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Patient perspectives on prenatal care delivery innovation: a call to action from pregnant high and low utilizers of unscheduled care

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# BOSTON UNIVERSITY SCHOOL OF MEDICINE

Thesis

# PATIENT PERSPECTIVES ON PRENATAL CARE DELIVERY INNOVATION: A CALL TO ACTION FROM PREGNANT HIGH AND LOW UTILIZERS OF UNSCHEDULED CARE

by

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# PATIENT PERSPECTIVES ON PRENATAL CARE DELIVERY INNOVATION: A CALL TO ACTION FROM PREGNANT HIGH AND LOW UTILIZERS OF UNSCHEDULED CARE

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#### **ABSTRACT**

Background: Rising rates of maternal morbidity and mortality and persistent disparities in care utilization and outcomes signal a need for new approaches to prenatal care delivery. This study uses perspectives of low-socioeconomic status (SES) pregnant women to generate features of a patient-centered intervention aimed at improving outcomes in high cost, high need pregnant individuals.

*Methods*: We performed a secondary analysis of qualitative interviews with Medicaid-insured pregnant high and low utilizers of unscheduled obstetric care. Using a grounded theory approach, we tightly mapped themes to generate intervention strategies with potential to improve prenatal care delivery.

*Results*: Three key themes translated into intervention features: social support, care delivery, and access. Unlike low utilizers, high utilizers had a desire for more social support, improved communication in care delivery, and access to timely and efficient appointments. For low utilizers, improved insurance access and the ability to opt out of support services that didn't align with their priorities were essential.

Conclusion: High and low utilizers of unscheduled obstetric care have unique ideas for improving their care. Targeted interventions to improve prenatal care can be tested to

potentially address unmet needs of vulnerable subgroups of low-SES pregnant women at risk for poor outcomes.

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# LIST OF ABBREVIATIONS

CHW Community health worker

ED Emergency department

SES Socioeconomic status

TCUP Triage Care Utilization in Pregnancy

US United States

### **CASE SCENARIO**

Patient NF is a 33-year-old presenting for care during her second pregnancy. She has an existing diagnosis of depression, anxiety, asthma, chronic hypertension, Hepatitis C, and polysubstance abuse. She presents to the hospital 16 times in her current pregnancy for a range of issues, including abdominal pain, infection, and acute intoxication. This includes 8 visits to an obstetric triage unit, 8 visits to an emergency room, and 8 inpatient admissions, not including her delivery admission. She signs out against medical advice on hospital day 4 after having her baby. She is later discovered to have passed away less than two weeks after discharge. In one study, approximately half of pregnancy-associated deaths are associated with an unscheduled hospital contact in the month prior to death, suggesting missed opportunities to intervene.<sup>1</sup>

#### INTRODUCTION

Although United States (US) neonatal mortality rates have declined in recent years, and maternal mortality rates have increased. Immulationally, disparities, particularly racial inequities, in maternal outcomes persist: Black women are significantly more likely to experience fetal death, preterm birth, and fetal growth restriction, and to have higher rates of maternal morbidity and mortality compared to White women. Identifying specific causes for these disparities is challenging. However, several barriers to care are associated with negative perinatal outcomes. Limited availability of providers, lack of access to reliable transportation, and lack of financial means to pay for healthcare costs, particularly through insurance, are all examples of access-related factors that are linked to maternal outcome.

Though it is promoted as invaluable to the health of the mother and baby, engagement in prenatal care is not necessarily associated with decreased maternal mortality and morbidity. Receiving adequate or adequate-plus prenatal care, classified using Kotelchuck's Adequacy of Prenatal Care Utilization Index, does not preclude the risk of women experiencing poor obstetric outcomes, with or without the presence of high-risk conditions. This suggests that some pregnant women's health needs are not optimally met despite their obtaining prenatal care. Quality of care varies among settings, and the procedures employed in prenatal care may not be the right measures of factors that affect outcomes, but at the very least, the visit to a provider offers an opportunity to catch problems as they develop and institute preventive measures. This opportunity should be available to all pregnant women.

The finding that disparities persist for populations that have access to care 10,18-20 suggests that optimizing outpatient prenatal care access alone will not address worsening maternal outcomes in the US. Disparities in health status and life circumstances are such strong determinants of worsening outcomes that they cannot be sufficiently addressed with a narrow focus on care utilization. Gadson et al.<sup>21</sup> propose a framework describing a complex relationship between structural and institutional factors – spatial access, insurance status, psychosocial factors, etc. –, prenatal care use, and disparities in maternal outcomes. Driven by race/ethnicity, various social determinants of health likely interact with biological factors and health behaviors to influence maternal outcomes. Studies that identified a presence of social disadvantage or psychosocial stressors such as homelessness, financial stress, and trauma as strong predictors of poor outcomes support this perspective. 10,22,23 Consequently, it is important to examine features of care provided to pregnant women along with medical risk and upstream social determinants of health to help inform approaches to reducing disparities in maternal outcomes. Counting utilization rates is too simplistic a measure of adequacy of care.

The Institute of Medicine has proposed five A's to measure access<sup>24</sup>: affordability, availability, acceptability, accommodation and accessibility. Availability of the services one wants at a site that is easy to reach and patient-centered (accommodation) is at least as important a determinant of effective utilization as financial access to care.

# High Utilization of Unscheduled Care as a Signal of "High Need"

Currently, real-time approaches to identify pregnant women most at risk for morbidity and mortality are not widely described in the literature, but are increasingly relevant to new initiatives, such as Medicaid Accountable Care and Pregnancy Medical Home models. Studies have sought to identify demographic factors and health statuses that are strongly associated with adverse outcomes. These predictors of risk generally include race/ethnicity, socioeconomic status (SES), the presence of pre-existing or high-risk conditions, and adequacy of use of prenatal care. However, the persistence of disparities in outcomes suggests a potential value in considering other signals that may identify a sub-population at greater risk.

