Published in final edited form as:

Health Care Women Int. 2020 May ; 41(5): 510–523. doi:10.1080/07399332.2019.1608206.

Positive Cancer Care in Peru: Patient and Provider Perspectives

Paul E Nevin[1], **Magaly Blas**[2], **Angela Bayer**[3], **Marina Angelica Chiappe Gutierrez**[2], **Deepa Rao**[1], **Yamilé Molina**[4]

[1]University of Washington, Seattle, WA

[2]Universidad Peruana Cayetano Heredia, Lima, Peru

[3]Univeristy of California Los Angeles, Los Angeles, CA

[4]University of Illinois at Chicago, Chicago, IL

Abstract

Peruvian women experience high mortality from reproductive cancers, partially due to suboptimal cancer care utilization and experiences. In this qualitative study, we examined factors contributing to positive cancer care experiences. Our sample included 11 cancer patients and 27 cancer providers who attended the First International Cancer Symposium survivorship conference in Lima, Peru in 2015. We conducted thematic analysis. Emergent themes revealed that, for patients, individualized empathic care by providers was an important facilitator to positive cancer care experiences. For providers, the ability to provide such care depended on provider norms and facility infrastructure to support such patient-centered practices.

Keywords

Breast cancer; patient-centered care; Latin America

Alleviating the burden of female reproductive cancers is a public health priority in Andean countries, including Peru (PAHO, 2013; Zelle et al., 2013). Despite relatively low incidence, Peru experiences high cancer mortality rates compared to other South American countries and other geographic regions, including North America (Desantis et al., 2015). These high mortality-to-incidence ratios exist in part due to suboptimal utilization of screening, diagnostic care, and treatment (Huaman, Kamimura-Nishimura, Kanamori, Siu, & Lescano, 2011; Soneji & Fukui, 2013; Zelle et al., 2013). Such suboptimal utilization reflects a myriad of barriers at individual, interpersonal, and systemic levels, including negative previous cancer care experiences (Hayes Constant, Winkler, Bishop, & Taboada Palomino, 2014; Huaman et al., 2011; Paz-Soldán, Bayer, Nussbaum, & Cabrera, 2012; Soneji & Fukui, 2013; Zelle et al., 2013). In response, Peruvian community campaigns have been implemented to address individual factors contributing to cancer care utilization, including providing education and addressing psychosocial barriers (e.g., fear, shame; CDC, 2012). Since 2004, multi-stakeholder efforts have been made to develop and implement cancer

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Corresponding author's contact information Yamile Molina, ymolin2@uic.edu, Telephone: 312-355-2679.

Disclosure. None of the authors have any financial interests or benefits to disclose.

control plans in Peru (INEN, 2006; Vidaurre et al., 2017). Most recently, Plan Esperanza, a population-based national plan to increase access to and quality of cancer care in Peru, was approved in 2012 (Vidaurre et al., 2017). The current study adds to growing multi-sectoral efforts by characterizing what are perceived to be positive cancer experiences among patients and understanding what factors contribute to such experiences in Peru. Such work will be helpful for future efforts to optimize utilization of cancer care and quality of experiences when patients engage in care.

Providers are important agents in patients' cancer care experiences (Arora, 2003; Ha & Longnecker, 2010; Hack, Degner, & Parker, 2005; Street, Makoul, Arora, & Epstein, 2009). A substantial body of work exists concerning negative cancer care experiences (Bone, Mc Grath-Lone, Day, & Ward, 2014; Brown, Ham-Baloyi, Rooyen, Aldous, & Marais, 2016; McCormack et al., 2011; Prouty et al., 2014; Thorne, Bultz, & Baile, 2005; Thorne, Hislop, Armstrong, & Oglov, 2008). For example, previous research has identified negative provider-patient interaction as an important interpersonal barrier to care utilization for Peruvian populations (Johnson et al., 2018). At the same time, researchers have begun to examine how providers can facilitate positive cancer care experiences, including patient-centered care. This literature has demonstrated a heterogeneity of patient perspectives on what is "positive" and "optimal", including cultural differences in types of support preferred, interest in shared decision making practices, and unique needs (Arora, 2003; Fuertes, Toporovsky, Reyes, & Osborne, 2017; Hedström, Skolin, & von Essen, 2004; Hohl et al., 2016; King & Hoppe, 2013; Y. Molina et al., 2015; Yamile Molina et al., 2014; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

