“The disease is mine, the body is mine, I decide”: Individual, interpersonal, and institutional
barriers and facilitators among survivors of women’s cancers in Andean countries

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Abstract

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Purpose: There has been a recent surge of national cancer plans to address high cancer mortality in Latin America, particularly in Andean countries. These plans primarily address institutional barriers (e.g., access, socioeconomic). Little is known about which individual, interpersonal, and institutional barriers may persist despite these policies. As well, little is known about facilitators, particularly from the perspective of cancer survivors, that can be leveraged in future research, practice, and policy.

Methods: In March 2015, we conducted 15 semi-structured interviews with survivors of breast and cervical cancers during and after a Pan American Health Organization-sponsored conference on women’s cancers in Lima, Peru. We analyzed data using an inductive content analysis approach.

Results: Survivors perceived multi-level barriers to engagement and retention in female reproductive cancer care in Andean countries. At the individual level, patients reported a lack of knowledge, psychological distress, and medical mistrust. At the interpersonal level, patients reported a visibly stigmatized identity due to hair loss, worry about burdening family, and insensitive provider treatment. At the institutional level, patients reported limited facility resources and poor coordination of care. Facilitators were also discussed at individual (resilient attitudes, self-advocacy), interpersonal (family support, cancer support groups), and institutional levels (financial assistance, insurance). Additionally, survivors provided recommendations for how to refine existing policy to improve the cancer care experience for patients (widespread education, provider sensitivity training, psychological support, increased treatment capacity).

Conclusions: Our findings suggest that policy solutions should incorporate patient perspectives to have a comprehensive impact on cancer health.

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Introduction

There are high rates of breast and cervical cancer mortality in Latin America as a whole[1–3] and Peru in particular[4, 5]. The breast cancer mortality-to-incidence ratio is nearly twice as high in South America as North America[3]. In 2010, breast and cervical cancers comprised 9% and 11% of Peru’s total cancer mortality among women, respectively[4]. Higher mortality likely partially results from the underutilization of screening and more advanced stage at diagnosis for this population[5–7]. For example, Peru’s primary cancer hospital, the National Institute for Neoplastic Diseases (INEN), reported that between 2007 and 2011 over 50% of breast cancer patients were diagnosed in stages III or IV (“late”) and only 7% in stage I[5]. In contrast, about 10% of breast cancer cases are diagnosed late in Northern Europe[1]. These trends are likely due to particularly low screening rates for cervical[7] and breast cancer[5, 6] in Peru. Indeed, most research in Peru has highlighted that institutional factors significantly impact patients’ cancer care experiences, including geographic disparities in quality care, high cost, and long bureaucratic delays[5–8]. In response, Peru, Bolivia, Colombia, and Ecuador have recently developed national cancer policies, strategies, or action plans[9, 10].

Policy solutions that alleviate institutional barriers are crucial. Simultaneously, multi-level approaches, which address factors at individual, interpersonal, *and* institutional levels, are increasingly important in the context of cancer prevention and control[11–14]. At the individual level, decades of international research have identified numerous barriers, including (but not limited to) a lack of information or misinformation[12, 14, 15], cultural beliefs[12, 14, 16–19], cancer worry/fear[20, 21], fatalism[22, 23], stigma[14, 24–26], psychological sequelae[15, 27, 28] (e.g., co-morbid depression[29–31], symptom-induced loss of self-confidence[32]), and medical mistrust[33]. At the interpersonal level, individuals may experience distress about burdening family, as well as stigma due to their condition[19, 34–36] or other marginalized social identities[14, 37]. Further, socioeconomic and access barriers are not the only institutional factors that may affect breast and cervical cancer mortality[7, 14, 16]. High-quality, coordinated services enable patients to optimize the benefits of greater access to care[8, 12, 13]. Notably, multi-level approaches are also helpful in understanding protective factors and facilitators to care. There is a substantial body of literature concerning facilitators at individual (e.g., hopefulness[38], active coping[38], self-efficacy[38, 39]), interpersonal (e.g., social support from family and peer cancer patients[38, 40–42]), and institutional levels (e.g., financial support[1]).

