own care. They wanted the provider to view them as an individual, that is, someone who knows "me" in contrast to knowing "us", that is Medicaid- insured, African American women. Women wanted their provider to take time, sit down, ask questions, and give information. They wanted to leave the visit feeling that they got cared for versus getting checked.

For most women, *knowing me and caring* is what mattered most about PNC. Several women described positive experiences where it appeared that the providers went over and above to engage with and help women. These positive experiences were primarily reported in the context of a well-established relationship with provider or a practice who knew them. A provider's gesture to one woman who was extremely anxious near the time of delivery neared was notable: The physician picked-up a tongue depressor and wrote his pager number on the stick and handed it to her. For women who had positive experiences, they received information that did make them feel more comfortable and safe with the pregnancy.

Enhanced Prenatal and Postnatal Care

The structure, process, and content of traditional PNC limit opportunities to fully address the needs of women with multiple medical and/or psychosocial risk factors. However, external to PNC is a network of community-based programs that can provide care coordination, home visiting, health education, social support and referrals. Such programs are often underutilized for women most at risk.

Many women described a complicated process of deciding to enroll in EPC, HS, or other programs. *Acknowledging the need for help* to a provider can be a difficult first step (Table 4). Some women were hesitant or scared that providers would perceive their need for help as a sign that they may not be able to take care of their baby, so they just indicated they had no needs. For women with mental health or behavioral risks, most described that they were

Table 4 Basic theme 3: Enhanced prenatal and postnatal care

Sub-theme 3.1. Acknowledging need for help

i. "When I was 16, and I really was really needing that help like, you don't know what you need, and you really don't have money to buy a lot. You're living with your grandma, your parents. I was so scared that if I didn't have these things, I was going to lose my baby. I was scared to tell them that I needed these things; they was going to think that I couldn't take care of my own baby. Plus the pride thing, I was just so poor I couldn't get the things for myself. So for them saying do you need? No, I don't need nothing"

ii. "But they do have a lot of…resources that I think, like... okay, I need this, I need money, I need diapers, I'm about to be homeless, and maybe they could just be more specific and say, okay, you know, write down what you need, this is what we have for you, you're going to get a call from this person from this program, you know"

iii. "Kind of say—ask them what do they need, tell them ·what they can offer them, so then they know. What do you need? I don't know. They need ·everything, you know. And then from that point, look at the program, see, okay, what program can kind of help them with this, and then say look, have a conversation. Social workers kind of scare you, I'm scared to tell them certain things, you know? Like, do you need? No"

Sub-theme 3.2. Letting caregivers in

i. "If they decide to have somebody come out, educate them, this is a safe place, you don't have to worry about it. Because she didn't know she was able to speak up. So maybe you could like let them know when you go talk to these ladies, let them know that it is a safe place, you don't have to worry about us coming, we just here to help you"

ii. "Because when I went and I filled out all that paperwork, they will say like what do you need or this is what we have available. Because, you know, maybe I had ·pregnant brain. It was so many programs, it was a little overwhelming. I couldn't keep track of what programs, who this lady was, where she was calling me from"

iii. "[A community health worker] Like there might be a Caucasian young woman, a black young woman, Hispanic young woman, and they should have them all fit to each one's needs. Like oh, this is an African American young woman and she comes from the inner city and she might have been raised in poverty, so they might want to have somebody actually come and speak to them that has a background or some type of experience in this that is qualified, that can relate to them, tell them look, if you feel any type of way, you can come to me and tell me"

