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"The problem is not detection, it is treatment": exploring why women needing pre-cervical cancer care are lost to follow-up at the hospital in Iquitos, Peru

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Abstract

Background The objective of this study was to explore the barriers to follow-up – as well as potential ways to reduce these – of women with cervical lesions suspicious for cancer who were ineligible for primary-level treatment and needed, but did not receive, hospital-level follow-up in Iquitos, Peru.

Methods In-depth, semi-structured interviews were conducted with 18 HPV-positive women requiring hospital-level follow-up but for whom there was no documentation of completion regarding their experienced barriers to follow-up and suggestions to reduce these barriers. After thematically analyzing these patient interviews, interview findings about these topics were presented to seven doctors and five nurse-midwives at both the hospital and primary care levels. Finally, 19 health authorities and professionals discussed all findings and identified action steps for systems-level changes at a group model building workshop.

Results Patient-identified barriers to hospital care were mainly: (1) a limited patient understanding of follow-up or treatment steps (both prior to and after the hospital visit), and (2) administrative challenges to obtaining appointments or follow-up care at the hospital. Patients identified the utility of a patient navigator for this process to reduce these barriers. The healthcare professionals concurred with the barriers identified by the patients and the suggestion of a patient navigator, but further elucidated suggestions for change, including (1) differentiating referral for those with suspicion for cancer to prioritize those patients when referred to the hospital, (2) increasing information flow between the different levels of care through an integrated patient registry, and (3) improving provider education regarding HPV and the standard of care. The group model building workshop served as a space to discuss findings and action items that could potentially make these changes possible to ultimately improve the continuum of care.

Conclusions Despite an overall increase in follow-up for HPV-positive women since the implementation of the new HPV-based screen-and-treat program, women suspicious for cervical cancer are still being lost to follow-up after

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being referred to the hospital. Systems-level improvements should focus on improving information about patient flow across the continuum of care for health providers and hospital staff (who make appointments), strengthening referral systems between primary and tertiary level providers through an integrated patient registry, improving health education on HPV and screening for patients, and establishing a patient navigation system.

Keywords Loss to follow-up, HPV, Cervical cancer, Hospital-level care

Background

Despite cervical cancer being the fourth most common cancer among women worldwide, prevention and control of this disease is feasible. Many high-income countries have substantially reduced cervical cancer mortality rates, attributing their success to human papillomavirus (HPV) vaccinations [1–3], high HPV screening rates [4], and timely treatment for those who need it [5]. However, levels of success vary, with many low- and middle-income countries (LMICs) facing challenges when trying to attain these same results [6–8].

In Peru, despite implementation of policies prioritizing cervical cancer prevention since 1998, and school-based HPV vaccination campaigns since 2006, cervical cancer remains the second leading cause of cancer-related deaths among women, with an estimated mortality rate of 13.8 per 100,000 [9, 10]. In Loreto, Peru's largest state that is located within the Peruvian Amazon river basin, the cervical cancer mortality rate is the highest in the country and is 2.6 times the global average [11].

In 2013, WHO published guidelines to support a new "screen-and-treat" approach for the early detection of cervical cancer [12], thus addressing system level challenges preventing women who had received a positive HPV result from obtaining follow-up care. The premise was to provide early treatment or intervention to those at risk (i.e., HPV positive), rather than monitoring for resolution of dysplasia or HPV positivity, which risks losing contact with them. Screen-and-treat models have been shown to be effective in reducing the incidence and/or mortality of cervical cancer [13].

An HPV-based screen-and-treat approach was successfully implemented in 2019 in primary health facilities that make up the largest health network in Iquitos, the capital of Loreto: the Micro Red Iquitos Sur (MRIS) [14]. The approach operationalized in Iquitos consisted of a visual assessment for treatment (VAT) for all women who tested positive for HPV, with thermal ablation with thermocoagulation for those eligible (no acetowhite lesions or lesions covering less than 75% of transformation zone), and referral to a specialist at the local hospital for those ineligible for thermal ablation (see Fig. 1). Although the documented loss to follow-up rate improved from 69.8 to 30% between 2019 and 2020 after the implementation of the HPV-based screen-and-treat model, mainly due to care completion at the primary level for most women, women are still being lost in the system after testing positive for HPV [15]. Unfortunately, barriers to completion of the HPV care cascade are common in other LMICs [16–18], and merit further exploration to ensure adequate management for those who are HPV positive [13].

