

# Indigenous Women Managing Pregnancy Complications in Rural Ecuador

## Barriers and Opportunities to Enhance Antenatal Care

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### ABSTRACT

Previous research has explored the potential use of digital health to support maternal health in the Global South highlighting the importance of understanding the socio-cultural context to inform system design. However, the experiences of indigenous women managing pregnancy complications in Latin America remain underexplored in HCI. We present a qualitative study with 25 indigenous pregnant women in an Ecuadorian rural community looking at their experiences during complications, their antenatal care visits and their access and use of technologies. Our findings highlight key barriers that hinder the use of antenatal care services and influence women's experiences managing complications. Based on the findings, we present opportunities for digital health centered on indigenous women to enhance antenatal care in rural Ecuador.

### CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI.

### KEYWORDS

Indigenous Women, Pregnancy Complications, Antenatal Care, Maternal Health, Digital Health, Kichwas

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## 1 INTRODUCTION

Maternal health is a global public health concern specially impacting low and low-to middle (LMIC) income countries [75]. Women who are illiterate and from low socio-economic status from rural and urban areas are amongst those who have lower access and uptake of antenatal care services [4, 33, 49, 67, 90, 132]. In particular, indigenous women are at risk of poor maternal and perinatal health outcomes as they suffer greater social, economic, and emotional vulnerability with extreme levels of health inequalities [2, 3, 129, 155]. Latin America (LATAM) is not an exception, extreme poverty, malnutrition, ethnic and linguistic differences, poor access to basic resources, education and health services [6, 15, 27, 79, 106] do not only expose indigenous women to discrimination but also put them at risk of serious pregnancy complications [6, 9, 17, 29, 109].

In this paper, we report a qualitative study with 25 indigenous pregnant women experiencing complications to uncover their care needs, experiences and challenges interacting with antenatal services and their access and use of technologies to inform the design of digital health tools to support antenatal care in rural Ecuador.

## 2 BACKGROUND

### 2.1 Maternal Health and Pregnancy Complications in Ecuador

In Ecuador, a small multiethnic and multicultural country [38], women are increasingly at risk of experiencing the double burden of malnutrition characterized by the coexistence of under nutrition alongside obesity and overweight [41]. Pregnancy complications such as obstetric hemorrhage, gestational diabetes and pregnancy-induced hypertensive disorders (e.g., pre-eclampsia, eclampsia) [55, 94, 105, 128] are major contributors to poor maternal outcomes. Women from low-income, rural and indigenous communities have limited access to healthcare services [81] and are at high risk of experiencing pregnancy complications [18, 78, 116, 151]. For example, severe cases of hypertensive disorders have shown high rates of poor perinatal outcomes, an increase of caesarean sections and admissions to the intensive care unit [116, 151]. Although the government has recognized the need to improve maternal health and reduce health inequalities through nutritional programs [120] and the last public health reform [46] promoting intercultural approaches [78, 148], these have not achieved substantial changes [126]. The maternal mortality rate has only decreased from 74 in 2005 to 64 per 1000000 live births in 2015 [153] and it is particularly high among indigenous women reaching over 100 per 1000000 live births in some provinces [105]. Major risk factors include maternal age, lack of awareness of warning signs and family support, and ethnic discrimination [18, 45, 112, 151].

### 2.2 Digital Health in the Ecuadorian Context

The use of information and communication technologies, digital health [154], is creating opportunities in Ecuador to support care practices in clinical and non-clinical settings [21, 24, 80, 125]. In clinical settings, digital health is facilitating the monitoring of vital signs [40], digitalization of medical records [56], communication and interaction between clinicians and with patients (e.g., WhatsApp) [22, 25], localization of medical areas and doctor's offices [143], and medical training and tele-consultations [147]. In non-clinical settings, mobile phones, apps, SMS, e-mail, online resources and social media (e.g., WhatsApp, YouTube, Facebook) are facilitating care after hospitalization [88] and self-care management of a variety of chronic conditions such as diabetes [92], hypertension [24], chronic kidney disease [21], asthma [23], and cancer [108] by receiving, looking and sharing information between patients and health staff. However, there is limited research exploring digital maternal health [87] and in particular among indigenous communities.

