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How do pregnant women and new mothers navigate and respond to challenges in accessing health care? Perspectives from rural South Africa

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ABSTRACT

Women in low- and middle-income countries and in contexts characterized by inequality face various interpersonal and structural barriers when accessing formal maternal and child health (MCH) services. These barriers persist even in contexts where programs to increase access to services, such as community health worker (CHW) interventions, have been implemented. However, while barriers to accessing care have been extensively documented, less is known about the diverse ways that women respond to, and navigate, these situations. This study explores strategies pregnant women and new mothers use to navigate and respond to health care barriers in a rural district in the Eastern Cape, South Africa. Twenty-six pregnant or recently delivered clients of the Enable Mentor Mother program were interviewed about their experiences of accessing formal MCH services. Interviews were conducted between February-March 2018 by an experienced isiXhosa-speaking research assistant, translated and transcribed into English, with transcripts coded and organized by themes using ATLAS.ti software. Facing resource shortages, inconsistent communication, and long travel times to clinics, participants employed diverse, innovative strategies to navigate interpersonal and structural barriers to care. While some participants chose to respond to barriers more passively—citing endurance and acceptance as practices of health system engagement—those participants who focused more on active responses tended to leverage their education, existing relationships, and available community resources to overcome barriers. Nevertheless, most participants described feelings of frustration and dejection. While CHW interventions may alleviate some of the burdens facing fragile health care systems in these contexts, these programs still rely on an underlying infrastructure of care that primary health care clinics and hospitals should be providing. Future programming should work in tandem with formal health systems and should support staff to improve quality of care provided to pregnant women, new mothers, and their infants to prioritize their health at a time of vulnerability.

1. Introduction

The perinatal period is a time of vulnerability for women and their infants that requires comprehensive, attentive health care to protect against risks to maternal and infant morbidity and mortality (Graham et al., 2016). Maternal and infant wellbeing is as much an individual as it is a societal imperative; the ability to seek and receive adequate health care during this life stage is central to promoting healthy development and enabling women and their families to flourish (Stenberg et al., 2014). Recently, global priorities have aligned to advocate for mothers and children during this critical time; the Nurturing Care Framework (Organization, 2018a), Sustainable Development Goals (Le Blanc, 2015), and drive for Universal Health Care (Ji and Chen, 2016) all contain provisions for improving outcomes for maternal and neonatal populations, especially in low-income settings. However, the poorest, most marginalized women often have negative experiences accessing health services, with health inequities impeding access to quality care (Finlayson and Downe, 2013).

Pregnant women and new mothers in low- and middle-income countries (LMICs) face significant barriers to accessing care, in both individual and structural domains, and may struggle to respond to these barriers in effective ways (Guliani et al., 2013; Langlois et al., 2015). On

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an individual level, health education and influences of social and family networks may drive how, when, and with what frequency pregnant women seek care (Binder-Finnema et al., 2015; Kifle et al., 2017; Munguambe et al., 2016; Scheffler et al., 2015). Interpersonal interactions also shape individual experiences of care, for example, how women are regarded and treated by health providers. A systematic review of interactions with maternal health care providers in LMICs, including doctors and nurses, found that negative attitudes and experiences outweighed positive ones and adversely affected patients' wellbeing and willingness to seek care (Mannava et al., 2015). Structural factors, such as infrastructure, transport affordability and availability, sufficient resources and medical supplies, and household vulnerability can also determine whether women are able to access care, and what these experiences are like (Abrahams et al., 2001; Puett et al., 2015). Women have highlighted the importance of structural factors in shaping their satisfaction with maternal and child health (MCH) care (Srivastava et al., 2015).