In other fields, researchers commonly analyze characteristics associated with high emergency department (ED) utilization to identify high need, high cost patients. In the 2014, the high utilizer population made up between 2.6 and 6.1% of patients presenting to the ED, yet they accounted for between 10.5 and 26.2% of total ED visits and 10.1 to 24.0% of total charges for ED services. Research in non-pregnant populations has demonstrated that this frequent use is significantly associated with being Black or Native American, homeless, low-SES, and Medicaid-insured or uninsured, in addition to lacking social support, suffering from chronic conditions and/or a significant level of psychiatric morbidity, and greater use of outpatient and mental healthcare services. These characteristics imply a complexity in the health needs of high utilizers that signals this population as "high need."

The Commonwealth Fund defines "high need" adults as those with multiple chronic conditions, with or without functional limitations that make self-care and

performing usual activities difficult. These high need patients disproportionately account for a significant share of ED visits and an overwhelming majority of adults with the top 5% and 10% of healthcare costs, in addition to higher self-reported psychosocial burden. Improving care delivery and management through interventions that address these patients' needs offers an opportunity to both improve health outcomes and reduce healthcare spending.

# **Pregnant High Utilizers of Unscheduled Care**

Pregnancy is a time of particular vulnerability with particularly proximal, measurable clinical and social outcomes. Pregnant women who frequently show up for unscheduled visits to the hospital may do so in addition to outpatient prenatal care obtained through an established provider or as their sole source of care during pregnancy. The latter is more suggestive of issues in access. Little is known about the characteristics of pregnant high utilizers and if they differ from pregnant women who are low utilizers of unscheduled care.

Secondary data analyses of existing data sets provide some demographic information about pregnant high utilizers, and whether they are in fact high cost, high need patients. In one prospective study using data from a randomized controlled trial with pregnant women, *Magriples et al.*<sup>37</sup> found that compared to users of an adequate level of prenatal care, users of inadequate and excessive care had significantly more unscheduled visits during their pregnancy. It was also determined that inadequate use correlated with low prenatal care knowledge by the third trimester and excessive use correlated with low

readiness to care for a baby by the second trimester. These findings align with what we know from previous studies of non-pregnant patients that establish a negative correlation between level of health literacy and ED use. <sup>38–41</sup> In pregnant women, use of unscheduled care is associated with certain medical and psychosocial risk factors, including young age, minority status, abuse, loneliness, psychosocial stress, mental health issues, greater ambivalence towards pregnancy, and reporting an unplanned pregnancy. <sup>42–44</sup>

# **Understanding the Perspectives of Pregnant High Utilizers**

Qualitative research provides an important tool to understand drivers of behavior in pregnant high utilizers from their personal perspective, rather than secondary data. It provides information on their needs (e.g., an appreciation of or want for positive and personal relationships with their providers<sup>45,46</sup>) and insight into their preference for unscheduled visits (e.g., lack of access is both a barrier to obtaining care and a factor that makes ED visits an appealing alternative to scheduled care<sup>47</sup>).

Using a mixed method study design, *Mehta et al.*<sup>48</sup> sought to understand patient preference for hospital-based unscheduled care in pregnant high utilizers compared to their low utilizing counterparts. Despite both groups being sociodemographically similar, high utilizers were more likely to report adverse childhood experiences coupled with an absence of coping mechanisms and lack of positive relationships or social support which elicit a sense of distrust. When it came to barriers that fueled their use of emergency care, high utilizers described comorbid health issues, poor care coordination, and dissatisfaction with services and clinic access as reasons that made unscheduled hospital-

based care on Labor and Delivery or in the emergency room more appealing. Low utilizers reported greater social support, but many similar issues with acceptability and access to care. These findings prompt further assessment of the needs and perspectives of each group in order to address gaps in the current healthcare system and ultimately improve maternal outcomes.

Women's perceptions of prenatal care play a key role in their decision to initiate and continue care.<sup>49</sup> Efforts to restructure care, currently underway in the publicly funded maternity care system<sup>50</sup> will be of greater impact if driven by the perspectives, preferences, and needs of the end-user: the high-risk patient. Additionally, understanding patient perspectives is essential to informing this process of improving quality of patient care.<sup>51–55</sup> This has been explored extensively in the high utilizer population in efforts to design interventions to reduce ED use and healthcare costs,<sup>56–58</sup> but not specifically in pregnant high utilizers. With this in mind, we sought to conduct a secondary qualitative analysis examining ideas for improving prenatal care in high vs low utilizing low-SES pregnant women in inner-city Philadelphia.

### **SPECIFIC AIMS**

Our prior work sought to identify barriers to care and preferences for seeking unscheduled obstetric care in low-SES pregnant women. The current study consists of a secondary analysis of qualitative data collected as part of the "Triage Care Utilization in Pregnancy" (TCUP) study,<sup>48</sup> analyzing high risk, high utilizers' ideas for improving care. The goal of this study is to use qualitative findings to generate ideal features of a patient-centered intervention grounded in the needs identified by low-SES pregnant women and aimed at improving outcomes in high cost, high need pregnant individuals at risk for experiencing maternal health disparities.

#### **METHODS**

Members of our study team have previously described the TCUP study. This was a study consisting of in-depth semi-structured interviews with 40 low-SES pregnant women at the point of unscheduled hospital-based care. Participants were approached and interviewed at the point of care in an obstetric triage unit of the Hospital of the University of Pennsylvania. Interviews were conducted by a community health worker (CHW) trained in qualitative interviewing by the Mixed Methods Research Laboratory at the University of Pennsylvania and from a low-income community.