Sub-theme 3.3. Engaging in mental health care

i. "They called me and asked me if they can come see me. I'm like, sure Why? They told me that they got a referral from my doctor, and they would like to do counseling with me. And I found it very helpful. I don't think that I have ever really known what depressed was, but I can honestly say that I was extremely depressed"

ii. "I got connected with my EPC nurse. When she came out, she was talking about it, and she's like talking about the group. I don't want to go to group and people talk about all their problems. She's like, are you sure you don't want to go. I was like no, I don't want to go. A couple weeks later, I'm like, well, I'm going to go, get out of the house. I'm tired of being in the house, and so when I went, I was like, oh, they going talk about a lot of problems, ask me questions. Then when I got here, it was nothing like I thought it was. It was different"

iii. "I guess my attitude going down and just being sad, and she's just like, I signed you up for this group and its 6 weeks so you're going to go. She's like I know you'll go already because I know you're free, so I was happy that she took that initiative to sign me up for it because it really helped"

iv. "You know, we always tend to think like we're the only ones going through what we going through, and you get out, you know, to be able to listen to others, and you realize that it's—you know, and I think like in our last group, I think everybody kind of like learned from each other. I like my one on one [therapy] because it makes it like about you for that moment"

Sub-theme 3.4. Community health workers, someone like me

i. "My SB CHW connected me to everything else that I needed and she would just call me, like sign her up (daughter) and everything I needed. When we were into the appointment, she would like call the person and do this step, doing the work, everything"

ii. "I mean, I just feel that they [CHWs] relate to a lot of things You know say you going through things that you're dealing with, and when you find yourself in, you know, some type of crossroad, they help you, you know, try to navigate your situation. I mean, I just think they go above and beyond their duties"

iii. "I think SB program is the best because they help you with so much, and you learn so much and you don't have to be scared. You can say how you feel and stuff like that, get your emotions out. I was going through a hard time. You got somebody to listen to you"

reluctant or afraid to accept help from programs. For some women, actually *letting caregivers in* their lives and homes was challenging.

Engaging in mental health care was even more difficult and often women indicated that they needed more than a referral. When they successfully engaged in group or individual mental health services, it was usually because a trusted Strong Beginnings CHW or EPC provider set in motion the referral and continued with supportive engagement over time. Several women noted that either their physician or care coordinator made a referral to the mental health provider that allowed an opportunity for the mental health provider to engage participants. Women did not have a problem with receiving a call directly from a mental health provider and most appreciated the help.

Although the participants did enroll in the Strong Beginnings program, how they got connected to help varied. Some women were asked during PNC by a nurse or social worker if they wanted EPC or SB; none of the women indicated that a PNC medical provider encouraged them to enroll HS, EPC or home visiting services. Women talked about their confusion about multiple home visiting and infant programs, the process of getting signed up, ending up with more than one program and sorting that out. Several participants discussed the challenge of scheduling and remembering visits and getting their home and children ready for a visit.

Table 5 Basic theme 4: Missed opportunity for women's health

Sub-theme 4.1. Skipping postpartum visit

i. "Yeah. I mean, I didn't go—like with my daughter, I went, because it was like my mom: You got to go; you got to go. Now it's like there is nothing wrong with me and my kid. My periods are regular and set. I should be fine. I should be fine"

ii. "And I did end up having an infection in my uterus, because I didn't go in. I didn't know—I had a really horrible delivery of the after effects. I bled real bad"

iii. "My babies are not that far apart. I had two small babies, it was wintertime, didn't ·want to bring them out, transportation, and I tried to reschedule, they said I couldn't reschedule, to go to my own doctor. They didn't try to help me get a doctor. I think it was because I was on the phone; trying to rush me off the phone. I don't have a doctor to this day"

iv. "And I remember when I used to go to my 6-week check-ups, I thought my womb was falling out. One time I used the bathroom and I felt like: I wonder if that's my cervix. When I say my cervix is falling out, your cervix is not falling out. Your bladder, your muscles kind of got to get back right"