For pregnant women and new mothers living in remote, rural settings, these challenges can be heightened. At an interpersonal level, the quality of care received at rural health facilities may be poor. Rural health providers have reported demotivation, dissatisfaction with rural postings, and high stress about resource limitations—resulting at times in what they acknowledge as poor treatment of patients (Melberg et al., 2016; Prytherch et al., 2013; Thi Hoai Thu et al., 2015). From patients' perspectives, a lack of mutual trust and experiences of mistreatment and abuse during health visits, including delivery, create a similar sense of dissatisfaction with services and reduce motivation to seek care, especially amongst the most vulnerable women (Adatara et al., 2019; Bohren et al., 2019). Structural challenges also persist. A study in rural Ghana highlighted difficulties that women faced in obtaining vehicular transport for MCH care, in large part due to location and poor road networks, leading them to opt for less safe transport or care options (Atuoye et al., 2015). In Liberia, increases in distance from a health care facility were found to have a direct, negative relationship with uptake of MCH care-seeking, predicting varying levels of engagement by rurally-based women (Kenny et al., 2015).

1.1. Responding to barriers to care

While these diverse challenges to seeking and receiving maternal health care have been well documented across LMIC settings, knowledge about responses to these barriers is limited. Some community-based efforts, such as women's groups, have shown promise in building capacity and sharing information (Morrison et al., 2010), and pairing savings initiatives with health education and social support (Shaikh et al., 2017). Community loan funds to facilitate maternity transport have also been found to have positive effects on facility-based deliveries, emergency access to care, and general uptake of health services (Ekirapa-Kiracho et al., 2017; Nwolise et al., 2014). On a more widespread scale, community health worker (CHW) programs may be able to improve linkages to care through educating and empowering clients and establishing communication channels and referrals systems (Lewin et al., 2010).

However, there is less evidence on how women individually navigate these complex multi-level barriers to accessing health care, at both interpersonal and structural levels. In settings where gender roles are clearly defined, or where men are working away from their homes, women alone may bear a greater responsibility for childcare, which includes accessing health services during pregnancy and following birth (Bougangue and Ling, 2017). The individual perspectives of these women can provide important insights into how pregnant women and new mothers experience the process of accessing care, and how their right to health care is being met or prevented. The strategies and solutions that these women devise can also provide a foundation for how government and other service providers tailor their care and craft appropriate responses (Kornelsen and Grzybowski, 2006). While many women face constraints related to poverty and marginalization, they employ diverse responses to health care barriers.

This study presents findings from the rural Eastern Cape in South Africa about how pregnant women and new mothers navigate and respond to challenges in accessing health care during the perinatal period.

2. Methods

This study employs a qualitative research method, and was part of a larger study evaluating the Enable Mentor Mother program aimed at improving maternal and child health and nutritional outcomes amongst vulnerable households. Ethical approval was granted by the Health Research Ethics Committee at Stellenbosch University (N16/05/062).

2.1. The Enable Mentor Mother model

The One to One Children's Fund established the Enable Mentor Mother program in 2016 as the first "social franchise" of the Philani Mentor Mother home visiting model (further referred to as Philani). Philani first launched its program to address maternal and infant mortality and malnutrition in a peri-urban area outside Cape Town in the early 2000s. Enable's social franchise transported this model to a new rural area, under new management, with continued support from Philani (Laurenzi et al., 2019; Rotheram-Borus et al., 2011). Enable's Mentor Mother model looks for women who may be "positive peer deviants"—caregivers who have managed to raise healthy children despite adverse circumstances. Potential Mentor Mothers are identified by traditional or other community leaders, as well as through advertisements. After submitting curricula vitae, a subset of applicants are selected to participate in a six-week training with experienced trainers. Training includes content on building client relationships, antenatal and postnatal care and nutrition, infant care and nutrition, HIV/AIDS, and social support. Trainees are invited to become Mentor Mothers based on their geographic location, and if they successfully pass a written examination at the end of training. Mentor Mothers work in their own communities, identifying and enrolling pregnant women and malnourished children, and deliver health education, support, and referral services to clients in their homes. Fourteen Mentor Mothers were recruited into Enable's first cohort in 2016, and one subsequently was promoted to a supervisory role, leaving 13 Mentor Mothers working in the original program areas.