### 2.3 Digital Maternal Health in the Global South

Digital health is supporting women and healthcare staff in LMICs to enhance maternal health [62]. Digital health has increased access to information and services through videos and text messages, promoting health education and enabling women to share experiences, receive reminders and support [12, 28, 68, 69, 133]. For health staff, it is enabling remote monitoring of pregnancies, providing training support, sharing knowledge and patient information [119, 121, 144]. Most digital health initiatives focus on helping community health

workers to gather accurate data during home visits, enhance screening and information-seeking practices, visualization of tasks and facilitate communication with women [34, 35, 76, 104, 145]. While the digital transformation in maternal health is opening up opportunities for HCI research for development (HCI4D) in South Africa [28, 50, 100, 133], Kenya [113, 114], Pakistan [12, 99, 127], India [35, 64, 72, 73], Bangladesh [138], Lebanon [140, 141], Uganda and Tanzania [68], there is limited research looking at women's experiences during pregnancy complications [12] and among indigenous communities [8, 57] and Latin America as a region remains unexplored for HCI4D research in healthcare [19, 135].

### 2.4 Socio-cultural and Infrastructural Challenges in the Global South

HCI4D research highlights the importance of understanding the sociocultural practices of the local context to inform the design of digital health technologies for the global south [36, 63, 111]. These challenges include existing household and community power dynamics, communication, environmental and infrastructural barriers, disconnected knowledges, beliefs, conflicts and distrust between multiple stakeholders [61, 91, 99, 111, 121, 138, 140]. Particular attention should be given to women's perceptions and relationships with the healthcare system to improve antenatal care [1, 10, 140, 141]. In Ecuador, social, ethnic, economic and regional inequalities [81] and the lack of human and physical healthcare infrastructure and access to Internet in rural communities [19] are impacting indigenous women's health and the healthcare infrastructure [7, 42, 78, 124]. There is a need to understand women's needs, contexts and lived experiences, and the sociocultural and infrastructural barriers that influence digital maternal health [64] especially in rural [111, 121] and indigenous communities and the potential role of ICTs in indigenous health [14, 57, 82, 150].

## 3 RESEARCH SETTING AND METHODS

We started a project to understand the sociocultural, and infrastructural challenges faced by indigenous women with pregnancy complications and how these influence the use of antenatal care services in rural Ecuador. While the project includes focus groups with pregnant women and interviews with healthcare staff, in this paper we only present the preliminary results from focus groups. The project team include a multidisciplinary group of researchers with background in public health, nutrition, human-computer interaction, social sciences and communication. Ecuador has a population around 16 million people [5, 37] and 7% of the Ecuadorian population identified themselves as indigenous [38]. 78.5% of indigenous people are located in rural areas of the Andean Highlands that are characterized by a difficult terrain with poor roads and steep geography [139] and are often bilingual (Spanish and Kichwa) [26, 71, 77]. The health sub-center where the study took place provides outpatient services including family general medicine and obstetrics and makes referrals and counter-referrals of patients and blood tests. It is located in Colta, a small town on the northwestern part of the Chimborazo province in the Highlands, a province with one of the highest maternal mortality rates [105]. Colta has ten subcenters and one public basic hospital (Publio Escobar). The last census in Colta shows that 94.9% of the population live in rural areas [130] and

93.27% of the population live in poor socioeconomical conditions [30]. 87.38% of the population are indigenous [30]. We recruited and identified participants with the help of the “family” doctor who did home visits. We invited women older than 18 years with non-severe pregnancy complications that attended the antenatal consultations at the subcenter and who spoke both Spanish and Kichwa. Women with severe complications, adolescents or those attending the emergency area were excluded. Upon the doctor’s recommendation, we did not compensate participants as it was considered inappropriate [74]. Participants signed or placed their fingerprint on the informed consent and a protocol was prepared in case of any discomfort during the study. The research was granted permission by community leaders of Colta and approval by Cardiff University Ethics Committee.