Interviews explored participant perceptions of, barriers to, and ideas for improving prenatal care. The interviewer specifically prompted participants regarding perspectives on group care and CHW models, as well as other ideas for improving care. The qualitative methods used in this study have previously been described in detail, and findings focused on differences in drivers of preference for unscheduled care in the two study groups are presented elsewhere.<sup>52</sup> The objective of this study was to conduct a comparative qualitative analysis of participant ideas of improving prenatal care.

# **Defining "High Utilization"**

Purposive sampling was used to create two study groups: high and low utilizers. "High utilizers" were identified as having 4 or more unscheduled visits (established as the upper 10% of repeat utilization in the study population) during their current pregnancy, while "low utilizers" were at least 36 weeks of gestation and had no unscheduled visits.

# **Mapping Participant Ideas to Design Intervention**

Using a grounded theory<sup>59</sup> approach, a coding structure was developed to include the major themes that emerged from the qualitative data relating to participant ideas for improving care. The first and principal authors coded the transcribed data by hand using grounded theory, searching for unique themes and iteratively developing a coding structure. Identified themes were then translated into key proposed features of an intervention design. These themes summarized participant ideas for addressing barriers to care and perspectives on potential prenatal care delivery innovations. Finally, the first and principal authors collaborated with the community-based interviewer/CHW to confirm alignment of the proposed features with participant perspectives. The resulting intervention framework was then presented to all study team members for validation.

This study was approved by the University of Pennsylvania Institutional Review Board.

#### **RESULTS**

Sixty-six of the 238 pregnant women approached were eligible to be included. Of the 66 eligible women, 26 declined to participate because of a lack of interest in participating (n = 11), not having time to complete an interview (n = 11), or experiencing too much labor pains to participate (n = 4). Forty participants were enrolled and categorized as either high (n = 20) or low (n = 20) utilizers. Enrolled participants were predominantly African American / Black (95%), reflecting the Medicaid-insured population served by the study site. There were no significant sociodemographic differences between the utilization groups (Table 1).

During the coding process, ideas that emerged from participant narratives regarding improvements in prenatal care were grouped into three overarching themes (Table 2). First, participants wanted improved support and reassurance, but found that the traditional structure of their prenatal care does not offer the means to address this need. Second, participants wanted more acceptable care delivery, with greater consistency, communication, and individualization of outpatient prenatal care. Third, participants wanted improved access to prenatal care—with more appointment convenience (accommodation and accessibility), walk-in availability, and unconditional insurance coverage during pregnancy. Though themes were similar among all participants, a few subthemes differed between utilization groups (Table 3), which will be discussed further within each theme below. Within each overarching theme, each subtheme was closely translated into a possible intervention feature (Table 4).

#### Social Support

Participants discussed interactions within the healthcare system that left them with an impression that their providers held biases and assumptions towards them that affected the care they received. This type of experience was particularly significant in high utilizers: "...some doctors will look at you thinking of the stereotype and point the finger at all...[M]aybe she's over exaggerating, or maybe it's this because they might not see certain things on a monitor. But, the monitor don't show everything that you're feeling or going through." For participants, this created a feeling of being stigmatized and isolated. As a result, they found it especially difficult to open up to providers, despite yearning for more support and personal relationships within their healthcare network.

Discussion of ideas pertaining to social support made up a vast majority of the participant narratives on ideas and hope for change. They expressed a desire for more education, reassurance, coaching and goal-setting to achieve behavioral modifications, and help navigating resources from their prenatal care. High utilizers in particular described coming to the hospital and healthcare system seeking sources of support during their pregnancy, particularly given greater lack of support in their personal life. However, their experiences in the healthcare system did not always match up with their hopes (Table 2).

Overall, a much wider variety in ideas around social support were proposed by high utilizers compared to low utilizers. Almost all ideas mentioned by low utilizers were also mentioned by high utilizers, but several additional topics were raised by high utilizers that did not appear in the low utilizer narrative. Specifically, high utilizers more commonly expressed interest in having a CHW to provide support. Other topics

discussed by high utilizers included seeking more education and reassurance after discharge, the health system as an explicit source of social support, and a strong desire for support and connection to others (both providers and peers).

Though their providers were able to offer them information and education on their pregnancy, many participants felt there still needed to be more patient education available, especially on pregnancy expectations for first-time mothers: "Explaining more about certain symptoms...this being my first child and I may not know. I'd say explaining more about labor, contractions, and stuff like that." Enhanced patient education could come directly from providers or through auxiliary services offered in the clinic, but several participants expressed a need for education that incorporated visual aids and hands-on learning: "I'm a visual learner. So, I need to see it. I can talk about it afterwards, but I have to first see it while you're explaining it, in order for me to grasp it."

Educational classes on topics such as childbirth, parenting skills, and resources for first-time mothers were also highly valued by participants. However, participants felt that promotion of such resources within the clinic needed to be improved. For many, it didn't always have to be their provider, as long as someone in the clinic brought it to their attention in a timely manner: "[I]f somebody came out in the waiting room, maybe, a couple times a day, to directly tell people about what's going on, as opposed to just putting a paper on the wall."

In addition to education, participants wanted their providers to offer more information to reassure them when they were worried about the progress of their

pregnancy. This was especially critical for high utilizers being discharged from the ED or triage with remaining concerns. Narratives showed concerns were not appropriately addressed before discharge, and that participants had unresolved underlying anxieties and traumas: "[My mom and I] had no idea why I was in this pain...I've never had a miscarriage before...I just – I went home with no information about what to do..."

Participants repeatedly expressed a need for providers to offer more explanation about their care and time to insure their questions are answered.