2.2. Setting

Enable's Mentor Mother program operates in a remote and rural part of Nyandeni Municipality (population 290,320) in South Africa's Eastern Cape Province (estimated population 6.5 million) (Statistics South Africa, 2011, Statistics South Africa, 2018). While South Africa's health system is characterized by stark differences in access and quality, the former "homeland" areas of the Eastern Cape have particularly poor health care outcomes. Nyandeni is situated within one of these areas, in the O.R. Tambo district, which has a maternal mortality rate well above the national rate (196.9 deaths per 100,000 live births, compared to the national 116.9) (Le Roux et al., 2015; Massyn et al., 2017). The O.R. Tambo was among the top 10 districts with the highest proportion of facilities reporting a medicinal stockout in 2017 (StopStockouts, 2017). Nyandeni Municipality has the lowest district-wide rates of early antenatal visit booking, with more than a third of pregnant women not completing antenatal visit before 20 weeks (Massyn et al., 2017). However, its inpatient early neonatal death rates are also well below the national average.

2.3. Recruitment

Participants were pregnant women or new mothers who had been

enrolled in the Enable Mentor Mother Program and were clients of one of Enable's 13 Mentor Mothers. To ensure a variety of different perspectives on the program and allow for geographic variation, an equal number of clients per Mentor Mother (n = 2) were purposively sampled from each Mentor Mother's caseload, which contained, on average, 30–35 maternal cases. The first author, CL, also checked that client characteristics varied by age and number of prior children. In cases where a potential participant was unreachable by phone, unavailable, or uninterested in participating, a backup participant sharing the same Mentor Mother was contacted instead. A number of clients initially contacted were temporarily working away from home (n = 3), were uninterested (n = 1), or were unreachable by the interviewer (n = 8) due to mobile network issues or a change to their contact number, requiring a backup participant to be contacted instead to reach the intended number of clients.

2.4. Data collection tools and procedures

Interviews were conducted from February–March 2018 by an isiXhosa-speaking research assistant, VN, with extensive experience conducting qualitative interviews. Interviews were guided by a semi-structured interview schedule. CL and VN met to discuss each question on the interview schedule to eliminate instances of ambiguity and revise the schedule for simplicity and clarity. The interviewer contacted potential participants, scheduled interview times, and visited each participant to conduct the interview in her home. The interviewer obtained written informed consent from all of the participants. Further, all of the interviews were conducted in participants' first language, isiXhosa. Throughout the two-month interview period, CL and VN discussed progress 3–4 times weekly, including individual interview highlights and challenges. Interviews were audio-recorded with permission from the participants. Interviews were, on average, 1 h each, with most interviews falling between 45 and 90 min' duration.

2.5. Transcription and translation

Interviews were transcribed verbatim and translated from isiXhosa into English. Transcription took place between April–October 2018. Two experienced isiXhosa-speaking transcribers listened to the audio recordings of the interviews, and transcribed the interview content using MS Word, translating directly into English. In some cases, specific words were left in isiXhosa to preserve their meaning (for example, traditional Xhosa beliefs/concepts about pregnancy). Alternative definitions were given as appropriate. A senior isiXhosa-speaking member of staff quality checked 50% of the transcripts for accuracy and determined them to be of high quality.

2.6. Ethical considerations

During informed consent procedures, the interviewer ensured that privacy and confidentiality were discussed, and that participants understood how their information would be used and were given the opportunity to ask questions. All consent forms were anonymized using a unique participant identifier, and this identifier was also used to label audio recordings, transcriptions, and data analysis files. The audio recordings were removed from the recording devices at the end of each day; they were first stored on a password-protected laptop in a locked room at the research site in Mankosi, filed by date completed and participant identifier, and later transferred to a cloud-based folder. This folder was used to securely transfer and complete the transcription and translation processes. Referral mechanisms were established in case of participant distress or additional challenges identified by the interviewer, but did not have to be utilized during the course of fieldwork.