### 3.1 Focus Groups and Data Analysis

We conducted three focus group discussions at the sub-center in a private room, with a calm environment, accessible to the participants to encourage attendance [44]. Focus groups are usable for generating rich understandings of participants’ experiences and beliefs [95], “well suited for problems in health research” [96], yielding “deeper insights” [142], and successfully applied with groups between 3 and 14 participants [44]. In particular, focus groups are suitable for exploring sensitive topics [48] especially around women’s health relying on the “collective sense of women’s solidarity” [152] and with pre-existing group interactions [44]. We chose to use focus groups considering the familiarity between participants and their strong sense of community and the family doctor and local researchers’ experience working with these communities and prior work using focus groups with Kichwas communities [20]. This method would enable indigenous women to feel more comfortable sharing experiences in a group setting bringing upfront the collective views of the women putting them in control of the group interaction [152]. Focus groups took place in January and February 2020 and lasted approximately 60-90 minutes. Discussions centered on women’s attitudes, challenges and experiences with complications with a focus on antenatal consultations, quality of care, symptoms, clarity of health advice, use of technology and general aspects to describe the participants. Open-ended questions were used to encourage participants to talk freely and to ask questions at any time and no personal information was collected (e.g., address). Participants had the opportunity to comment after the sessions if they did not feel like talking about a particular issue. The researcher acted as a moderator [44] and was female to align with the socio-cultural norms in Kichwas communities [20]. Based on previous research with these communities [20], the moderation was shared between the female researcher (a trained Spanish-speaking notetaker) and a bilingual speaker (Spanish/Kichwa) per focus group (a nurse assistant, a research assistant, and a pregnant woman) who was there to assist in the event that participants preferred to express themselves in Kichwa rather than Spanish (about 50%). Notes were taken and 90% of discussions were audio recorded and transcribed in Spanish, removing instances to personal data. For the analysis, a transcription of the recordings was made first by the researcher and assisted by the research assistant who speaks Kichwa to translate terms, words or expressions into Spanish when

needed and complemented with notes. A thematic analysis [16] was performed in Spanish using open coding and constant comparison, observing the particularities of the transcripts before grouping the codes into themes. Two members of the research team reviewed the transcripts and created or discussed emerging themes looking for saturation.

## 4 FINDINGS

Three focus groups were conducted with ten, thirteen and twelve women respectively. Participants’ age ranged from 19 to 43 years (average age 27.34) and they were between 7-13 weeks of pregnancy (10 weeks average) at the time of the study. All participants self-identified themselves as part of the Kichwa ethnic group. Seven participants were single, 12 married, three divorced and three were living with a partner. The majority of the participants (21) had agriculture as their main occupation, two were primary school teachers, and two identified as carers of the children at home. Seven participants were in their first pregnancy and 18 were multiparous mothers. Pregnancy complications included preeclampsia (7), gestational diabetes (8), vaginal bleeding (6), placental complications (3), and other (1). Two participants commented after a session.

### 4.1 Barriers to Antenatal Care

**4.1.1 Unknown terminology used during consultation, referral process and around the subcenter.** Aligned with previous research [63], a major barrier reported was the unknown medical terminology used by the healthcare staff during the consultation. As a consequence, many participants left the consultation without fully understanding the treatment plan. A participant stated, “*Doctors do not speak Kichwa, and so there are many things I do not understand. . .*”. Kichwa is predominately an oral language and one of the limitations is the lack of a written alphabet [26], making it difficult for non-indigenous people (i.e., doctors) to speak Kichwa where no direct translation exists for medical terms. Many participants reported that the information provided in connection to the referral system was not clear, “*I was referred to a big hospital in Riobamba, because I got high blood pressure, but they gave me a paper and I did not know what to do with it*”. The unfamiliar medical terms made it difficult for women to understand referrals and get timely access to care services. Although participants valued signs (toilets, pharmacy, exit) in Kichwa at the subcenter, all information boards displayed health messages (e.g., HIV and pregnancy) with complex terms in Spanish.

**4.1.2 Long waiting times for consultation and missing appointments.** Similar to non-indigenous patients in resource constrained settings [107], participants stressed that long waiting times influenced their use of antenatal care services as it was difficult for them to wait while they had other responsibilities and occupations. A participant commented “*We have to wait a lot of time and we have so many things to do*”. Most participants were in charge of growing food crops and feeding and watering animals, in particular “*cuyes* [guinea pigs]”. Apart from farming work, housework and childcare, women sold their products and animals on Thursday at the town’s market. Participants mentioned missing antenatal appointments at the subcenter or hospital as these were difficult to integrate into everyday work and life.