Many participants also wanted advice and resources for achieving health goals and lifestyle and behavioral modifications. For example, they wished their providers gave them more advice on what foods to eat and to avoid. When asked what could a provider do to help a women stay healthy during pregnancy, one participant states: "Encourage you to eat healthy, exercise, take your pre-natal vitamins and things like that." Most commonly, participants did not only want medical reassurance during pregnancy; they also wanted support from their providers to address the social aspects of their lives that contribute to their health and the health of their baby: "A lot of people don't know who to turn to or don't have their family's support at home."

Notably, high utilizers expressed significant interest in connecting with peers to seek and offer reassurance: "...[A] support group where you sit down with other women like you, and you talk and you find out what other women are going through and you can probably give advice, receive advice. This is a good thing." They perceived such a network to be beneficial for those who need it, but groups ideally should be modest in size and the information shared by members should be respectful and confidential in

order for participants to feel comfortable.

Although all participants thought groups to be positive aspects of care and despite demographic similarities, low utilizers overwhelmingly expressed opposition or indifference when asked about personal interest in participating in such groups. Unlike most high utilizers, they did not think it a beneficial service to meet their needs or preference (Table 3): "I'm kinda solo. I don't like to be around a lot of people, so I just do stuff independently." Their narrative also reflected less openness to group environments: "...[B]eing around a bunch of other pregnant women is kind of annoying. You're all going through your own mood swings, your own symptoms, and half the time, everybody's irritated." High utilizers, on the other hand, were excited about the potential of having a space to meet others with similar experiences.

Overwhelmingly, participants agreed that having someone to help them locate and coordinate with existing social services resources would be beneficial to reducing care fragmentation: "Just be a person that could point me to a direction of help that I need like my problem with childcare or if somebody had transportation ... Just a go between type person to help you find resources." They sought supports that were suitable for their individual needs and agreed that it would be helpful to have someone in the clinic to make a face-to-face connection with and help encourage their engagement in care. Ideally, having someone, such as a community health worker (CHW), who they could reach out to or who could reach out to them outside of the clinic was seen as beneficial, as long as expectations for how and when such interactions will occur could be individualized: "Yeah. I think if [visiting me at home] was a part of the program... If I

communicated with her, if she asked me and said, hey, would you mind if I visited you once a week or once a month or whatever, and I said, sure, let's set up a time. But if she was just coming by, like don't come by my house. That could be too much." Though participants thought it would be helpful to have someone in the clinic that could support them during their pregnancy, the support needs to be individualized and respectful of patient's circumstances. For participants, acknowledgement and respect of personal boundaries was an essential element of any integrated social support.

Intervention features grounded in these participant ideas about social support are summarized below (and in Table 4):

Integrate CHWs into care teams and childbirth education efforts

The CHW was recognized by participants as an individual with shared life experience in whom to invest trust and confidence, who could provide both emotional and navigational support during pregnancy. To meet participant needs, CHWs should be members of the prenatal care team, and may also serve as doulas to pregnant women, providing care and support during their labor and post-partum care. By integrating CHWs into care teams, care for pregnant women can be extended beyond regular clinic visits.

With permission from the patient, CHWs can personalize care on a weekly basis through phone calls and/or brief home visits. These interactions will be spent identifying behavioral goals and coaching towards lifestyle changes, identifying non-medical barriers (transportation, childcare, housing, food, insurance, etc.), problem-solving to navigate those barriers, and helping the patient prioritize topics to discuss with their provider at

upcoming appointments. If desired by the patient, the CHW may also accompany them to prenatal appointments for support or to serve a more active role as an advocate for the patient during discussions with the provider. Familiarity with the needs and preferences of the individual patient will also inform CHWs in designing and leading educational workshops and support groups within the clinic setting.

# Group prenatal care support

For patients who are interested, shared prenatal visits offer pregnant women an opportunity to obtain both medical care and peer support during their pregnancy.

Facilitated by members of the prenatal clinic's care teams, group sessions will be spent performing appropriate health assessments before engaging in activities on health topics and discussion of concerns shared by the group. To insure the individual care needs of each patient are addressed, visits will also allot time for patients to meet one-on-one with their provider.

## Care Delivery

As a result of interactions within the healthcare delivery system not meeting their expected, participants expressed a need for improvement in communication and a change in the way they are engaged in care. Ideas about care delivery were further grouped based on 4 out of 6 domains in a framework on healthcare delivery systems proposed by the Effective Healthcare Stakeholders Group of the Agency for Healthcare Research and Quality: <sup>60</sup> patients, culture, care processes, and infrastructure (Table 2).

For low utilizers, there wasn't much discussion of ideas for improving care delivery or a consistency in subthemes among participants. Ideas for care delivery came primarily from high utilizers, who overwhelmingly wanted to feel heard and seen by their providers and experience more rational care: "Just listen to what I have to say. I'm telling you I'm in pain, I'm in pain. Oh man, as simple as that. Just listen. It's not even about pain, but I'm telling you, whatever I'm telling you really try to address the issue, don't just swipe me aside and log me in as one of your notes."

High utilizers' ideas for change centered around improving consistency and completeness in the way in which their health records are shared between inpatient and outpatient services. From their perspective, this would positively impact the care that they received in the ED or triage unit and at post-discharge outpatient visits: "And if the [ED] doctors are not communicating with the OB/GYN doctors — and I'm a patient here, so it's like, you have all my records. I've been here since birth. I've never been anywhere else... [I]n a matter of four hours...I've seen four doctors and not one helped me. They just kept on asking me the same question over and over and over again..."

High utilizers also expressed a desire to have their voices and opinions heard by their providers and taken into consideration when decisions about their care were being made. "...I feel like until today, that was the only doctor that has really listened to what I said and actually started on tests to what I was telling him versus trying to push me out." They also discussed wanting their test results and other medical information to be conveyed in ways that was easy to understand, and to leave each encounter feeling satisfied that their questions were answered. "...I have to go research it. [I]t wasn't

talked about. All... they do when I come into the hospital is – all your tests came back normal. What tests? Talk to me about the tests." Because of this, participants discussed often having to seek out medical information available through phone applications and web resources to make up for the lack of individualized care and advice they receive from their providers: "[A]ll your provider really does is tell you what's going and what you should and shouldn't do. Nine times out of ten, it doesn't always fit you, but you've got to take half of what they say and half of what you know and kind of put it together." Participants subsequently expressed an interest in having the option to integrate their care with existing electronic resources.