2.7. Data analysis

Data were coded and organized using ATLAS. ti qualitative software. All transcripts were read and coded with a specific focus on data related to experiences of accessing health care, challenges in accessing care, and responses to these challenges, using an inductive coding method. While participants were interviewed as part of a larger study to explore their engagement with and perceptions of the Enable program, their experiences of accessing health care emerged as important aspects of these interviews. From an initial list of 98 codes inductively generated from the full participant interviews, 14 codes specifically related to accessing health care. Interviews were re-read with a closer focus on this particular aspect of the data, and an additional 14 codes were identified; thus, 28 relevant codes were ultimately identified regarding these experiences, challenges, and responses. This final code list was shared with a second coder, SG, who read and coded three transcripts. Double-coded transcripts were compared to ensure consistency. Themes and sub-themes, discussed with co-authors, were generated from grouping similar types of barriers and responses together.

3. Results

A total of 26 participants were interviewed between February and March 2018, representing two clients per Mentor Mother. Participants' mean age was 26.9 years (SD = 5.77), eight were married (30.8%), and 10 were first-time mothers (38.5%). 57.7% of participants had been enrolled in the Enable program during its first six months operating in Nyandeni (July–December 2016). The 28 codes identified in the interview transcripts were grouped into 2 themes and 4 sub-themes (Table 1). The majority of participants described accessing health care at one of two government clinics in the local area.

3.1. Responding to interpersonal barriers to care

Discussing interpersonal interactions in clinic settings, predominantly with facility staff, participants described a lack of communication that they had come to expect, and accept, as well as poor quality care tied to resource shortages and inconsistent procedures at clinics.

3.1.1. Passivity and acceptance in interpersonal interactions with health care staff

Participants were mindful of tacit patient-provider hierarchies as they spoke about adopting passive strategies to maximize their chances of being treated in a timely way, or at all.

PID2: I keep quiet …

Interviewer: Mmm, are you afraid?

PID2: No, I'm not afraid, but I just want them to help me … Because if I can express myself, I might go back [home] hurt … I have to wait.

She later continued:

If you go there, you must be calm and relax, because you would feel like they are not paying attention to you because you are so many, others came for their own problems … then you don't have to rush them, you must wait for them.

Table 1
Themes from participant interviews.

1. Responding to interpersonal barriers to care
1.1 Passivity and acceptance in interpersonal interactions with health care staff
1.2 Navigating interpersonal interactions more assertively
2. Responding to structural barriers to care
2.1 Frustration and hurt from repeated systemic failings
2.2 Troubleshooting and planning ahead

Returning home "hurt," at not having been treated at all, was something that other participants raised concerns about. To some women, acceptance or "endurance" was part of the process of receiving care:

They do shout at us, but since we are women we endure, just if she is shouting at you but doing it for you (PID21).

While participants articulated the challenges and mistreatment they encountered, and the consistent frustrations experienced during clinic visits, they also chose to defer to health care providers and wait their turn.

Some participants adopted a more accepting approach to barriers to care, sharing various reasons for this decision. Often, they attributed poor interpersonal engagement from health staff to larger health systems issues that those staff faced. Participants said they fully expected clinic visits to be a daylong commitment, and some explicitly lamented "*there is nothing you can do*" (PID11). Most participants' days began with time-intensive travel to the clinic, "*then when you get there, you sit for long and be told to wait, wait, and wait, you will be waiting for long*" (PID20). Some participants accepted the limitations facing their clinics and staff, sharing a degree of sympathy once these challenges were communicated to them. Noting that clinics tend to be out of stock on a regular basis, one participant noted:

PID25: They say … but, shame, they do explain to us, they say that they order treatment while they still have [it] in stock and then it would delay, a day or 2 weeks or 3 weeks without it.

In other cases, health providers were less communicative and less systematic. Another participant described how nurses operating alone often had to choose one group to start with:

Maybe a nurse may come, for example the one that works with children. She weighs, she immunizes and does antenatal care all alone, then maybe the nurse would say "no I'm going to start with those who are pregnant, new mothers must wait" or say "I'm going to start with new mothers." Clinic procedure does not depend on time, it does not matter even if you woke up in the morning or not (PID3).