Sub-theme 4.2. Going to the ED during the perinatal period

i. "If I feel it's an emergency, I'm not calling anybody. If I feel like I can wait, then I call the nurse, like see what I can do"

ii. "I go the ER and I have the Lord take care of me…if I call my doctor, they don't answer the phones, you have to pick a message and stuff, and you have to wait for them to call you back, like something serious going on, like I am having a heart attack or if I'm having some pain real bad, I'm going to the ER"

iii. "I had an infection in my left breast, mastitis. I didn't know what that was until it happened. I had a real bad fever with that. I didn't even want to feed her. I was just sick. I went to the emergency room. Because my doctor, he couldn't get me in to see him, he said go to the emergency room. I was like, well, can't you give me something for the fever? No, you go there"

iv. "Once I came home, it was like hard to take care of my baby. I started having really bad headaches. I was having breathing issues, and I just felt like at any moment like I was going to collapse and I didn't want that to happen. I went to the hospital, and he was watching my blood pressure. He's like, can you sit down? I'm like, can I tell you what's going on? He's like, I need you to sit down right now. He said, your blood pressure is so high, I'm surprised you haven't had a stroke. And my Medicaid, they ended up cutting it off, so I didn't really know how to get my blood pressure medication. I went back to the ER and they actually told me to quit taking my high blood pressure medication, because now my pulse is dropping too low to continue to take it. So they want me to switch to water pills that won't mess with my pulse, and it will also lower my blood pressure"

v. "They refer you to a regular doctor. They give you a list of which ones. They give you the number. A lot of us don't take advantage of health care after we have children because we don't consider it that important, ·well, we don't need a six-week checkup. We do honestly need to have it. It is good to have ·a doctor. And I'm just now realizing that"

vi. "They should really, really try to emphasize to the mothers. Even though they're not receiving OB care, you know, a mother that has a one-year old child probably needs to see a doctor, Everybody doesn't need to go to Planned Parenthood anymore. We're not 15 anymore. You need a regular doctor to do your things"

Sub-theme 4.3. Not knowing about contraception

i. "I got pregnant off the patch, but I have tried every type of birth control, even the five year ID. It created multiple kidney and a lot of different health issues, so I had to have the emergency thing removed. I don't do birth control anymore either. I did abstinence for almost 3 years. Then I had my baby"

ii. "They told me that they couldn't do anything because I had an IUD in my arm, and they couldn't do anything about it because I go through [hospital name], so I had to go there and it was an emergency because I was having real bad headaches, real bad bleeding, and they told me that they couldn't take it out. I had to go to my doctor, so I had to wait for a couple months, and I still was having problems. Now they all of a sudden took it out, but since I had it taken out, I haven't had no problems, no headaches, no nothing"

iii. "My cousin, went from the shot to her getting her implant, so it was like I watch a lot of people talk about their issues of getting shots or what they been through. If they been through all that, why would I want myself go through all that. My cousin said she bleeds a lot, and my sister, she goes through it. They all going through it for not having kids, but I couldn't do it"

iv. "No, I just kind of weighed my options, because of my mom. She has IV. I don't know exactly what it is, but she had to have it surgically removed. So I just was not trying to go that route. I had more than one doctor's appointment to get birth control. But I was so scared that it was going to mess my body up, because before then I never had birth control. I was like I'm never having anything foreign in my body, you know?"

Participants in SB received care from CHWs, frontline public health workers who are trusted members of the community (American Public Health Association Community Health Workers Section 2009). Women often referred to the CHW as someone who can relate to me; as *someone like me*. Most women agreed with the participant who explained it was important to have an African American, Hispanic, or Caucasian CHW similar to the woman's own race/ethnicity. Women related many instances of service navigation; one participant also described the CHW as someone who could help them "navigate" their situation when going through a difficult time. Participants talked about how they could share how they feel, get their emotions out, and the CHW listened. In the context of home visits, where women could be seen every other week, CHWs provided intensive peer support.

Women's Health: A Missed Opportunity

Following birth, many women had ongoing health problems and some did not complete a postpartum visit; others used the Emergency Department (ED) for childbirth-related problems and chronic illness. Although women were assigned a

primary care provider by their Medicaid health plan, few women mentioned a regular provider. S*kipping the postpartum visit* was due to competing family priorities or questioning the value of the visit (Table 5). Women described that the visit was not important, hard to do with a new baby, and not emphasized by their providers. If they missed appointments, they were rescheduled, or some were told to go back to their regular doctor.