Despite the emergence of multi-level approaches, relatively little work has evaluated *which* barriers and at *what level* national cancer plans should address cancer patients' well-being. Such research must focus on treatment, in addition to screening/early detection, in populations from low- and middle-income countries (LMICs). Understanding the extent to which barriers, and at which level, persist in the era of new Andean country cancer policies is important for future research, practice, and policy. Characterizing facilitators and protective factors in care in this new era is also relevant to leverage potential strengths in the future. As well, it is important to obtain patient perspectives and recommendations on solutions that can address multi-level factors and optimize care. Accordingly, we conducted a pilot study with a purposive sample of survivors at a regional cancer survivorship and informational conference on Plan Esperanza. We aimed to examine breast and cervical cancer survivors' narratives to elucidate solutions to multi-level barriers faced during cancer care in Andean countries. Survivors are ideally positioned to provide information on the multi-level factors influencing the cancer care experience because they have engaged in self-advocacy within their own care[43]; have served as navigators and examples of success to newly diagnosed and unscreened populations[38]; and may have experience serving as advocates within research, practice, and policy settings[19, 43, 44]. The findings inform women's experiences on the Andean cancer care continuum, leading to policy recommendations for clinics, hospitals, and Plan Esperanza and similar cancer plans.

Methods

Participants and Procedures

In-depth interviews with 15 survivors were conducted at the March 2015 First International Cancer Symposium survivorship conference in Lima, Peru. Using a purposive sampling strategy, female cancer survivors were asked to participate in this study at the conference, a likely place to find resilient survivors. Participants' eligibility criteria were: 1) previous breast or cervical cancer diagnosis and 2) initiated or completed treatment for breast and cervical cancer. Survivors were from Peru, Colombia, Ecuador, and Bolivia.

Ethical approval was obtained from the University of Washington and the Universidad Peruana Cayetano Heredia institutional review boards. After informed consent was obtained from all participants, four experienced Latina researchers conducted interviews with survivors in private rooms. Each one-hour interview was audio-recorded and transcribed verbatim in Spanish by a professional transcriptionist. Participants were asked open-ended questions following a semi-structured interview guide (see Table 1) and received \$3 compensation.

Qualitative Data Analysis

Two Spanish-English bilingual research assistants independently open-read and coded all transcripts to identify themes and subthemes that emerged, using inductive content analysis and the principle of constant comparison from grounded theory[45]. The research assistants developed a codebook and code definitions, compared the two sets of coded interviews, and then came to a consensus on individual codes for quotations. Data were further organized using ATLAS.ti 7.5.12 software outputs and matrices. Identified quotations were translated into English by both research assistants and compared for accuracy with bilingual study team members.

Results

Table 2 depicts our study sample's demographic and clinical characteristics. Themes emerged in this study in alignment with the social ecological framework, on the individual, interpersonal, and institutional levels (Figure 1). Below, we describe different barriers and facilitators that emerged within these levels. Finally, we report survivors' recommendations for how to improve existing cancer policy.

Barriers

Individual

Lack of knowledge exacerbated all barriers these survivors faced, from symptom identification, screening, diagnosis, treatment, to recovery and involvement in advocacy. Although a few breast cancer survivors had yearly mammograms, attended screening campaigns, or did self-exams, other participants had postponed screening because they were **unfamiliar with cancer's symptoms, urgency, and relevance**. Participants were clear about the importance of risk awareness and screening information:

“Here we need information. I was scared to death because I did not have information. If I had had the information, I would have gone immediately to the doctor.” (*age 51*)

About half of participants discussed some **fear of the medical system**. For example, one participant feared being a medical “guinea pig” or killed by the treatment. Another explained her fear of contagious fatalism in the cancer hospital, which she considered a product of ignorance. Participants described other women's fears of painful mammography or “uninhibited” male doctors, which two women identified as a cultural problem.

“I think that many people, out of fear, don’t go to the hospitals. I think that the doctors should go to the communities, especially to the low-income communities. Sometimes, due to our ignorance, we don’t know what prevention is. In my case, no one ever talked to me about it.” (age 63)

Cancer worry was another major emergent barrier. Many women postpone visiting oncologists, even for free screenings, because they fear receiving a life-changing diagnosis. One participant affirmed this fear of both doctors and the diagnosis as the reasons why she and her friends all delay screening. After diagnosis, the majority felt their **death was imminent**. Multiple women worried about leaving children or parents without caregivers. Not surprisingly, many participants cited **depression** in themselves or others. Several declared depression, not cancer, is what kills cancer patients, including prompting patients to skip appointments.

“I am a person who is always informed. I always read a lot and I thought I knew everything about cancer. And then when I got it, the first thing I thought was ‘well, I’m going to die.’” (age 39)

Interpersonal

Hair loss emerged as a significant trauma associated with interpersonal interactions and indicator of women’s stigmatized identities as cancer patients:

Survivor: It’s a stereotype among women, that a woman without hair is not sexy, beautiful... it [hair] is a feminine feature.

Interviewer: And your breast?