The act of showing up at the clinic did not guarantee that an individual would receive care; participants mentioned that this was often left to chance, or just "how things work," and indicated that there was limited action they could take to change this situation.

3.1.2. Navigating interpersonal interactions more assertively

3.1.2.1. Empowerment and education as important tools. Other participants adopted responses that were more direct, electing to resist or make their voices heard, and spoke about the impact of education and awareness of their rights. A young mother who spoke of nurse mistreatment shared:

They [nurses] have that belief of they can treat people in any way, the way she likes …. You would find out that some people are not able to oppose what they are saying. So when I grew up, I realized that I cannot tolerate that (PID11).

This approach was not common for most participants, and this particular woman cited her higher education and self-confidence as playing a role in advocating for her own health needs. Other experiences illustrated participants' sense of empowerment in clinic-based interactions based on routine home visits with their Mentor Mothers.

PID18: The difference is, sometimes when they are telling me something at the clinic, they tell me things that I know already [from my Mentor Mother] …

Interviewer: Okay, so you go there already with your information?

PID18: Yes.

To some, having the additional support of a Mentor Mother became a way to better understand the information given to them at clinic, and also equipped them with information that they might use to question and engage health workers. This participant spoke about complaining to a nurse about being overlooked, and noted: "*Obviously, it can't be not heard when you are angry*" (PID18). Participants' communication strategies also included drawing attention to urgent health needs, especially in cases when the health facility staff was taking a break:

You must shout if your child is not okay … up to a point [where] even someone who is passing by the road can hear (PID1).

Drawing on their own education and tested strategies, as well as on additional Mentor Mother support, participants described assertive strategies for being helped.

3.1.2.2. Special relationships as a means to receiving care. Other participants indicated that the best way to access care was through being "*known by*" (PID18), or "*hand in hand*" with a nurse (PID2). Seeing a system that did not serve its patients equally or with care, these participants stated that existing personal relationships with clinic staff sometimes worked in patients' favor, having experienced this personally or observed it with other patients. Additionally, as clients of the Enable program, some participants described the tangible impact of having a Mentor Mother to facilitate referrals for special cases. One participant said, of her Mentor Mother, *"you cannot end up dying in her presence"* (PID2), indicating that having a Mentor Mother meant having access to necessary care and attention regarding important health needs. Having a referral in-hand often meant readier access to care for participants.

Interviewer: When [your MM] writes you this letter, does it help you when you go to the clinic? For example, the nurses—are they not saying, "where did you get this letter?" and so on and so forth?

PID12: No, they would look at it and ask which Mentor Mother gave me this … who gave me this, and I would tell them I got it from my Mentor Mother called [MM name], then it would be signed, then they would ask me about the pains I am feeling.

The additional support and treatment that participants cited—whether through nurse familiarity with Enable, or through personal connections—conferred a sense of empowerment, enabling them to access further channels for recourse when facing routine health barriers.

3.2. Responding to structural barriers to care

In addition to sharing interpersonal challenges during clinic visits, participants described substantial barriers to receiving quality care related to structural shortcomings.

3.2.1. Frustration and disappointment from repeated systemic failings

Many participants shared feelings of disappointment, as well as diminished motivation to seek health care, after not receiving adequate services. Structural barriers, such as 2-h trips on foot to the nearest clinic, compounded these systemic failings. Speaking about medicinal stockouts, a participant labeled these regular occurrences as displaying "*carelessness from the government*," asking, "*they know the life of that person depends on that treatment, so how can they not have treatment?*" (PID25). These responses were exacerbated when participants took initiative by keeping track of required immunization dates, or had an ill child needing medicine, and were not sure whether or when they would be able to afford a second trip (PID17).

You just feel disappointed, having no interest to get back there again, because even that time you will be going there to check, not knowing if [immunizations] are available (PID6).