Many women reported *going to the ED* for childbirth-related health problems (e.g. infection of uterus, incision, or breast) and chronic illness (e.g. hypertension, diabetes). The seriousness of some of the episodes seen in the ED was troubling; for one woman, life threatening. Participants talked about episodes of unexpected, severe pain (e.g. head, chest, abdominal) and bleeding (vaginal) symptoms, and feelings of panic that motivated ED use. Few of the women with chronic health problems talked about a regular doctor. Instances of ED use were also common across the prenatal period when participants were distraught, scared, and felt they needed help immediately. Most women talked about illness episodes as if separate from prenatal and postnatal care.

Some women did use a primary care provider's office when they need urgent care and a few had access to a nurse line. One woman reported an episode where she was scared, the receptionist recognized her anxiety, and had her stay on the line until she could talk with a nurse who calmed and helped her. When asked about having a regular provider, one woman suggested that maybe now they needed a doctor and more than just access to birth control.

Although women were repeatedly asked about their plans for birth control, *not knowing about contraception* was common. Most women were troubled by contraception options and many women appeared to know little about how their bodies functioned, even though contraception education is provided by EPC, Strong Beginnings, and medical providers. Many struggled to find the right words to talk about contraception. Women did talk about the side effects they had experienced and often related the bad experiences of their friends or family members. Some indicated their symptoms made them afraid to use contraceptives; few related positive experiences with birth control methods or advocated methods. A woman reported her indecision about contraception led to another unplanned pregnancy; now following that birth, she still remains unsure, worried about side effects, and not using contraception.

Global Themes

Two global themes, present in all phases of the perinatal care continuum, were identified: (1) Communication with Providers and (2) Perceived socio-economic and racial bias. A summary of global themes and subthemes with a representative sample of women's quotations are presented in Tables 6 and 7.

Table 6 Global theme 5: Communication with providers

Sub-theme 5.1. Is anyone listening?

i. "Make me feel like you are listening to me, instead of just coming in and like yep, yep, yep, and we'll do this, this, and this and then leave. It's like did they actually take care of me?"

ii. "Providers act like I don't know anything just because I am poor. I want to learn: didn't get nothing out of it; keep repeating; feel like I'm not smart enough to ask questions"

iii. "I felt like when I had my pregnancy birth plan to go through—I'm sorry, were you finished?"

iv. "If you're explaining something to them and you're really trying to give them your all with that, and they say, yeah, I understand, okay, well, I'll see what I can do, and they just leave you. I don't like all that, you know. They need to be a little more compassionate, just a little bit. I am not saying you got to be crying over my situation or nothing, but just, you know?"

v. "My history should speak for itself. Read my file before you come in. Don't ask me. Know me before you get here. It makes me feel like just because I got Medicaid, I'm poor, I don't know no better. I'm not smart enough to ask you those questions. It's not that. It's just as a doctor, you should be one step ahead of me"

vi. "They (providers) get kind of apprehensive and don't really want to deal with you; they want to hurry up and get done with you as soon as possible"

Sub-theme 5.2. It's confusing

i. "I don't know what you all are saying. I mean, I'm like I don't know what you all talking about (patient with fibroid tumors). I don't know what you are saying"

ii. "They say I score high and they just left it, oh, it's postpartum depression. But it's like no, I'm trying to tell you it's not. I've been depressed all my life. But since I never said nothing, they never did nothing. Like since I never said nothing in the years past, when I score high, they didn't do nothing but send me a social worker to talk to me"

iii. "I was wondering because my lupus was acting up, and it was acting up to the point where I was going back and forth to the hospital, back and forth to the hospital, so last time I went, she was like, well, contact your doctor. I said, so if it gets worse, I just stay home. She said, yeah, stay home. I said, but if my lupus gets worse to the point where I can't breathe or stuff happening, you want me to stay home? She said, yeah, stay home or call your doctor"

iv. "Well, I just don't let 'em be. You can't just tell me, oh, you just got gas or you just got heartburn because I've always been like real analytical. If you tell me heartburn, I'm like, well, what makes you think I got heartburn. How do you know it's gas just by looking at me"