Previous studies conducted by the Proyecto Precancer research team have examined barriers associated to loss to follow-up care, both prior to the screen-and-treat program (women with abnormal Pap smears who did not return for results or follow-up) and after the implementation of the HPV-based screen-and treat among women who tested positive for HPV but did not return for results and/or a VAT [15, 16]. The current study focuses on identifying barriers associated with loss to follow-up at a different level of care: among women who were HPV positive, received VAT, but who were ineligible for primary-level treatment with thermal ablation (e.g., due to suspicious lesions, inability to visualize transformation zone). The specific objectives of this study were to (1) explore barriers to hospital-level follow-up among HPV-positive women ineligible for thermal ablation, and (2) identify and discuss actionable solutions to reduce hospital-level loss to follow-up.

Methods

Setting

This study was carried out in Iquitos (estimated population of 400,000), the capital of Loreto, and the world's largest city accessible solely by air or water transport. Approximately 67% of Loreto's population is covered by the *Seguro Integral de Salud*, Peru's public health insurance program, which covers those living in poverty or extreme poverty. While most of the state is served by small primary health facilities, Loreto has only three public hospitals: in Iquitos, a local hospital with gynecology but no oncological services, a regional hospital with theoretical gynecology and oncological services (though the oncologist works mostly part-time, and there are no radiation services), and another hospital in the smaller city of Yurimaguas to the South, which is many away hours by boat.

The MRIS, the largest health network in Iquitos, serves roughly 127,000 people and is comprised of 17 primary level health facilities; the distance between these primary level facilities and the local hospital that receives referrals from within the MRIS varies from 4 to 56 km. The population served by the MRIS can mostly access the hospitals

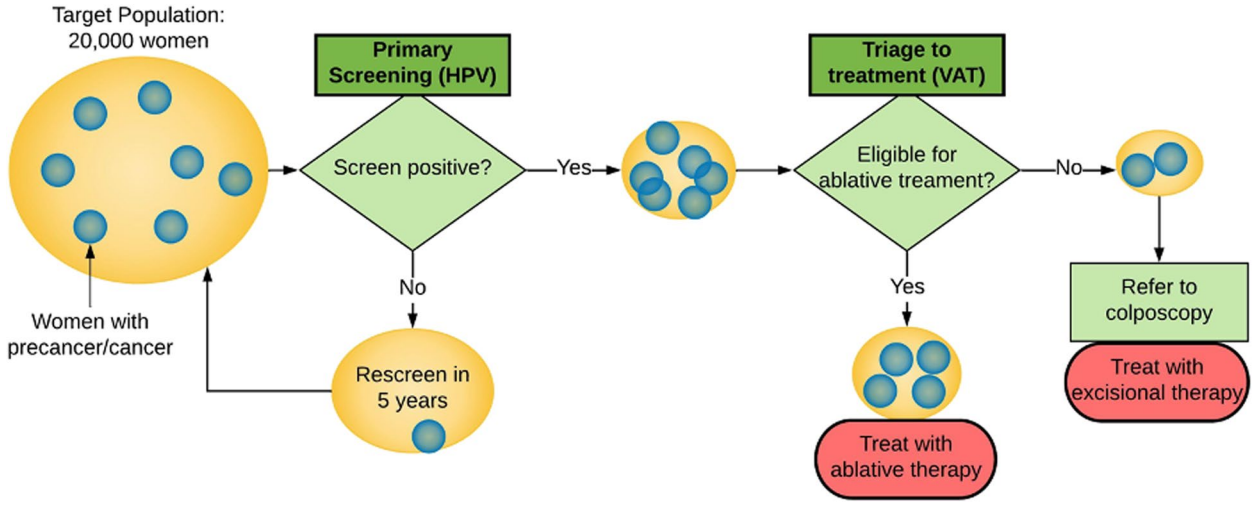

Fig. 1 Cervical cancer screen-and-treat model in MRIS, Iquitos

Table 1 Participant types/system roles and numbers

Role	Number
Phase 1: Patient Interviews	
HPV-Positive Women Lost to Follow-Up	18
Phase 2: Collaborator Interviews	
Primary-Level Physician	1
Primary-Level Midwife	2
Hospital-Level Physician	6
Hospital-Level Midwife	3
Phase 3: Group Model Building Workshop	
Primary-Level Midwife	4
Primary-Level Physician	5
Hospital-Level Midwife	1
Hospital-Level Specialist (2 Gynocologists, 2 Oncologists)	4
Administrative Assistant	1
Nurse	2
Regional Health Authority	2

via road travel (those living in urban and some peri-urban sites), and/or a combination of river and road travel (rural). As reported in previous papers [14–16], Proyecto Precáncer and local and national stakeholders launched a new HPV-based screen-and-treat cervical cancer program in 2019 within the MRIS. Approximately 20,000 women aged 30–49 within this network were eligible for this program. As a result of this new approach, there was a 3-fold increase in the number of women screened at the primary level in addition to a 37.2% increase in the number of HPV-positive women who completed the continuum of care [14].