Participants also spoke about feeling unrewarded for their efforts such as taking a day off work to attend clinic for her child's immunizations:

When I decided to go on that day, I would have told myself that day is for the clinic … maybe I would be busy on the day they say I must go [return again], it is worse [harder] that I am here [working] at the creche now, I would have asked permission for that certain day (PID7).

Participants also conveyed how these experiences restricted their choices, or their ability to act in their own or their child's best interests. While stockouts were common reasons for not receiving needed care, participants who required more comprehensive clinical care also struggled to move between facilities because of lack of funds:

I do not want to lie, it was when I was still pregnant, I was in pain, I went to the clinic and when I got there, they wrote me a letter to go to [the hospital] and I did not have money to go … I came back home sister, I did not go because I was borrowing money and I was not getting [earning] money and there is no other way because from here to [the hospital], it is R20. So I couldn't, sister, because of that (PID10).

Another participant spoke about "*just losing power*" from repeatedly frustrating experiences, which made her less inclined to attend the next given date; she explained that she might, in response, take her time and "*go there on my own date that came to my mind*" (PID21). Some participants relayed stories—their own or their neighbors'—when they did finally attend clinic after a scheduled visit and were summarily reprimanded for their tardiness.

3.2.2. Troubleshooting and planning ahead

While many participants took stockouts and onwards referrals personally, there were other participants who sought to circumvent structural challenges in other ways. They adopted problem-solving approaches, focused on preparation with the understanding that many other aspects of seeking care were out of their control. To ensure they were able to return to clinic when it was next required, participants found various ways to set aside money for transport:

If I know that this week is my appointment date … I keep the money for myself, know that I have this date, on the 15th I need to go to the clinic. If perhaps if I had money on the 12th, I will keep it for myself, then I will go to the clinic with money for lunch and travelling (PID26).

Another participant said that she sometimes relied on her mother to help her cover the cost of clinic trips (PID14). While not every participant was able to problem solve in these ways, these women were able to improve their odds of receiving much-needed preventative care by having some social support as a means to gain important access to financial and emotional support.

Facing recurring stockouts, some participants spoke about adopting more flexible approaches: stocking up on essential medicines from the pharmacy, or linking with other neighbors to procure medicines. Often, these experiences were communicated as hypotheticals to the interviewer:

Sometimes if my child is sick now … and the clinic is far away when I'm here, there is no transport and I'm here … what am I going to do? I have to take those medicines and help her in the moment (PID24).

Walking through a set of options, another participant described her reasoning:

PID26: If there are no medicines this week, you will stay and come back another week or buy yourself at the chemist [pharmacist].

Interviewer: If you don't have money for chemist?

PID26: If you don't have money for chemist, there is a[nother] clinic this side … We also go there, however they don't run out of them for long time here, they have them, but when they happen not to have them, we cross to that clinic.

Citing how far town was, another participant said if she were desperate to get her child's medicine, she would ask a neighbor or acquaintance headed towards town to help (PID3).

Lastly, relying on community networks in a different way, participants spoke about using their Mentor Mothers as a communication channel to access care more readily. One participant noted that if a mobile clinic was scheduled to be in her area, her Mentor Mother would phone her or her husband and indicate what time they should be ready and where they should go to improve chances of her baby receiving timely immunizations (PID5). Having a Mentor Mother to both inform and motivate this participant allowed her to access alternative forms of health care more easily.

Although participants were not able to fundamentally change the nature of the problems they faced, they shared methods for coping in ways that increased their chances of better health outcomes.

4. Discussion

The barriers and challenges that pregnant women and new mothers face in accessing care have been well documented in LMIC settings; however, less is known about how women respond to these challenges. We set out to understand the health access experiences of pregnant women and new mothers in a remote, rural part of South Africa—and more importantly, to gather perspectives on how they individually navigate and respond to barriers to health care access. Participant responses at both interpersonal and structural levels reflected diverse modes of navigating persistent barriers, yet also revealed an ongoing struggle to maintain motivation in the face of these challenges.