The four intervention features derived from participant ideas on care delivery below aim to improve communication and continuity while empowering pregnant women to have a more active role in their healthcare (Table 4):

*Implement a perinatal health information exchange system regionally* 

Information exchanges leverage technology so different parts of the health system can share information more easily. This requires agreements and shared technology between stakeholders but may help enhance communication and reduce waste and low-value care during the transition between inpatient, emergency, and outpatient settings, and across health systems.

Allow pregnant women to carry summaries of their own medical records

To meet participant requests of improving communication and sharing of medical information across sectors of the health system, we propose an intervention feature that allows use of cards or applications where patients can access parts or all of their own medical records, pregnant women can take their medical record with them. This offers increased sharing of health information with the patient and gives them a greater sense of being informed and involvement in their care. Additionally, it helps enhance communication of medical records when patients happen to utilize different parts of the health system.

Tailor clinic visits with patient checklists; use support people as communication aids

Provide patients with a list of important aspects of care that closely correspond to their gestational age at that particular visit. Patients can be encouraged to select topics they want to review during with their provider at this visit, and can write in additional topics or questions—this can be done alone or with a support person or care navigator. Providers will use the visit checklist as an agenda or guide to their discussion with the patient in the exam room.

Integrate smartphone applications into prenatal care

Given the existing availability and use of pregnancy smartphone applications

(apps) by patients, interventions that support direct integration of apps into prenatal care

can further enhance the content of information available to pregnant women. Prenatal

clinics may promote recommended apps to their patients and advise patients to discuss

with their provider and CHW how best to rely on the information the apps provide vs contacting the clinic with medical concerns.

#### Access

Participant ideas on access to care were analyzed using the Institute of Medicine's five A's to measure access<sup>24</sup>: availability, accessibility, accommodation, acceptability, and affordability (Table 2). Participants expressed a desire to centralize their care in the clinic, however, the existing structure of outpatient care scheduling often created impediments to doing so: "I guess it takes two or three weeks to get an appointment so if I have an issue I can't talk to them right away about it which is probably why I visited the ER so much." Appropriately, they wished for an increase in prenatal clinic provider supply to address issues of availability and accessibility while maintaining continuity in care. Participants suggested having more providers, extended clinic hours, or provision of walk-in prenatal services, which would create more opportunities to consult with their provider on medical concerns rather than seek emergency services.

Both high and low utilizers shared similar frustrations with accessing their providers through scheduled prenatal care visits. However, the narratives of high utilizers included more discussion of access barriers than did that of low utilizers, informing their ideas for change (Table 3). In particular, high utilizers expressed issues and ideas regarding scheduling flexibility and decreasing appointment wait times, while low utilizers focused solely on insurance coverage.

A few high utilizer participants expressed wanting to receive services equal in value to the time they have to wait to be seen: "... I might decide to not come to some

visits, because it can be frustrating, sitting here for hours, for them to take your blood pressure and measure your stomach." Though some participants associated high quality care with testing, including blood pressure monitoring and blood work, the context in which testing services were delivered played a role in their perceived acceptability of care. In this example, a lengthy wait time just to get tested was not acceptable.

Conversely, participants wanted their time spent in the exam room with the provider to be adequate and thorough: "I have literally met doctors who mispronounced their own name because they're talking so fast. And first of all, they're [keeping me waiting] 40 minutes for my appointment. Then they want to rush me five minutes. They don't listen. They don't take the time. I understand you're busy and the medical profession is crazy, but...that's how lives get lost and people mistake medication or... they get hurt." For participants, having enough time to make sure their concerns were completely addressed by their provider offered the greatest value to their visit.

Many low utilizers described affordability of care as a barrier to continuity. This group of participants discussed a need to address changes in insurance policies, fragmentation in coverage, and confusion or lack of knowledge of which services insurance does and does not cover as a means of assuring pregnant women remain plugged in to prenatal care. In advocating for insurance coverage that promoted prenatal provider continuity, one patient describes her encounter with changes in insurance policies during her pregnancy: "[A]nything can happen to me during my pregnancy and the first thing you want me to do is to run to the emergency room instead of having my regular visits...[T]hat's wrong...[to] just discontinue me because you all decided to

switch [insurance policy] during my pregnancy. At least I think they should have gave me the opportunity...[W]ho is going to take me 38 weeks into my pregnancy for a prenatal visit?" While some participants described being self-efficacious while navigating insurance barriers, others expressed feeling helpless and wishing they had someone in their clinic to help them navigate such situations. Overwhelmingly, both high and low utilizers felt that unrestricted access to obstetric care through unobstructed insurance coverage is an essential right that pregnant women deserve regardless of employment status or ability to pay.

Four intervention features emerged from participant ideas for change centered around the theme of access (Table 4):

Provide appointment slots for advanced-access scheduling

Providers at prenatal clinic can offer a percent of daily clinic appointments as same-day slots for advanced-access scheduling on a first-call, first-serve basis.

Incorporating this appointment type into the clinic will improve appointment wait times and waiting room times while maintaining provider continuity.

*Improve continuity and visibility of care teams* 

Upon intake into prenatal care, patients should be oriented to the members of their care team and the role they should expect each member to plan during their pregnancy.

Patients should be able to meet their care team members initially to discuss and align goals and regularly during the course of their prenatal care to facilitate the patient's

comfort in accessing other members of their team as a source of medical advice if their provider is unavailable. Efforts should be made to maintain outpatient prenatal provider continuity during pregnancy.