Study design

This study was conducted in three phases. First, semi-structured interviews were conducted with 18 women who were referred to, but did not complete, hospital-level follow-up to explore the reasons why they did not receive follow-up care, as well as what they felt would have helped them obtain follow-up care. Second, we created a visual depiction of the system and its barriers from the women's perspective (see Supplemental Fig. 1) that was used as a discussion point for the semi-structured interviews with 12 health professionals working at different system levels to elicit other barriers and suggestions for change. Finally, all data was presented in a group model building workshop with key health and hospital authorities and health professionals from different levels of care with the shared goal of identifying and developing actionable system solutions to reduce these barriers (Table 1).

Patient interviews

Sampling and recruitment

Eligible interview participants were women with a positive HPV molecular test who received VAT but were deemed ineligible for thermal ablation at the primary care level, referred to a hospital for follow-up, and had no record of care completion within three months of referral. Specifically, they lacked records for one or more of the following: (1) attending a hospital appointment, (2) completing treatment after such an appointment, or (3) receiving confirmatory test results (e.g., biopsy). Women were excluded if they had evidence of treatment (e.g., at a private facility) or a negative confirmatory test.

Recruitment took place from August to September 2022. Using a registry-generated list of women without hospital follow-up, we verified care completion with nurse-midwives at primary health facilities and two hospitals based on the specified criteria. The research team then contacted or visited eligible women to invite them to participate. All 20 invited women agreed to be interviewed, but only 18 proved to be eligible, and so the data from the two ineligible women was not included

in the overall analysis (one had received follow-up not reflected in records and the other was no longer covered by the public health insurance program because she had acquired employer-based health insurance coverage).

Interview process

Interviews, conducted in Spanish during September and October 2022, took place at participants' homes, workplaces, or by phone when in-person meetings were not possible. Informed consent was obtained beforehand. Two experienced female Peruvian research assistants led semi-structured interviews, focusing on HPV screening and treatment (see Supplementary File 1). A cervical cancer screening process map guided discussions, emphasizing follow-up steps, test results, patient education, referrals, system facilitators and barriers, and recommendations for improvement (Fig. 1). All interviews were recorded, transcribed, and supported by field notes for context, though these notes were excluded from analysis.

Stakeholder interviews

Sampling and recruitment

Healthcare professionals were eligible for interviews if they were doctors (gynecologists, oncologists, primary care physicians) or nurse-midwives involved in cervical cancer prevention and control at two hospitals or two primary care facilities in Iquitos offering VAT and thermal ablation. The research team created a list to capture diverse roles across the screen-and-treat program stages. Twelve professionals (see Table 1) were recruited, and all agreed to participate. Recruitment ceased upon achieving thematic saturation across stakeholder levels regarding the cervical cancer care trajectory.

Interview process

After obtaining informed consent, interviews took place in Spanish in a private space at the participants' workplaces in February 2023. The interview guide was structured around a visual depiction of the system utilizing findings from patient interviews, with barriers occurring at six main timepoints of the continuum of care (see Supplementary File 2 and Supplementary File 3, respectively). The interviewer focused on the specific barriers that were relevant to their own roles and places of work, as well as their suggestions for addressing barriers and potential system-level changes. All interviews were recorded and transcribed. Field notes were reviewed but did not inform data analysis.

Coding and analysis

A mix of deductive and inductive codes were used to analyze all data using Dedoose. Deductive codes followed the chronological steps of the care continuum, while inductive codes were based on barriers, as well as the suggestions for change, that emerged at each step. The women's interviews were coded after completion of all 18 interviews and prior to the initiation of stakeholder interviews. Stakeholder interviews were coded after completion of all 12 collaborator interviews. For the stakeholder interviews, we created a similar codebook to the one used to analyze women's transcripts, but grouped stakeholders' suggested changes into individual-level and systems-level, further subdividing by the specific barrier the change was aimed to address. Two researchers read through and coded the transcripts, meeting after five interviews to ensure codebook was complete and to discuss coded transcripts to ensure consistency. Once researchers were coding consistently (more than 90%), one researcher coded the remainder of the interviews.