**4.1.3 Affective dimensions of the healthcare settings.** Feelings of embarrassment and shame can take place in connection to medical examinations and can be a reason for not seeking health and is influenced by the sociocultural contexts [101, 149]. In our study, many indigenous women felt nervous discussing intimate problems, others felt very uncomfortable when showing their private parts. A participant commented “*I feel embarrassed when showing my body or intimate parts to strangers*”. Sociocultural norms in relation to nudity can pose stressful feelings of embarrassment over women. Some participants were concerned about being perceived as “stupid” by health staff when asking questions. A participant expressed “*if I do not understand something, I feel embarrassed to ask again*”. At the city hospital, participants also felt ashamed for asking questions when not knowing where to go. Many participants feared negative reactions from doctors or were concerned about what doctors thought about them.

**4.1.4 Delayed use of antenatal care services vs home-based remedies.** Aligned to [99], women were unaware of warning signs during complications. Many participants commented that they did not often seek help for their health or use the antenatal care services regardless of the number of pregnancies, failing to recognize warning signs like pain. A participant stated, “*when I feel pain, I prepare an ‘agüita’ [similar to an herbal tea] or take a pill, and do not go to the health center*”. Home-based remedies and self-medication were often practiced following the advice of female relatives (e.g., mothers) or friends.

**4.1.5 Traditional gender structures in indigenous communities.** Similar to other cultures with patriarchal systems [93, 98, 99], gender roles in the Ecuadorian Andean communities are also prominent [20]. Participants commented how they followed their husbands’ decisions who often discouraged them from using antenatal care services. A married woman commented “*my husband does not like me to come often*”. Participants in general were positive about the home visits: “*It is good that they [doctors] are visiting us at home, I did not know that I got a control check and the doctor arrived to explain me*”. However, other participants mentioned that their husbands did not like the home visits in the case of male doctors, “*If a female doctor comes there is no problem, but if a male doctor comes, my husband gets mad*”. Gendered and social expectations of women’s behaviors within the indigenous male-female relations influenced women’s agency and help-seeking practices contributing to their marginalization.

**4.1.6 Intentional non-adherence to medications.** Similar to previous studies with non-indigenous people [31, 131], participants reported intentional non-adherence when deciding not to follow the medication regimen. A woman commented that she skipped her medication due to a bad taste “*The other day I was having pain, the doctor prescribed me some large white pills, but they were bitter, and I did not take them*”. Other participants mentioned that the family doctor provided iron supplementation, but they did not take them due to stomach pain. The lack of medications at the subcenter and women’s low socio-economic status influenced antenatal care as women had difficulties purchasing medications, “*we do not have money to buy the pills that are not available [at subcenter]*”.

**4.1.7 Poor road accessibility and lack of public transportation.** Some participants reported that they felt that the long distances between their home and the health subcenter made it difficult to attend antenatal consultations. A woman stated, “*I live far away, and buses are not frequently coming*”. The high altitude, steep topography of the mountains and poor road accessibility in rural communities [139] in the Andean region required women to walk long distances to the nearest highway in a steep terrain and wait for hours for public transport [47] missing appointments at the subcenter or hospitals.

## 4.2 Access and Use of Technology

Twenty-two participants reported using social networks (e.g., Facebook, WhatsApp) in Spanish because their children and family used them and it was cheap as “*sometimes we can recharge with \$3 dollars and we can use WhatsApp all month*”. Five participants reported using the radio and few of them played videos in YouTube in Spanish assisted by their children. Two participants had computers at home, but noted they did not know how use them. Eighteen participants had used computers during their learning at school and had received a computer’s introductory course years ago at the community “*Infocentro[telecenter]*”, but still found them difficult to use. Participants could get access to computers and Internet at the “*Infocentro*” and free Wi-Fi near the administration office (“*Junta Cantonal*”). The government implemented a network of Infocentros to contribute to the development of rural communities providing access to computers, Internet, and other e-services. Colta has one Infocentro with 6 workstations [60]. About the potential use of ICTs for antenatal care, participants commented that a simple application with short health messages could be helpful.