Communication with Providers

Women often felt it was hard to get their PNC provider's attention; they had to get them to physically stop during a quick, routine check-up visit. Then, participants had to put the pieces of their story together and hope they had given the provider enough information. Women talked about the energy it took to re-tell their information over and over again, and wondered, *is anyone listening?* (Table 6). One

Table 7 Global theme 6: Perceived socioeconomic and racial bias

Sub-theme 6.1. Being dismissed

i. "She did not spend a lot of time in the room. It did make me feel like you couldn't get your questions in. They immediately answered and then shoot you down. You know, when you are a pregnant woman, you are sincerely concerned about this health problem, because you are experiencing ·something that you feel is not normal and for it to just be immediately dismissed, it makes you feel like well, why did I even say anything"

ii. It's like she is so used to it and you are just another pregnancy, so she doesn't see you for an individual; she just does her things and leaves"

iii. "I feel the baby move, she's like: No, you're not, you're not even that far along. I'm like: I do feel my baby move. If I told her I'm in pain, something don't feel right, she's always like: Oh, no, no, you're not. She always told me I'm wrong at everything. I didn't like that"

iv. "You know, I notice with African American women, they quick want to give us shots or birth control immediately after we have our children. I was like, is that for to stop the bleeding, she says: No, you need to be on birth control. Oh, it's the Depo. I said: I didn't ask for that particular one. She says: That's typically what we give you"

v. "They did that to me [Depo shot]. You didn't even ask me. You didn't know if I wanted that form. You didn't even know if I was keep having sex; you didn't know nothing. I didn't sign nothing and they just poked me"

vi. "I feel like they should ask. Because a nurse told me if you're going to breast feed, you don't want to be on Depo. And I was planning on breast feeding. You need to communicate with us, just like we got to communicate with you"

Sub-theme 6.2. Putting on a face and keep going

i. "I even had one cab driver put that in like bold writing. It's not like we're getting cash (get vouchers). Turn left, that's all I could tell you. I know nothing about no cash, sir"

ii. "You tell them [PNC practice staff] your information has not changed, they still trying to pressure you, that's agitation…they just be doing that because they know they can get away with it, agitation"

iii. "I got a big green sticker [on my file], that's Medicaid, why they even do that. It should be in the back. Why they put on your file, Medicaid?"

iv. "At least pretend like you care while you in my sight before they go off, you know?"

v. "If you complain too much or do anything that's not right at one clinic, they can blackball you from going to all the rest of the clinics"

vi. "Sometimes they can't go back to a clinic because I have been late too many times"

woman spoke to the risk of not being able to communicate her concerns; the provider might not have what was needed to figure out her problem. Women indicated that they wanted to know more about pregnancy from their PNC providers, but they often felt like providers didn't share information if they didn't ask the right questions. Some women perceived that providers viewed them as not capable of understanding, so did not share information.

Although, women primarily talked about difficulties communicating with PNC providers, it was also notable how hard it was for women to describe their health problems, even though they were in community programs designed to provide considerable health education. This was particularly true for women with chronic health or contraception issues. They often struggled to explain what they knew with confusing terminology. Not understanding their symptoms, consequences, or treatments, many women described interactions with providers as, *it's confusing*. For some women, the confusion provoked anxiety. While some women knew how to find health information and make sense of it, many women felt as if they didn't get enough information to understand, make choices, and feel in control.

Perceived Socio-Economic and Racial Bias

Most women felt like they were being treated differently because of Medicaid insurance; and some women felt their treatment was influenced by their race. They described perceived provider judgmental attitudes and stereotypes of pregnant women who are Black and poor. They also perceived unsaid things: extended waiting, Medicaid labels on their files, and non-verbal facial expressions from staff.