Group model building workshop

Recruitment

Key stakeholders – health authorities and professionals – in the cervical cancer prevention and control program within the MRIS were identified by members of the Proyecto Precancer team, along with the cancer coordinator of the regional Ministry of Health. The 19 invited parties included: doctors and nurse-midwives working in the gynecology and oncology departments at the two hospitals, the referring primary-care facilities, and from various rural primary-care facilities; and hospital administrators and regional health authorities. The workshop was held on February 23, 2023.

Workshop process

We started the workshop with short introductions since most individuals knew each other, followed by verbalizing our shared goal of developing the most efficient and patient-friendly cervical cancer screening and management system, and then presented interview findings to generate discussion among participants.

Following the presentation, stakeholders were divided into primary or hospital levels to address how to address barriers identified at that level. Each group was facilitated by two Proyecto Precancer team members to ensure a rich discussion that included multiple perspectives, before aiming to reach consensus on what could be done to improve the system, by whom, and how. Actionable steps were identified in each group and shared with the other group, and those present committed to making changes.

Results

Sample characteristics

Seventy women ineligible for thermal ablation were referred to the hospital, with an average age of 39.1 years (out of 58 whose ages were recorded). Referrals came from six of 17 primary care facilities, and the women

were from urban (20), peri-urban (5), and rural (26) MRIS regions (out of 51 cases with available information). We interviewed 18 women aged 30–49, with an average age of 38.8 (based on 13 recorded ages), including at least one from each of the six referring facilities. Most interviewees (15) were from urban neighborhoods in Iquitos, one from a peri-urban area outside Iquitos, and two from rural areas. Health professional details are presented in Table 1. Two main themes emerged from the interviews with patients and health care professionals: (1) limited understanding about HPV, a positive diagnosis, and the steps for follow-up (before and after reaching the hospital level), and (2) administrative challenges obtaining appointments or follow-up care at the hospital.

1 Limited understanding about HPV, a positive diagnosis, and the continuum of care

Women expressed uncertainty regarding what exactly it meant to be HPV positive and/or ineligible to receive care at the primary level; this was also reported by health professionals. The confusion and frustration women described also led to fear and distress: "*I thought I was going to die; I spent some days thinking I was going to die.*"

> *I felt bad because they told me I have cancer, that I will die early… I was so upset that I stopped going to the health post, what can I do, if so much time has passed and they didn't call me [for follow-up], they wasted the whole month, they treat me like an animal, it's not right, but I got my treatment, I went to the regional hospital.*

The non-standardized trajectory of referrals also led to confusion, which perpetuated distress. Women who are HPV positive and require hospital level follow up are referred to either the gynecology unit at one of the hospitals or the oncology unit of the other; this can lead to confusion about the possibility they had cancer, or as one woman referred to oncology described:

> *In oncology, I always knew that's where people go with cancer, and I felt that I was sick, and I felt nervous and scared because one time I went there with a friend to get her mother's results who had cancer, and she told me that there [the oncology unit] is where people go with advanced cancer.*

This lack of knowledge persisted upon reaching the hospital, as many women described confusion regarding which department to visit and what to expect when finally seeing a provider. This confusion seemed to stem from a disconnect within the hospital system and the lack of clear policies at admissions about where to make the appointments: "*They said to me [at gynecology], 'How are they going to refer you to oncology if you don't have cancer? You should have come to us.*"

Health professionals also recognized the communication challenges within and between the primary and tertiary levels of care. In addition to, and possibly related to, the communication challenges, health professionals identified high turnover rates of medical personnel and staff at all levels of the healthcare system as a barrier to successful engagement of women for treatment follow-up. Further, it was suggested that medical personnel at times do not have a holistic or current understanding of the new screen-to-treat program, and some are not aware that the current best clinical practices have shifted from Pap smears to molecular HPV testing that is either self-administered or performed by a healthcare professional:

> *In Loreto, doctors of any specialty that is not cancer do not know anything about cancer. They only know what cancer is, nothing more. Given that, if doctors that do not have anything to do with oncology don't know anything about cancer, imagine the knowledge level for the general population. So we have a lot of work to do in terms of training, education, re-structuring the levels of care to be able to grow and better manage this pathology.*

Women's limited understanding of next steps in their care persisted after hospital visits and diagnostic tests like colposcopy or biopsy. Some expected a call about their results but never received one, leading to fear and concern for themselves and their families. Others faced challenges accessing results or follow-up care. Over time, many women developed feelings of indignation and hopelessness. One participant expressed surprise at being contacted during the interview, as it was the first time anyone had reached out to her since undergoing additional testing following her initial positive HPV test at a health center.