# Create a drop-in pregnancy support center

A drop-in obstetric center located in the community staffed by members of obstetric care teams (e.g., nurse, nurse practitioner, midwife, physician's assistant, CHW, doula, nutritionist, social worker, etc.) designed to provide a space for psychosocial and medical support for pregnant women after hours and on weekends.

# Health insurance screening, education, and enrollment

Upon intake into prenatal care, patients should be screened for insurance eligibility and guided through the plan enrollment process. Subsequently, patients should be provided with an overview of services covered by their plan and expectations for maintaining eligibility to prevent gaps in care and unanticipated co-pays. Health insurance education should be revisited with the patient on a regular basis as a means of communicating changes in policy or plan, and with the hope of detecting changes in eligibility in a timely manner.

*Table 1* – Demographic characteristics of pregnant high vs low utilizers of unscheduled care.

<b>Table 1</b> Demographic characteristics of pregn	Low Utilizers (n=20)	High Utilizers (n=20)	p-value
Age (mean)	25.0 years	25.5 years	0.75
Race			
African American / Black	19 (95%)	19 (95%)	1.0
Education			
Less than high school	4 (20%)	1 (5%)	
High school / equivalent	11 (55%)	11 (55%)	
Some college	5 (25%)	5 (25%)	
Collegiate / higher	0 (0%)	3 (15%)	0.07
Sexual orientation			
Heterosexual	19 (95%)	17 (85%)	
Bisexual	0	3 (15%)	
Lesbian	1 (5%)	0	0.23
Relationship status			
Single	7 (35%)	6 (30%)	
Dating	5 (25%)	5 (25%)	
Partnered and / or living with partner	6 (30%)	6 (30%)	
Married	2 (10%)	2 (10%)	
Separated	0 (0%)	1 (5%)	1.0
Insurance status			
Currently Insured	18 (90%)	19 (95%)	1.0
Insured Prior to Pregnancy	16 (80%)	12 (60%)	0.30
Parity			
Mean number prior births	1.65	1.15	0.35
Primiparous	6 (30%)	7 (35%)	0.74
Visit history			
Number unscheduled visits (mean)			
Self-reported at study visit	1.1	5.9	<.0001
In system by end of pregnancy	1.8	7.5	<.0001
Gestational Age at study visit (mean)	38.8 weeks	29.3 weeks	<.0001
Discharged after study visit	10 (50%)	16 (80%)	0.04
Obstetric Triage Acuity Score (mean)	3.05	3.70	0.07
Prenatal visits in system (mean)	5.4	9.2	0.01
Postpartum follow-up visit	7 (35%)	12 (60%)	0.11

Source: Previously reported by Mehta et al. in Mehta PK, Carter T, Vinoya C, Kangovi S, Srinivas SK. Understanding High Utilization of Unscheduled Care in Pregnant Women of Low Socioeconomic Status. *Women's Heal Issues*. March 2017. doi:10.1016/j.whi.2017.01.007.

*Table 2 – Participant-proposed ideas for improving prenatal care.* 

Theme	Domain	Subthemes
Social Support	Education	More education upon inpatient discharge to help ease concerns and prevent readmission.
		Enhanced pregnancy education, particularly for first-time mothers.
	Reassurance	Reassurance and encouragement to match patient's pregnancy experience.
	Goal-setting	Access to coaching and resources for achieving health goals and lifestyle and behavioral modifications.
	Navigating resources	Assistance with connecting to social support resources in and out of clinic.
Care Delivery	Patients	Individualized care to align with patient's prenatal needs and expectations.
	Culture	Patient-centered communication during patient-provider interactions.
	Care processes	Enhanced communication, continuity, and coordination between hospitals, clinics, and inpatient and outpatient services.
	Infrastructure	Integrate care with beneficial phone applications and web resources that patients already rely on.
Access	Acceptability	Shorter wait times for higher-value care.
	Accessibility	Alternatives to consulting provider for unanticipated concerns outside of scheduled visits, such as walk-in or drop-in services.
	Accommodation	Increased variety in timing of appointments offered.
	Affordability	Uninterrupted insurance coverage during pregnancy.
	Availability	Increased supply of timely appointments.

Source: Authors' analysis. The five measures of "access" are drawn from a model described by the Institute of Medicine in McLaughlin CG, Wyszewianski L. Access to care: remembering old lessons. *Health Serv Res.* 2002;37(6):1441-1443. The four dimensions of "care delivery" are drawn from a six-dimension model described by a subgroup of the Agency for Healthcare Research and Quality's Effective Health Care Stakeholders Group in Piña IL, Cohen PD, Larson DB, et al. A framework for describing health care delivery organizations and systems. *Am J Public Health.* 2015;105(4):670-679.

**Table 3** – Intervention ideas most important for pregnant high vs low utilizers of unscheduled care.

Theme	High Utilizer Group	Low Utilizer Group
Social	Enhanced patient education upon	Support services should be optional/for
Support	discharge.	those who desire to participate.
	More individualized support with navigating resources outside of clinic.  Coaching to achieve health goals.	
	Desire to connect with peers.	
Care	Efficient communication between	N/A
Delivery	providers and between different sectors	
	of the healthcare system.	
	Improved communication during patient-provider interactions.	
Access	Improved appointment access (i.e.,	Stable insurance coverage during
	greater scheduling flexibility and	pregnancy.
	reduced appointment wait times).	

Source: Authors' analysis.