Women talked about *being dismissed* in encounters, and some felt that providers believed they didn't need to know or weren't smart enough to know (Table 7). If they asked questions, women were concerned they might be perceived as difficult. Dismissive and biased interactions were particularly common around the issue of contraception. Women described numerous instances where they felt an injection (Depo-Provera) was being forced on them during recovery from birth.

Some women talked about iterative experiences of bias, needing to *put on a face and keep going*, across the perinatal period, and also within episodes of care. Many described a stressful process that builds up, often starting with the cab driver, then the office staff, the PNC provider, and others. A few women reported challenging their care, and some worried about the negative consequences that might happen if confronting bias. Although the hospitalization experience was beyond the scope of this analysis, participants particularly perceived bias during the labor, delivery, postpartum hospitalization experience.

Discussion

Most women's efforts to engage in early PNC were hindered by procedural barriers, transportation issues, and appointment delays. While some women had positive experiences, many women were unclear about what they actually got from PNC, although, they wanted to learn, actively participate in their care, and feel like they were known and cared for by providers. Dependent on referrals at PNC, most women

lacked opportunities for early engagement in community-based HS or EPC programs that could provide risk screening, care coordination, education and help secure basic health resources early in pregnancy.

Some women did not complete a postpartum visit; several used the ED during the postpartum period for birth and postpartum related problems; many were fearful of contraception methods and had trouble successfully using contraception; and, few spoke of using a regular medical provider. Women coped with confusion, lacked knowledge about their health, had difficulty in communicating with providers and, for some, perceived socio-economic and racial bias in their care. Notably present were descriptions of women with complex health and social problems receiving episodic, unsatisfying care; although for some, additional help was found within a well-established relationship with PNC or community provider. Remarkably absent from women's perceptions of care were any connections among PNC and community-based HS or EPC programs or supportive transitions to primary care after birth.

Our findings are consistent with the results of other studies of low-income African American women and experiences with barriers and facilitators of PNC and postpartum care (Phillippi 2009; Teagle et al. 1998), using the ED (Clark et al. 2010), the postpartum visit (Martin et al. 2014), contraception confusion (Hodgson et al. 2013; Yee and Simon 2014), engagement for mental health (Goodman and Tyer-Viola 2010; Grote et al. 2007; Roman et al. 2009; Sacks et al. 2015), and provider communication and economic and racial/ethnic bias (Bennett et al. 2006; Chapman et al. 2013; Dovidio et al. 2008; Hall et al. 2015; Salm Ward et al. 2013; Slaughter-Acey et al. 2013, 2016; Verlinde et al. 2012).

However, this study identifies multiple system issues that could be addressed to improve women's experiences of care across clinical and community services. Implications of the findings will focus on these system issues, especially across clinical and community services.