Confusion was exacerbated by another issue that emerged in some interviews: dual practice (i.e., practicing medicine in both public and private systems). Specifically, women mentioned that a hospital level nurse-midwife would require them to see her at her private practice for a Pap smear or other diagnostic before she would schedule an appointment with the hospital doctor; some women stopped trying to see the hospital doctor at that point. In a few instances, women resorted to natural medicines or other "vitamins or medications" that some nurse-midwives promoted as helpful for their condition.

Overall, women expressed that they felt that the formal health system had abandoned them.

> *I went to the health post because I had to go there to make my appointment [for treatment] for the end*

of July, but when I arrived, the midwife told me that they couldn't do it because the machine was broken, but that they would let me know. So I told her, "I will come back at the end of September." She told me "Okay," but they still haven't called me, they haven't even given me my results, because the midwife told me they were going to bring some new equipment, I don't know what.

All 12 healthcare professionals recognized patients' struggles in coordinating their own care, attributing this to poor coordination between hospital units and the lack of a patient registry system.

2 Administrative challenges: multiple trips to the hospital for appointments and follow-up

While most women were eventually able to figure out how to make an appointment at the hospital through the guidance of nurse-midwives at the primary level, this process proved to be a challenge. They attributed this to a lack of familiarity with the in-person appointment-making process, miscommunication from providers about where to go or who to ask for, and the lack of support and guidance in making these appointments (i.e., in one hospital, they get seen in gynecology, in the other at oncology). Not a single participant interviewed was able to receive care upon arrival at the hospital on her first visit, and over half had to make at least three trips to the hospital before receiving care; the main reasons given for the multiple trips to the hospital were the doctor's unavailability despite having a scheduled appointment (e.g., last-minute conflict for the doctor), overbooking of appointments, the referral form expiring after two months, requiring patients get a new referral form from their primary level facility and start the process over, or the doctor or other health professionals being on strike:

The fourth time I came back, I got the appointment. [The first time] they told me that even though the doctor was there, he had to operate [and was unavailable]. They told me to come the next day. Then the next day, [I went, but] the doctor said he wasn't coming, he's coming tomorrow. And the next day, I went and they were going to see me, but the appointment that I had supposedly made was not made, so he wasn't there. The doctor was on vacation.

Women reported that repeated hospital visits led to a loss of time and money that they did not have; they felt they needed to prioritize caring for their families. Some expressed frustration with the inefficiency of the system, which delayed care and allowed their disease to progress. Many health professionals sympathized with the difficulty and time-consuming nature of making appointments, receiving care, and navigating the healthcare system:

Unfortunately, I think that we have a failed system, an inefficient system that does not work, that is not responding to demand, and unfortunately this is not just at the hospital level, but starting at the primary level. Before, you could go to a health post or a health center, get in line, and you would be seen that same day. Now, you have to go to a health center as if it were a hospital and they tell you "we have appointments in two weeks," so the supply is very little. But the issue is not just supply, but also the health centers' logistical capacity is very poor. So, if we do not improve that capacity, if we do not expand supply, the system will continue to collapse.

3 Suggestions for reducing barriers

At the end of all 18 patient interviews, interviewers provided education on HPV, cervical cancer, and the continuum of care in Iquitos. For women needing follow-up appointments, interviewers coordinated the appointments and provided guidance on logistics. All participants expressed that such assistance would be highly beneficial throughout their care journey. One participant stated:

It would be easier to have a designated member of the health facility, and someone there that would know if and when the patient had to come to each facility. It would also be helpful if there was someone, maybe a health professional, who we could call and follow up with. This would be helpful because then the patient would not have to do all that.

Health professionals also suggested the benefit of a patient navigator, including one that could be available by phone. Many also recommended that a friend or relative accompany the patient at appointments, with the idea that an extra set of ears would help capture results and the next steps of care.