## 5 DISCUSSION AND CONCLUSION

Our study highlights key challenges influencing not only the use of antenatal care services but also women’s experiences with pregnancy complications (gestational diabetes, preeclampsia, etc.) in a rural LATAM community. Major barriers relate to the healthcare settings (consultation, complex medical terminology, long waiting times) and sociocultural (gender roles, norms and traditions), behavioral (intentional nonadherence to medication), emotional (feelings of embarrassment), and environmental (steepness of the terrain, poor road accessibility, low-frequency of public transport) factors that influence the health-seeking practices of indigenous women resulting in missing appointments and delayed access to care, exacerbating the existing clinical risks of pregnancy complications. Reflecting on these challenges and on previous HCI4D research understanding rural women’s needs, our study extends existing research on digital maternal health [72, 99, 111, 138, 141, 144], indigenous communities [8, 57] and postcolonial computing [136] as the health needs and experiences in LATAM contexts still remain poorly understood in HCI4D and health research [20, 135].

In the context of Kichwas communities, similar to other resource-constrained settings [72, 113], our study revealed the potential use of social and mobile technologies to support health-seeking practices in contrast to computers that seem difficult to use and not available at home. Although participants favored the use of simple interventions, these might not be enough to support the overall pregnancy care experience. Simple interventions such as apps with

translations of medical terminology [134], reminders, automatic voice calls, SMS and persuasive messages [12, 59, 72, 113], could have limited impact in these communities. For example, the complex medical terminology was difficult to understand in textual and verbal form in Spanish with little translation available in Kichwa due to its writing limitations. Furthermore mobile technology can offer opportunities to enhance doctor's home visits [34, 35, 121] and the medication informational order [31, 32] (e.g., what, when, how and why to take a medication) at home, and can facilitate the self-management of gestational diabetes to control weight gain [53]. Introducing self-monitoring devices both at the rural subcenters and at home can facilitate the early detection and management of hypertensive disorders during pregnancy [102, 103]. However, digital health should go beyond supporting medical care and one-way strategies [146] and focus on understanding and supporting indigenous women's wellbeing [51, 89] accounting for the ethnic diversity and sociocultural and affective dimensions of health beyond language.

One way to achieve this is to take advantage of the indigenous sense of community through the use of community-based participatory approaches [14, 43, 65, 91] to help women voice their concerns, receive support, and help balance [137, 138, 141] the unequal gender relations and hierarchies within households and healthcare settings. Thus, future research should explore how to enable indigenous women to construct the experiential knowledge by promoting community participation through for example community radio shows [97, 140] or low-cost video projections [73] in Spanish and/or Kichwa. The combination of oral, visual [63, 64], art-based [85] and traditional dance [66] can help explain the risk of complications and help women distinguish between warning signs and normal changes of pregnancy and encourage them to speak up and seek help. Considering the lack of connectivity in the Highlands, this will require the establishment of community wireless networks [118, 122, 123] to enable interaction and content sharing within the community [117]. Collective interventions should promote empathic care [70] and social support [115] encouraging participation of partners [114], caregivers, and the community, helping preserve [58, 110] the indigenous knowledge, traditions, and language that are unique to Kichwa communities. Last, our study highlights how women perceived social risks (cultural, emotional) [11] in relation to healthcare staff and settings having fears of judgement and embarrassment. Future research should look at how spaces and places influence indigenous health and the affective atmospheres of clinical encounters [83].

Our exploratory work has limitations. First, even though our inclusion criteria did not target a particular period of pregnancy our participants turned out to be within the first 7-13 weeks of pregnancy. The collective opinions, concerns and experiences of this group, even if they shared experiences from previous pregnancies (only 7 participants were in their first pregnancy), might not provide an overall picture of the complications in this geographic area nor account for all experiences throughout the pregnancy journey and maternal age (e.g., adolescents). Second, although all women identified themselves as bilingual and knew each other and confirmed they were comfortable during the sessions, a few of them had problems articulating their opinions. To deal with this, future work should consider conducting studies in Kichwa

to increase participation as well as the use of visual methods [86] to support the discussions and help women externalize emotions and feelings when they are shy or when literacy can be an issue, increasing sensibility towards women's lived experiences [85]. Our next step includes analyzing the staff interviews looking at similarities and tensions between women's and staff perspectives. We are also looking for funding to follow up on this work combining socio-material approaches [84] and practice theory [13, 39, 52] with community-based participatory approaches [14, 43, 65, 91] to further understand indigenous women's needs and experiences and involve them in the design of digital health interventions [54]. Our findings are far from complete and we encourage the HCI community to further investigate indigenous women's reproductive health needs in LATAM contexts to inform the design of culturally appropriate digital health tools to enhance women's health in the Global South.

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