1. *Integration of PNC with community-based HS and EPC care coordination*: Although PNC has limited resources to serve women at greater risk, community-based HS or EPC programs can address their needs. Partnerships among clinical and community providers could facilitate a team-based care approach; that is, care delivered by multiple providers who work to accomplish shared goals within and across settings to achieve coordinated, high-quality care (Jennings et al. 2016). Collaborative agreements could specify referral arrangements, scope of services, specific roles and responsibilities, and mechanisms for technology supported communication across sites (Tschudy et al. 2013). The North Carolina Medicaid EPC is an example of a collaborative PNC and EPC program (Johnson and Gee 2015). The Center for Medicaid and Medicare is now testing the maternity home concept, that is EPC to expand access to care and care coordination to deliver a broader array of health services (Centers for Medicare & Medicaid Services 2012). Given reports of provider bias, partnering with community-based programs and CHWS could also afford PNC providers the opportunity to better understand the perceptions and needs of women living in difficult life circumstances (Cheng et al. 2015). Further, some HS programs offer health equity training that could be of value to providers.
2. *Earlier, easier PNC initiation*: Women with multiple risk factors should be connected to PNC, Strong Beginnings HS, EPC or other community programs in the first trimester of pregnancy (Lu et al. 2010). EPC programs could help enroll in health coverage, get pregnancy confirmation, access transportation, and share risk assessments with PNC to tailor care, especially for those with prior adverse birth outcomes. Early HS and EPC enrollment could be triggered at the first prenatal call to PNC with referral to SB/EPC, allowing for risk screening and access to resources even before the first prenatal medical visit.
3. *Enhanced Engagement in HS, EPC, mental health and other services*: Referrals to services alone is often not enough to keep vulnerable women engaged in using additional health care resources. Accepting help is a complicated process, especially for women with behavior health issues (Grote et al. 2007). PNC providers, in integrated care models, could support increased enrollment in Healthy Start and EPC. Then enhanced engagement interventions can be delivered by CHWs, trained to provide peer support, or trusted nurses and social workers who deliver services in a woman's community (Grote et al. 2007).
4. *Expanded PNC, HS and EPC content to address women's health mechanisms to increase health literacy skills, and redesigned PP visit as bridge to primary/interconception care*: Our findings support that the content of PNC needs to be tailored to meet the needs of those with chronic illnesses, prior adverse outcomes, and behavioral health issues. Additional strategies are needed across settings to address health promotion (e.g. weight gain, exercise) and education about basic female anatomy and physiology, contraception methods and side effects, including the behavioral support to help women be successful in reproductive life planning. This expanded content can be accomplished if PNC, HS and EPC collaborate to standardize content, reduce redundancies, and tailor content based on risk. HS programs, committed to client empowerment, can strengthen efforts to help women increase health literacy skills and fully participate in medical visits. Efforts are

needed to accommodate women's needs for a postpartum visit (e.g. scheduling with infant's visit) and transition mechanisms to primary care for interconception care.

Our study has several limitations. Although our results are consistent with other studies, our sample size was small. The population was recruited from a local HS program whose participants were significantly more likely to have higher percentage of medical and psychosocial risk factors than other Medicaid-insured African American women in the county or in other EPC programs (Meghea et al. 2014). Therefore, our findings are applicable to women at high medical/psychosocial risk who participate in a HS or EPC type program and cannot be applied to all African American, Medicaid-insured women. Further, our purpose was to understand women's perspectives across a broad perinatal period to identify system issues. Therefore, we were limited in reporting in depth about many aspects of the process of care, including the hospitalization for birth.

In sum, Medicaid-insured, African American women face challenges in participating in perinatal services, across clinical and community settings, that put them at disadvantage for receiving quality care. PNC, HS and EPC providers could work together to streamline and integrate a burdensome process for initiating care, improve the process and content of care, and enhance engagement in services. As HS and EPC programs typically maintain care coordination and home visiting for 1–2 years post birth, instead of a missed opportunity, the perinatal period could be a gateway to primary care and long term, better health (Johnson and Gee 2015). Finally, while some women had positive interactions, others reported they often felt confused, diminished and discriminated in their interactions with providers. Our findings call attention to the pressing need to address socioeconomic and racial/ethnic bias in health care if persistent disparities are to be reduced and health improvements realized.

Acknowledgements The authors thank the Strong Beginnings clients who participated in the focus group and so generously shared their experiences and stories. We also thank Drs. Stephen Rechner and Melinda Johnson and Susan Henning, MSW, Spectrum Health, AHRQ project collaborators, for developing strategies to improve a system of care. The study was supported by grant number R18HS020208 from the Agency for Healthcare Research and Quality (AHRQ) and the Strong Beginnings Federal Healthy Start program (Health Resources & Services Administration, Maternal and Child Health Bureau and W.K. Kellogg Foundation grants). The content is solely the responsibility of the authors and does not represent the official views of the Agency for Healthcare Research and Quality.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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