It would help if the health center had a phone number that patients could call to know if they have to go back to the heath center, or if there was a health professional that they could call for follow-up. That way the patient would not have to do all of this, to travel to the hospital, wait up to six months and still not have their test result. Because what are you supposed to say to the patient? Once you get your biopsy, come back in six months? I can't say that. That's not a viable option. There should be a better solution. There should be a phone number to call,

that's my recommendation, so that after the doctor sees you, if there is follow-up pending or you have to make another appointment, you call that number, and they tell you if they will be able to see you.

Health professionals proposed three other changes that would they felt would reduce patients' barriers to getting follow-up care. They acknowledged the lack of an integrated patient registry as a barrier, and noted that such a registry would improve information flow between the different levels of care. They also recognized that for various reasons, including staff turnover and lack of proper communication channels, some hospital staff may make appointments for patients in the wrong service, simply because they do not know better. Finally, there was agreement that one could not expect women to know much about HPV and its continuum of care when health professionals and hospital staff were also lacking education on this, and suggested provider education on this topic and on the new screen-and-treat model.

Group model building: actionable items for change

The identified barriers and suggestions for change were presented at the group model building workshop with health professionals held in February 2023. Stakeholders then divided into two groups based on their expertise for further discussion of these topics. Discussion themes and key action steps from the workshop are presented in this section.

1 Prioritization of patients with a high risk of cancer

The health professionals all agreed that HPV-positive women who are ineligible for primary-level treatment due to suspicion for cancer need to be prioritized when referred to the hospital. Suggestions included updating the referral form for these patients, to include an "urgent box" that can be checked, or asking the provider making the referral to call one nurse-midwife directly to ensure that patient was prioritized at the time of making an appointment. This latter suggestion was shared among all present to ensure a do-able action that could be carried out immediately since all key stakeholders were at the workshop.

As this topic was explored, hospital professionals discussed the speed at which they could intervene with a patient with suspected cancer. Initially, the oncologist mentioned being able to operate on urgent cases within days. Further clarification led to the reflection that, prior to any surgical intervention, the patient needed to be cleared by cardiology and obtain some blood tests, and that sometimes there are delays involved with these additional steps. For example, there may be no appointments in cardiology at the end of a month, requiring the patient to return at the start of a month for available appointments which might be weeks away. The head of oncology recognized this was an unnecessary and dangerous delay, and committed to speaking to the head of cardiology to find ways to speed up pre-surgical appointments.

2 Increasing communication between levels of care, including via a patient registry

Many collaborators expressed the importance of a direct provider-to provider referral process to ensure that each of the levels of care has some awareness of the referral. They described how this would be more effective than sending the patient with a slip of paper to a provider without notifying that provider. WhatsApp groups were also highlighted as an effective way for nurse-midwives to communicate between the different levels of care.

Stakeholders from all levels of care discussed the lack of an integrated patient registry, making patient management nearly impossible. They suggested that the registry should include information such as the types of tests performed, the results, follow-up appointments attended, and treatment recommended and received, among others. The patient registry discussion led to the discussion of a patient navigator, since this would help guide patients as well. The cancer coordinator present explained Peru's REF-CON (*referencia y contrareferencia*) system, which was designed to assist providers in patient follow-up. Specifically, the REF-CON system is meant to be used by primary level providers to send patients to tertiary level care ("REF" for reference), and then by tertiary level providers to inform the primary level what was done and the needed follow up ("CON" or counter-reference). This small group decided it would be more efficient to evaluate the REF-CON system's effectiveness for the cervical cancer prevention and control system than to try to create a new system. One doctor recommended adding a feature that would create an alert or notification for the nurse-midwife when a patient did not initiate or continue treatment, so that the nurse-midwife could contact the patient to reschedule her appointment. Despite a commitment to testing this system that is already familiar to most, the cancer coordinator left their position within weeks, and this effort did not proceed.

3 The utility of patient navigation

Multiple models for patient navigation were discussed based on systems that the healthcare professionals had seen in other departments or facilities. The models included using volunteers and health workers as navigators who could provide education, advice, and logistical plans for patients in terms of next steps of care. For example, when the Proyecto Precancer interviewer found patients who had been lost to follow-up to explore their barriers, she provided information and assisted women

in making appointments. Both the women and health professionals commented on the value of such a person in the system, while recognizing the difficulty to fund such a role. Another option discussed was the possibility of having a health professional running a telephone line to track and follow up with patients and be available to them for orientation or education.