*Table 4* – *Proposed intervention features based on participant ideas for change.* 

Theme	Intervention Features	Intended Outcomes
Social Support	<ul> <li>Integrate CHW into care teams and existing childbirth education.</li> <li>Connect patients with social services resources.</li> <li>Group prenatal care support.</li> </ul>	<ul> <li>Increased understanding of where to find support in the medical setting and how to use the support available.</li> <li>Improved self-efficacy in achieving health goals.</li> <li>Decreased isolation.</li> </ul>
Care Delivery	<ul> <li>Health information exchange.</li> <li>Prenatal cards or applications.</li> <li>Visit checklists.</li> <li>Integrate technology already in use.</li> </ul>	<ul> <li>Increased care coordination.</li> <li>Increased engagement and satisfaction with care.</li> </ul>
Access	<ul> <li>Advanced access scheduling.</li> <li>Enhanced care team visibility.</li> <li>Drop-in pregnancy support center.</li> <li>Insurance screening and enrollment.</li> </ul>	<ul> <li>Decreased scheduling frustrations</li> <li>Increased use of scheduled outpatient care.</li> <li>Decreased reliance on ED and triage services.</li> <li>Reduced care fragmentation.</li> </ul>

Source: Authors' analysis.

#### **DISCUSSION**

Through a secondary analysis of existing research, this paper aims to use patient perspectives to propose interventions that may improve prenatal care delivery for low-SES, Medicaid-insured pregnant women. The themes identified reflect the barriers pregnant women face in navigating the existing care system and corresponding ideas they have proposed for improving the care they receive. It has been established that that high utilizers of unscheduled care have higher unmet needs. We see from our results that they also have different ideas for what their prenatal care can look like in order to address these needs.

We found that compared to low utilizers of obstetric triage, high utilizers proposed greater integration of peer support and reassurance into care. High utilizers also emphasized a need for improved communication between different sectors and providers in the healthcare system. They were skeptical of CHW accompaniment or home visits, however, they were still open to the idea as long as clear boundaries could be respected. On the other hand, low utilizers showed less openness to CHW involvement. Thus, although both groups expressed a desire for increased access to the healthcare system and improved care delivery, high utilizers demonstrated a greater need for support and reassurance.

It is interesting that our results show that high utilizers are more willing to integrate support into their care delivery, despite demonstrating greater distrust in the healthcare system and in their personal lives. However, given that high utilizers disproportionately report adverse childhood experiences and psychosocial vulnerability

during pregnancy,<sup>48</sup> their desire for a more robust support system during pregnancy is logical. This demonstrates the importance of incorporating patient perspectives into intervention design as a means of achieving a patient-centered medical home. Literature also describes a relationship between social support and trauma that is mediated by mental distress.<sup>61,62</sup> This relationship encourages a need for more intense support for this subgroup. Low quality of life and mental distress induced by trauma may be remedied by improvements in perceived social support and coping skills. The most vulnerable women in our society may benefit from earlier traditions of social childbirth and midwifery – communities of women providing therapeutic support, both physical and emotional, to one another during pregnancy, delivery, and postpartum.<sup>63</sup> This study provides several intervention strategies that health systems can consider implementing to address unmet needs in subgroups of vulnerable pregnant patients.

Findings from this study may help health systems improve health care delivery for low-SES pregnant women, particularly through the expansion of our limited understanding of the patient care needs of pregnant high utilizers of care as a specific subgroup. As expected, our participants endorsed significant psychosocial needs, illness, histories of trauma, and isolation, yet these needs are not necessarily addressed or prioritized by the current Medicaid-funded prenatal care delivery system. We already know that there is a strong association between high utilization of unscheduled care during pregnancy and increased risk of depression, 64 characteristics of high prenatal distress, 37 and the presence of several other psychosocial barriers and risk factors. 48 These

results prompt a need for interventions that address psychosocial needs for at-risk pregnant women.

Evidence supports the role of CHWs as effective in helping improve health outcomes for low-SES populations.<sup>65</sup> Evidence also indicates the cost-effectiveness of CHW care: despite introducing an increase in labor costs, improved obstetric outcomes associated with CHW support may reduce the overall cost of care.<sup>66,67</sup> CHWs offer support from someone ideally from a background similar to that of the patient, who understands their culture or community given shared life experience. It is important to point out that though the CHW can be an effective and integral part of a patient's care team and engagement with them is encouraged, the services they offer should be presented as optional, adjustable aspects of care in order to respect patients' boundaries and levels of comfort and preparedness for attachment.

## **New Delivery Models for Medicaid-funded Prenatal Care**

The need for non-traditional approaches to prenatal care delivery is reinforced by a failure of improved prenatal care utilization to be followed by corresponding decreases in adverse outcomes.<sup>68</sup>

Recent interest in developing alternative prenatal care delivery models to improve birth outcomes for women enrolled in Medicaid through the *Strong Start for Mothers and Newborns* initiative has introduced research on centering/group prenatal care, birth centers, maternity care homes, and home visitation as non-traditional approaches to prenatal care.<sup>69</sup> In randomized controlled trials, CenteringPregnancy<sup>70</sup> has demonstrated

reduced rates of poor reproductive and obstetric outcomes and increased positive perceptions of care received, particularly in Black women.<sup>71,72</sup> Prenatal care coordination through home visits performed by CHWs, whether alone or as a member of a nurse-CHW team, lead to a significant increase in services delivered and patients engaged,<sup>73</sup> resulting in reports of improved psychosocial support<sup>74</sup> and decreased rates of low birthweight.<sup>75</sup> Similarly, state Medicaid programs that provide community-based doula care have seen a reduction in rates of preterm delivery and caesarean delivery of full-term births when pregnant women utilize the service.<sup>66,76</sup>