Survivor: No, that is not visible, but hair is, then everyone sees you. (age 38)

Almost all participants **worried about burdening their families** throughout the screening, diagnosis, and treatment phases, which occasionally affected disclosure. A few participants waited to tell family until they received a definitive diagnosis, to avoid triggering unnecessary stress. Some participants did witness family members develop physical and psychological problems after finding out. During treatment, multiple participants hid discomfort so their family would not suffer. Emotionally burdening one’s family also affected participants:

“I think the ones who suffer most are the family, more than the individual, and you suffer because you see them suffering. ... Because you get used to the pain and all that, you get used to them poking you here and doing something to you there. But the problem is that your mother and siblings are sad and suffer; that’s the problem.” (age 39)

Although most participants eventually found supportive health providers, about half referenced some **insensitive treatment by providers**. Multiple participants perceived doctors delivering their diagnosis to be brusque or inappropriate, and lacking encouragement. This discouraged some women, promoting fear and mistrust. Other participants described nurses making offensive statements to them or other cancer patients, such as this 46-year-old woman who fought back verbally when nurses yelled at elderly or Quechua-speaking patients:

“People from the hospital should not treat others that way, especially not cancer patients. Because we do not have a cold or cough; we have cancer, and the behavior should be a little nicer.”

Institutional

Participants experienced barriers related to **limited facility resources**, including paperwork, bureaucracy, and insurance access issues, such as being unaware of SIS (Seguro Integral de Salud - Peruvian public insurance) eligibility and enrollment processes. Multiple women referenced long waits attending public hospitals:

“Sometimes there are problems of limited time; it [INEN] is a very small hospital for the number of patients who go because people come from all over Peru. Maybe you just have to have some patience, because they make you wait. Many times I have gone at 6am and I have left the hospital at 6, 7 at night.” (age 46)

Waits also involved longer-term bureaucratic delays: one woman caught her early-stage cancer in a yearly mammogram, but her diagnostic resolution was delayed 8 months by insurance and biopsy referral issues.

Participants further reported **poor coordination of care**, including medical misdiagnosis. Despite their fortunate status as survivors, six participants had received one or more misdiagnoses. Misread tests and unclear or missing instructions caused stress, out-of-pocket costs, complications, and delays, usually for months, but in one case for more than a year, which sometimes led to increased cancer staging:

“I felt a very small lump. I remember I went to get it checked out. They did an ultrasound but said that it was nothing serious, that it did not require a biopsy or anything. So then a year went by.”
(age 39)

After multiple tests and months of delays, two misdiagnosed women with financial ability traveled long distances for competent cancer care.

Facilitators

Individual

Participants told their cancer stories with remarkable **resilience**. While all portrayed cancer as difficult, many survivors experienced post-traumatic growth from cancer, reportedly becoming closer to God or family, or learning valuable lessons, including this 60-year-old woman:

“Now, I think [cancer] should not be synonymous with death. Cancer should be synonymous with life, because it gives you an opportunity to figure out what you have in life that’s worth fighting for.”

Many participants used **self-advocacy**, determination, and protests to obtain necessary resources for screening and treatment. This took the form of asking questions at appointments, following up after misdiagnosis, rejecting misinformation and stigma, and making decisions independently, like this 46-year-old participant whose doctor suggested she consult with family before a mastectomy:

“I told him, ‘Here, there is no need to consult my family. The disease is mine, the body is mine, I decide,’ because I have children and my children are still small. So, I opted for [the mastectomy].”

Four participants confronted institutional delays with intense verbal fights, two of whom threatened to call the press and thus successfully reduced hazardously long waits at public hospitals.

Interpersonal

Strong family support helped women survive in myriad ways. Most participants initially accessed treatment because they knew someone familiar with the medical system. Seven participants received family assistance in making these connections, including siblings who knew an oncologist, or relatives who were medical professionals. For example:

“I remember that an aunt told me, ‘Don’t wait a month; I have a friend, an oncologist who works at INEN, and they can check you over. You have nothing to lose.’” (age 39)

Almost all participants said family members provided emotional, informational, or economic support throughout the cancer experience. Despite worrying, participants quickly confided in their sister, daughter, or other family members about their symptoms and received prompt recommendations to go to the doctor or to INEN. Family and friends often accompanied participants to appointments. Some relatives lent money or provided advice about SIS. Family members also played the essential role of providing encouragement, which often motivated decision-making:

“I truly learned how to confront [the fear]... my son told me, ‘Mom, don’t be afraid. If the doctor says they should take out a breast, let them take it out, even if it’s both of them.’ So, I faced it with courage.” (age 67)

Many participants shared how **cancer support groups**, often sponsored by hospitals and doctors, provided significant psychosocial and informational support:

“I’m glad that at least there are people who cheer up, who see that they can be on chemo and their treatments without losing their joy, you know, and feel happy doing [support group] activities. It also helps me a lot. It’s like, I don’t need a psychiatrist or psychologist or anything. It has helped me a lot because it makes me feel good, it makes me feel relaxed, happy. Like I say, I think in those moments I am happier than I was before, when supposedly I was well.” (age 39)

Given the commonness of negative cancer care experiences, the majority of participants engaged in **community volunteering** with their support groups during and after treatment. The majority of participants and their peers offer one-on-one encouragement and information in their community or while waiting at hospitals:

“Because we have time to speak with other patients, I always tell them to not be daunted, to not be afraid, to have courage. Sometimes they are recently diagnosed, they cry. ‘Me too’, I say, ‘I went through the same, I also lost weight, I also got depressed, but look how I am now, I am well, I am upright. You will be like this too, you have to have patience, lots of faith in God, and faith in the doctors.’” (age 46)

Institutional

Financial ability and access to insurance were important facilitators for these participants’ survival. Those with private cancer insurance usually received faster diagnosis and treatment and had fewer institutional barriers than participants with public or no insurance. Low-income Peruvian participants were able to afford care through Plan Esperanza, which they accessed via SIS (Table 3).

“In my case, I did not encounter barriers because of the insurance policy I have. I did not have to struggle against the health system. They gave me everything easily... Surgery could have very well been delayed—if it had been through the regular system—between 2 or 3 months, without

reconstruction. So, I think that among [my country's] population, women have a very hard time, they have to struggle a lot.” (*age 38*)

In addition to interpersonal advocacy for others, some survivors participated in **local and national advocacy**. They joined awareness campaigns to share their stories, including speaking on TV or radio:

“I think that, based on my experience, we survivors have a very important role, because fear decreases upon seeing that one can survive.” (*age 56*)

Recommendations

To improve cancer care, participants recommended ensuring **destigmatizing** (“cancer is survivable if detected early”) and **instrumental** (“don’t stop treatment”) **information** is provided to all. Principally, preventive care and screening knowledge must be promoted. Participants recommended widespread education and suggested focusing on women’s empowerment and caring for their bodies. Publicizing cancer’s symptoms and treatment through radio and school forums was proposed, with additional screening events. To address lack of knowledge, improve morale, and reduce stigma, participants recommended newly diagnosed patients interact more with survivors:

“I tell you truly that the best person who can help a person with cancer is someone who went through it.” (*age 60*)

Some participants expressed that **after diagnosis** cancer patients need more psychological support at the institutional level, including sensitivity training for doctors and more visibility of complementary services such as nutrition counseling and support groups. Greater availability of high-quality cancer detection and treatment nationwide and within the national hospitals, was mentioned by several, including this 46-year-old participant:

“...There should be, I reiterate, more places, more hospitals, and improvement in the scarcity of chemotherapy rooms. At INEN for example, there are 120 patients daily, but more patients [come]. Sometimes there are no spots and then they don’t give it [treatment] to them, they prolong their chemotherapies. And the more days go by, the cancer keeps advancing.”

Discussion

This exploratory study assessed if and how systemic solutions to cancer control may be improved through obtaining patient perspectives on the multi-level issues faced during cancer care. Identifying the individual,

interpersonal, and institutional barriers highlight areas that may be further targeted by policy. Understanding what individual, interpersonal, and institutional resources these participants used to overcome barriers can further enhance cancer policies nationwide and within hospitals.

Notably, most barriers and facilitators identified have been well-studied in other contexts. Consistent with recent qualitative studies with breast cancer survivors in LMIC and low-income settings[19, 36], fear of the medical system, fatalism, cancer worry, and lack of knowledge about cancer and its treatment are prominent individual barriers while interpersonal facilitators in common included the importance of family support and interactions with survivors. In contrast to findings in other LMIC settings[2, 36], these Andean country breast cancer survivors did not report substantial stigma or worries related to mastectomy or losing their romantic partner. In line with others works[38], our study suggests that engagement in cancer support groups provides crucial social support and psychological health benefits during treatment, including resilience. Local and national advocacy also likely facilitates social support via connections with other cancer survivors[44]. Documentation of these barriers and facilitators provide necessary data for multi-level policy change in this specific local context.

This study begins to fill a gap in research identifying what barriers persist in the era of Andean country national cancer plans such as Peru's Plan Esperanza[10], through the use of important, underused stakeholders – the patients and survivors themselves. Survivors can play a pivotal role in developing and executing these curricula via advocacy and policy involvement[43]. By engaging survivors and incorporating their experiences, future psychosocial and multi-level interventions can address barriers of stigma among cancer patients and within the community, while simultaneously confronting lack of awareness about prevention, insurance, and timely cancer screening.