These findings illuminate the extent to which individual women engage in a broad range of strategies to cope and maintain dignity in the face of a health system that does not consistently serve them. They reflect similar themes to the case stories presented by Eyles et al. (2015), where South African health-seekers and providers alike detailed narratives of endurance, resilience and resistance (Eyles et al., 2015). However, importantly, our findings also expose a level of exhaustion, disenchantment, and lack of trust in an institution established to provide equitable care in addition to (and in spite of) participants' navigating and strategizing. As ongoing global initiatives attempt to improve the quality of maternal and newborn care, as a means to ensure dignity and equity for all women (Organization, 2018b), these considerations are even more important. By paying attention to what women are already doing in this realm—to weigh their best chances of accessing services, and being seen and treated—we can begin to understand the complexity of their experiences and how to best frame policies for improving equity.

Other recent literature from South Africa helps put these findings in context. Passivity in patient-provider interactions is common in a traditional, paternalistic model of medicine (Kaba and Sooriakumaran, 2007). Such interactions are commonplace in rural settings in South Africa in particular, and may be driven by a lack of external or community-driven accountability mechanisms (Berlan and Shiffman, 2011; Cleary et al., 2013), poor supervision and leadership to drive quality care (Maphumulo and Bhengu, 2019), health worker burnout (Khamisa et al., 2017; Nesengani et al., 2019), and low health literacy (Safiya et al., 2009). For rural women, especially in the former "homelands", hierarchies between patient and provider have been reinforced through the re-engineering of district-level primary health care (van Ginneken et al., 2010). It has been argued in these contexts that a "covert contract" exists, where patients adopt the idea that they need to be a "good" patient (Frosch et al., 2012; Joseph-Williams et al., 2014), who does not question advice or actions of a health professional. Often, authoritative approaches from health providers, who may not engage patients in decision-making or attempt to use the encounter to support patients, can set the tone for unequal interactions. Other research has

shown that providers may struggle to prioritize sensitivity in clinical encounters when there are more pressing structural concerns (Bhattacharyya et al., 2015). Likewise, from participant perspectives, "enduring" was seen as a default response. Many women did not see themselves as able to demand better care, further entrenching power divides between patients and providers as patients simply accept and "endure."

We found that some women responded to both interpersonal interactions (e.g., facing poor treatment from health providers) and structural failings (e.g., experiencing repeat medicine and/or immunization stockouts) with a diminished motivation to return to clinic. Other literature echoes these themes, with women who have experienced punitive treatment by health providers at clinics—for skipping appointments, for example—voicing a reluctance to seek care (Foster et al., 2010; Honikman et al., 2015; Munguambe et al., 2016). For some women, the financial cost of multiple return trips to check on medication stocks is not viable (Bedwell et al., 2017). These responses, while they may be a result of higher-level shortcomings, reinforce health inequities by decreasing the number of health contacts for mother and child and disincentivizing the effort needed to receive adequate care.

The range of responses shared could also be framed as reflecting emotion-focused and problem-focused coping (Lazarus and Folkman, 1984). This model, devised by Lazarus and Folkman, differentiates coping responses to stress as either focusing on managing the emotions associated with the stressor, or tackling the underlying problem causing that stressor. Some participants' responses were linked to personal feelings, especially when they faced recurring challenges: reflecting on these experiences was a way of sharing underlying frustrations that they felt unable to effectively change. Other women embraced more active, problem-based coping mechanisms, by attempting to prepare for adverse circumstances, or carrying out small acts of resistance. Some participants specifically mentioned the instrumental function of their Mentor Mothers, facilitating access to immediate care or identification of a health problem in a way that had not been previously possible. However, overall, problem-based tactics were often more restrained. Unable to seek further care because of financial constraints, women spoke of returning home empty-handed; unable to be seen and treated as individuals in an overburdened clinic, many opted to stay quiet or "endure" instead of openly defy a health provider. While participants described finding small ways to "gain power," it is important to recognize that not all were able to channel this approach. Importantly, a number of participants detailed both types of responses.