Though all models show potential to reduce healthcare costs, they are inconsistently implemented and funded, and tend to be available to low risk rather than high risk patients. A reformed prenatal care delivery system that offers tiered models to match maternal risks factors and patient preference may enhance care delivered, improve outcomes, and reduce avoidable healthcare costs. 68,69,77 For instance, home visitations and group prenatal care for women with high-risk pregnancies and psychosocial risk factors, respectively, are more appropriate and cost-effective alternatives but may be best implemented in segments, not to all, of the pregnant population. 68,71-75 Likewise, integrating care with resources patients already find comfortable and familiar could be a cost-effective approach to enhancing prenatal care and subsequent obstetric outcomes. An example of such a resource is technology, since the use of the internet and smartphone applications has been reported by pregnant women to be beneficial in obtaining information to fill gaps in what they receive from their prenatal care

Patient perception of a lack of social support is known to be strongly associated with greater distrust in their provider and the healthcare system. Ro-82 This presents an opportunity to benefit from interventions that enhance support systems in the care setting. However, more research on how patients who demonstrate less trust can benefit from social support is needed. Specifically, future research should assess how non-traditional models of prenatal care that emphasize social support, such as CenteringPregnancy, impact the care received by and subsequent obstetric outcomes for pregnant women who are high risk.

#### Limitations

A limitation of this study is a small sample size, which limits our ability to generalize or transfer our findings to a broader patient population or distinct subpopulation. Additionally, participants were preferentially prompted about certain intervention strategies by a community health worker, perhaps creating social desirability bias.

# **Implications for Practice and Policy**

Our study offers the opportunity to tailor and adapt intervention design to meet the specific needs of a hard-to-engage patient population. The results from this study demonstrate a need for alternatives beyond traditional prenatal care for low-SES pregnant women. Evaluating the needs and ideas of patients in order to determine appropriateness of potential interventions is a valuable step in doing so. For example, though a visiting

nurse program has been shown to improve prenatal care engagement and pregnancy outcomes, 83–85 this is not the case for a key subgroup: mothers managing significant psychosocial burdens. 73,86–88 Here we see that large-scale interventions may have a variable impact. These findings further support the need to use patient perspectives in creating quality, rigor, and individualization in social support programming in the healthcare system, and highlight the importance of patient satisfaction in achieving a patient-center medical home.

The intended outcome is for healthcare delivery systems to implement some of the intervention strategies proposed in this paper based on their patients' needs and available resources. Future health policy and program planning efforts should consider these elements in reducing disparity in rates of maternal morbidity and mortality. Though we will never know if such an approach could have made a difference for patient NF, healthcare systems should not miss future opportunities to incorporate patient perspectives into system-level approaches to improve care for particularly vulnerable pregnant patients.

## **CONCLUSION**

This study describes the use of a qualitative study design to develop patient preapproved innovation to improving prenatal care delivery. Given the need to address
persistent disparities in maternal outcomes, this approach allows the experiences and
perspectives of those patients acutely affected – Medicaid-insured pregnant high and low
utilizers of unscheduled obstetric care – to guide how we think about solving issues
within our existing healthcare system. In doing so, we gain a better understanding of the
gaps that exist in care that may be associated with poor maternal outcomes, and which
solutions would best be received by the patients they are intended to help.

## LIST OF JOURNAL ABBREVIATIONS

Acad Emerg Med Academic Emergency Medicine

Am J Emerg Med American Journal of Emergency Medicine

Am J Manag Care American Journal of Managed Care

Am J Med American Medical Journal

Am J Obstet Gynecol American Journal of Obstetrics & Gynecology

Am J Public Health American Journal of Public Health

Anesth Analg Anesthesia & Analgesia

Appl Nurs Res Applied Nursing Research

BMC Health Serv Res BMC Health Services Research

BMC Nursing

BMC Pregnancy Childbirth BMC Pregnancy & Childbirth

Clin Obstet Gynecol Clinical Obstetrics & Gynecology

Contemp Clin Trials Contemporary Clinical Trials

Curr Opin Obstetrics Gynecol Current Opinion in Obstetrics & Gynecology

Emerg Med J Emergency Medicine Journal

Health Aff Health Affairs

Health Serv Res Health Services Research

Int J Public Health International Journal of Public Health

Issues Ment Health Nurs

Issues in Mental Health Nursing

J Adv Nurs Journal of Advanced Nursing

J Am Hist Journal of American History

J Am Med Assoc Journal of the American Medical Association

J Cutan Aesthet Surg

Journal of Cutaneous & Aesthetic Surgery

J Gen Intern Med Journal of General Internal Medicine

J Health Commun Journal of Health Communication

J Matern Neonatal Med Journal of Maternal-Fetal & Neonatal Medicine

J Med Internet Res Journal of Medical Internet Research

J Midwifery Womens Health Journal of Midwifery & Women's Health

J Natl Med Assoc Journal of the National Medical Association

J Obstet Gynecol Neonatal Nurs Journal of Obstetric, Gynecologic, & Neonatal

Nursing

J Palliat Med Journal of Palliative Medicine

J Perinatol Journal of Perinatology

J Psychosom Obstet Gynaecol

Journal of Psychosomatic Obstetrics &

Gynecology

J R Coll Physicians Edinb Journal of the Royal College of Physicians of

Edinburgh

J Racial Ethn Heal Disparities Journal of Racial and Ethnic Health Disparities

J Women's Health Journal of Women's Health

Matern Child Health J Maternal & Child Health Journal

Med Care Medical Care

Med Care Res Rev Medical Care Research & Review

Obstetrics & Gynecology

Paediatr Perinat Epidemiol Paediatric & Perinatal Epidemiology

Pediatr Emerg Care Pediatric Emergency Care

Popul Health Management Population Health Management

Public Health Nurs Public Health Nursing

Public Health Reports

Public Health Reports

Qual Health Res Qualitative Health Research

Semin Perinatol Seminars in Perinatology

Soc Sci Med Social Science & Medicine

Women's Heal Issues Women's Health Issues

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# **CURRICULUM VITAE**