Based on these women's accounts and other Peruvian key informants' reports[8], there are persistent institutional barriers (e.g., miscoordination of care) that should be relieved through multi-level policy changes[12]. Strategies already exist in the United States context[13, 15] to improve resource allocation by hospitals, Plan Esperanza, and insurance providers. Whenever possible, institutions should incorporate family education and involvement[12] and essential support group activities in patients' recovery, and provide spaces for cancer patients' concerns to be addressed promptly[19]. Provider sensitivity and communication trainings, as recommended by our participants, can reduce distress, misinformation, and stigma among patients[12, 24]. These survivors are adamant

that future cancer patients not suffer as they have, and therefore nationwide education efforts must promote a culture of prevention throughout society, as recognized by cancer literature in LMICs[2] and elsewhere[12].

This study has two principal limitations. First, our findings may not be generalizable. Our participants do not necessarily represent other cancer survivors who do not attend survivorship conferences. Additionally, three of the four countries represented in our study have only one participant; the rest are Peruvian, likely a result of the conference's location in Lima. Second, our study focused primarily on patient perspectives, but other perspectives are also warranted to develop policies that are responsive to all stakeholders' needs. Assessing key informant perspectives such as family members and hospital staff would enhance knowledge about cancer survivorship in Andean countries.

Despite these limitations, these survivors contribute richness of experience across socioeconomic strata, geographic regions, and levels of prior knowledge about cancer and the medical system. Our results may not be generalizable to all survivors in Andean countries but nevertheless provide insight into the struggle to achieve survivorship, mainly utilization of individual, interpersonal, and institutional resources to overcome barriers and cultivate resilience. Follow-up research should explore barriers and facilitators to engagement and retention in care among less-privileged Andean survivors of women's cancers, including indigenous and rural survivors.

Fig 1 Conceptual Framework, informed by Ashing et al[43] and Molina et al[44]

Table 1 Sample questions from semi-structured interviews	
Illness Phase	Questions
Symptom disclosure	<p>When you first noticed a change in your health, did you share your symptoms with a friend or family member? Why or why not?</p> <p>What was their reaction and/or advice?</p> <p>How did you respond?</p>
Care-seeking	<p>Could you share how your symptoms progressed?</p> <p>What motivated you to seek medical attention at that time?</p> <p>Could you share where you sought medical attention? Why did you choose there instead of another place?</p> <p>Can you share what happened in that first visit?</p> <p>Could you share any barrier you encountered when looking for medical attention, and how you overcame those?</p>
Diagnosis	<p>How did the health providers or healers respond to your worries?</p> <p>Were you alone or accompanied?</p> <p>Could you share your first reaction when you were diagnosed?</p> <p>Can you share when you disclosed your disease to a friend or family member?</p> <p>How was that experience and how did you decide to do that?</p>
Treatment	Tell me about your experience with the treatment.
Advocacy	<p>Have you participated in any visibility or education campaign directed at promoting early detection? If so, can you share that experience?</p> <p>What impact did those interventions have?</p>
Recommendations	<p>What do you think are the main barriers for women engaging in care?</p> <p>How do you think early detection could be improved in Peru or your home country?</p>

Table 2 Participants' socio-demographic information
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	Peruvian	Non-Peruvian
N	12	3
Mean Age (Range)	56 (39-67)	49 (38-60)
Education Completed	Primary or less: 2 High school: 4 Superior/Technical: 7 University or more: 2	High school: 1 University: 1 Graduate: 1
N without children	6	1
Stage at diagnosis	I: 3 II: 4 III: 5	I: 2 II: 0 III: 1
Mean years since first diagnosis of reproductive cancer (Range)	4.0 (0.8-9.3)	8.1 (2.4-13.8)

Table 3 How survivors paid for cancer care				
Cancer ultimately covered by:	Peruvians	Non-Peruvians	Income level	Selected explanations
Private insurance	4	3	All mid or high	1 (non-Peruvian) still had to pay for medicines out of pocket, because her insurance did not obtain them on time. 1 (Peruvian) was falsely accused of hiding pre-existing condition, was denied cancer coverage, then qualified for estranged husband's insurance.
Public insurance: SIS/Plan Esperanza	5	-	All low	Relatives recommended SIS. Some were unaware of SIS: 2 spent much money out of

				pocket first.
Out of pocket only	3	-	1 high 2 mid	1 (high-income) had financial ability, 1 did not qualify for SIS, 1 private cancer insurance was unusable for negative test results despite actually having cancer.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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