This discussion sparked a conversation among stakeholders about a person who had once assisted indigenous people from remote areas of the rainforest to navigate the hospital system when needed. They thought this patient navigator worked for a non-governmental organization (no one was sure who paid for his role) and would become involved when there was a referral from an indigenous community where individuals are less connected to the health system and may not speak Spanish. Discussion of this person triggered enthusiasm that the hospital – at some point in the past – had such a patient navigator, and that it could be possible to create such a role. The two hospital administrators committed to learning more from their colleagues to find out who paid for the patient navigator and to explore the feasibility of onboarding patient navigators.

4 Improving provider knowledge regarding HPV and continuum of care

Finally, during the workshop, stakeholders recognized that providers needed to improve their own knowledge regarding HPV screening and treatment and the need for a uniform continuum of care that providers and health administrators recognize. Two recommendations were made in this regard: (1) developing curricula (including on the continuum of care) on HPV-related training for OBGYN residents, medical students, and nurse-midwife students, and (2) enforcing a uniform continuum of care and appropriate triage system for managing patients at the hospital level. On this second issue, some professionals recognize that some colleagues engage in dual practice, and feel they are unable to address it directly without consequences for themselves. They also recognize that constant turnover in their administration requires a better orientation system that ensures that those scheduling appointments and handling patient care are aware of the expected procedures for the continuum of care in their facility.

Discussion

Many of the barriers identified in the health system in Iquitos are not uncommon. LMICs like Rwanda, Kenya, and Ethiopia all struggle with high loss to follow-up for women with HPV or cervical cancer due to similar factors such as long travel distances, lack of patient registry systems, inadequate patient navigation, poor understanding of HPV, transportation costs, household obligations, fear of treatment, and delays in medical services [17–19]. Each country has specific barriers, including decentralized healthcare in Rwanda, cultural and logistical challenges in Kenya, and delays and costs in Ethiopia [17–19]. However, following the implementation of a new HPV-based screen-and-treat model in this unique setting in Latin America, where stakeholder engagement in the decisions and steps was high and "fresh," our data suggested that loss to follow-up at the hospital-level among HPV-positive women remained high. Given the consequences of loss to follow-up for these high-risk patients, it was important to explore and discuss this loss for future tailored responses.

Our findings have policy, programmatic, and research implications. First, developing and implementing training programs for providers would address the women's lack of a clear understanding of their disease and the healthcare system, by first training the providers involved in teaching them. These trainings must not only focus on content, but also teach providers how to convey information in a way that matches their patient's health literacy level. This could include visual tools, such as a flowchart with instructions of the patient's next stage of care or provision of written material. Health literacy trainings for physicians has improved health outcomes for patients in several different countries, from the United States [20] to Iran [21]. Health literacy training programs that are tailored to the health care system at hand and that keep in mind the socioeconomic and cultural contexts of the patients are also recommended by the CDC to improve health outcomes [22].

Second, a telephone-based patient navigation system could support women in scheduling appointments, accessing their results, and navigating the healthcare system as a whole [23, 24]. To compensate providers for "giving out results" (a specific code in the system), the current system requires that women take the primary level referral to the hospital in person to make an appointment, then go to an appointment, then return to the hospital to pick up a paper copy of their results to make a follow up appointment, and so on. The burden is on the woman. A new remote health service provided via computers, phones, and other digitized systems, called Telesalud, has been gaining momentum in some of the larger health centers [25], and some alternate phone and message-based systems were used during the COVID-19 pandemic. Could it be possible to create a new system code for providing results over the phone while still allowing the health facility to be compensated for this activity?

Third, in Iquitos, new technology has rapidly entered people's daily lives, where many have access to both phones and the internet, at least in and close to the city. People commonly use platforms like Facebook,

Instagram, or WhatsApp to communicate and get their information. These platforms could be an invaluable tool to support HPV-positive patients in navigating the health system in Peru by providing an accessible way to get information while using the technology they already have at their fingertips [26]. On the other hand, the digital divide could lead to even less support for the most vulnerable who do not have consistent access to phones and/or internet connections, or who are not computer literate. To ensure that further inequities do not arise, these mobile-based solutions should supplement, not replace, the current system that requires patients to pick up their results in person. Further research is needed to explore and pilot patient navigation models for this population.

The final implication concerns the high turnover rates of medical personnel and staff, resulting in them not having a holistic understanding of the new screen-and-treat system (and likely other clinical practices or procedures). Health professional societies, such as the Colegio Medico del Peru, must develop systems for updating their personnel on current information on HPV and its treatment, whether through development or approval of new courses or classes on topics like HPV and its treatment to their members. Furthermore, having virtual onboarding and training systems for new health staff (which supposedly exist, but are not actually put into practice) could be beneficial for efficiently dealing with the high turnover rates. Availability of such material online would reduce the time and effort to train individuals regularly. This would also ensure that healthcare professionals have access to updated information, as currently most providers travel to Lima for training purposes.