While South Africa's health system is rooted in a history of fragmentation and inequity, other similar countries, such as Brazil, have found success in integrating the public health system to be more aligned with the needs of poor communities (Jurberg, 2008). Brazil's primary health care-focused Family Health Strategy utilizes health teams including one physician, one nurse, one nurse assistant, and up to six CHWs, which serve pre-defined catchment areas (Andrade et al., 2018). Despite variability in health-seeker experiences, studies gathering patient perspectives have found generally high satisfaction with geographical accessibility, acceptable services, and interpersonal interactions (Fausto et al., 2017; Gaioso and Mishima, 2007). Although CHWs such as Enable's Mentor Mothers can provide motivation and social support for pregnant women and new mothers who may struggle in accessing routine care, they operate as an add-on to the government health system rather than an integrated part of it. As such, Enable still relies on a separate functioning health infrastructure to accomplish program goals, unable to replace formal health services (Tulenko et al., 2013). For programs designed to connect clients to resources, expand health education, and promote uptake of safe preventative health practices, an absence of adequate services, as well as structural barriers to accessing formalized health care, can limit the scope of these program goals, or render them unattainable (Blacklock et al., 2016; Kok et al., 2015).

4.1. Implications of these findings

Our findings highlight both interactive and active responses by pregnant women and new mothers as they faced considerable challenges in accessing care for themselves and their infants. Making women more aware of their health rights is a central part of confronting these persistent challenges, however, these efforts must take place within a broader enabling environment. These findings illustrate the need to prioritize supportive patient-provider interactions in clinical settings, and to integrate these interpersonal approaches with more innovative solutions that can increase access to care. Promoting principles of shared decision-making in pre-service and ongoing clinical training, which is well-theorized and researched between doctors and patients, could be an important first step, with primary health care professionals encouraging and preparing patients to actively participate in the clinical encounter (Joseph-Williams et al., 2014). This approach has been shown to improve patient satisfaction, preserve a sense of patient dignity and autonomy, and reduce the burden on the physician (Schain, 1980). Women's satisfaction has been found to be correlated with provider empathy in low-income settings, especially among women who recorded experiencing birth complications (Bazant and Koenig, 2009). This speaks to the importance of recognizing that across all contexts, interpersonal aspects of care should be emphasized equally alongside structural improvements. However, this approach necessitates equipping health providers with the necessary skills and competencies to supportively engage patients at all stages of the medical encounter and provide empathic professional services. Improving provider communication skills and giving space for patients to provide feedback may enhance the quality of care, even in overstretched health facilities (Pantoja et al., 2017).

On a more immediate level, for CHW programs in LMICs in particular, it is imperative to establish strong linkages between these types of programs and existing primary health care infrastructure. In the foundational work that happens before pilot programs are implemented, or successful models are taken to scale, targeted communications with locally-embedded health facility management are essential. Lastly, mobile clinics may be an important bridging mechanism, delivering health care services to remote communities and making services more accessible for the most vulnerable who may struggle to travel to bricks-and-mortar clinics (Yu et al., 2017).

4.2. Limitations

By virtue of our participants' inclusion in a home visiting program, they are not necessarily the most vulnerable—they ostensibly have more available support and a better grasp of relevant, essential health information. However, their experiences reflect typical health care experiences of women of childbearing age in their setting as corroborated by programmatic staff and co-residents. For this reason, they are central to providing a more detailed picture of patient perspectives and how health care services in remote places operate. Further research disentangling barriers to care might encompass interviewing a larger sample of women, or incorporating a more detailed observational or ethnographic data collection effort recording barriers to care across a range of methods, such as journaling or case note/record review.

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Author statement file

CL conceptualized the study, oversaw data collection, transcription, and translation, coded all transcripts, and wrote the first draft of the paper. SG provided quality control for the coding of transcripts and also

offered important feedback on the drafts of the paper. VN co-designed the interview guide with CL, conducted all interviews, and provided valuable input to the methods and discussion sections. BC, SS, and MT offered critical conceptual and technical feedback to the study design and writing of the paper. All authors read and approved the final manuscript.

Declaration of competing interest

None.

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