Limitations

This study was conducted in the MRIS network, selected due to its centralized location and its comparatively efficient documentation system. The barriers and suggestions for change may not be applicable to other regions of Peru or Loreto due to differing structural and geographic barriers. For example, most women living in the MRIS – which is in or near Iquitos – speak Spanish, whereas women from more remote regions likely face additional linguistic and cultural barriers, particularly if indigenous. Additionally, we conducted a limited number of interviews (aiming for saturation), but over-represented the more urban areas of the MRIS because our research team was only able to locate three of the approximately 20 eligible women who lived in rural areas. The women we did interview were themselves difficult to find (approximately 1.5–3 h to find each woman) because many had moved and/or had changed their telephone numbers. When a woman did not answer the phone, our research team went to her last recorded address. If that woman no longer lived at that address, our research team asked neighbors for updated contact information to locate her. While we did not find all of these women, we were able to locate many, but ultimately, our findings reveal the significant barriers causing loss to follow-up while living within hours of the hospitals, and this would only be worse for women living further away. The time required to find each woman also depicted another reality for this system: it would be difficult to task a health worker to follow up with missing patients under these circumstances in this setting. Another limitation was incomplete data. Our registry uses primary data forms and when information is missing, it is updated via a physical search through clinical records, but the system is not perfect. Although interviews with healthcare professionals were conducted in the workplace and could result in some feeling careful about what they reported, these interviews were conducted in private offices and our research team had been working closely with the professionals over several years, so we believe this established trust led to honest answers. Finally, many of the women interviewed discussed the barriers they faced when getting care at the hospital in the context of COVID- 19. While COVID- 19 was unprecedented and may have caused further fragmentation of care, we were unable to determine which, if any, barriers were heightened by COVID- 19. Despite these limitations, major patterns emerged in our interviews and workshop regarding barriers to accessing tertiary level care and future suggestions for change.

Conclusion

Despite an increase in follow-up for HPV-positive women overall since implementation of the new HPV-based screen-and-treat approach in Loreto, women who are at a higher risk of developing cervical cancer are still being lost after their referral to the hospital level for care. Factors associated with the loss to follow-up included the lack of understanding of next steps of care and about HPV, as well as the challenging processes to make appointment and obtain follow-up care at the hospital. System improvements should focus on developing an integrated registry that can be accessed by primary and tertiary level providers, testing and implementing a patient navigation system for women, and improving dissemination of health education and administrative processes via internal hospital processes, as well as health programs, professional societies, and virtual programs.

Abbreviations

LMICs	Low- and middle-income countries
HPV	Human papillomavirus
MRIS	Micro Red Iquitos Sur
REF-CON	Referencia y contrareferencia
VAT	Visual assessment for treatment

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

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Authors' contributions
A.C.B., V.P.S., and G.M.S. conceived and designed this study. V.P.S., C.H., E.J.R.L., R.M., J.B., R.R.R., L.D.C., K.G.D., L.W., R.L.L., and J.V.V. contributed to the data collection and curation. A.C.B., R.T., L.N., and V.P.S. contributed to data analysis, drafted the manuscript, and made substantial edits. L.N., V.P.S., G.M.S., and J.K.T. edited the final version. All authors read and approved the final manuscript.

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Data availability
The dataset supporting the conclusions of this article is available upon reasonable request and with the participants' permission, pursuant to the terms of the IRB approval.

Declarations

Ethics approval and consent to participate
Our study adhered to the Declaration of Helsinki. Ethics approval for this study was obtained from the institutional review boards at: Asociación Benéfica PRISMA (CE0251.09), Tulane University School of Public Health and Tropical Medicine (reference number 891039), the University of Maryland School of Medicine (IRB#061614), Hospital Regional Loreto (ID- 002-CIEI- 2017), and Hospital Apoyo Iquitos (065-ID-ETHICS COMMITTEE HICGG- 2018). As approved by these IRB committees, all participants provided verbal and written informed consent to participate.

Consent for publication
Not applicable.

Competing interests
V.P.S., on behalf of the Proyecto Precancer, received discounted prices and/or donated supplies from Copan and Cepheid. The authors declare that they have no other competing interests.

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