One gap in positive cancer care literature concerns the focus on the experiences of women living in the United States and other high-income countries, which may not be generalizable to women living in different socioeconomic and sociocultural contexts within low- and middle-income countries. For example, clinical empathy may be particularly important for US-based Latinas, many of whom are of Mexican descent, because of their transnational status and limited ability to access family and friend supports (García, 2017; Yamile Molina et al., 2014). Their preferences, shaped by these unique experiences, may differ from Latina women living with their family members in Latin America. On the other hand, clinical empathy may be universally important for Latina immigrants and nationals, if preferences reflect broad sociocultural norms and values within Latin America (Bonilla & Bonilla, 1998). Research is warranted to clarify these different scenarios.

Another gap in positive cancer care literature concerns the focus largely on patient perspectives. Consequently, theoretical models regarding positive cancer care experiences and patient-provider communication have had detailed, comprehensive conceptualizations about interpersonal and intrapersonal determinants (e.g., patient socio-demographic and psychosocial factors; clinician demographic and professional factors; patient-provider concordance and relationship dynamics (Feldman-Stewart, Brundage, & Tishelman, 2005; Lafata, Shay, & Winship, 2017; Mead & Bower, 2000)). Models have however been relatively less detailed in terms of interpersonal factors from the perspective of the provider and systemic factors (Lafata et al., 2017; Mead et al., 2000). While Lafata and colleagues (2017) described community/policy, delivery systems, and clinical contexts, the specificity of *which* aspects of these contexts however and *how* they may influence exchanges between patients and providers was not specified. Mead and colleagues (2000) identified specific aspects of providers' environments (e.g., professional norms, performance incentives and goals, accreditation, government policies); yet, *how* they affect doctors' attitudes, values, knowledge, and consequent behavior is not well-specified. This gap in conceptual frameworks reflects a relative dearth of qualitative research concerning providers' perspectives on communication and cancer care overall (Najjar, Davis, Beck-Coon, & Carney Doebbeling, 2009; Prouty et al., 2014). Obtaining providers' perspectives may be however useful for comprehensively understanding the multi-level determinants of positive cancer care experiences, given patients may be able to identify interpersonal and institutional factors in healthcare (e.g., negative patient-provider communication, limited faculty resources) as part of their personal journeys (Johnson et al., 2018). Thus, patients may not necessarily know exactly how interpersonal interactions with providers may be affected by and/or intersect with the complex healthcare systems in which care is situated.

We seek to address these two gaps in the literature by leveraging the strengths of a qualitative, inductive approach to comprehensively assess patients' and providers' viewpoints on positive cancer care experiences in Peru. First, we will explore Peruvian patients' perspectives on positive cancer care experiences to examine what is shared with patients from other countries and what is unique. Second, we will assess patients' and providers' perspectives in terms of interpersonal and institutional factors that affect positive cancer care experiences.

Methods

Setting

The current study is a secondary analysis of a larger study focusing on cancer survivorship experiences in Peru. These cancer survivors' perspectives on women's cancer barriers and facilitators in Peru have been previously published (Johnson et al., 2018). The parent project was conducted in March 2015 during the First International Cancer Symposium survivorship conference in Lima, Peru.

Procedures

All procedures and materials were reviewed and approved by all participating institutions' Institutional Review Boards. During the conference, researchers identified and recruited cancer survivors and providers to participate in, respectively, individual interviews and focus groups. Eligibility criteria for patients were: 1) 18 years or older; 2) Spanish speaker; 3) previous breast cancer diagnosis; and 4) initiated or completed treatment for breast cancer. Eligibility criteria for providers were: 1) 18 years or older; 2) Spanish speaker; and 3) self-identified as a healthcare worker who has provided care for patients diagnosed with cancer. If eligible, participants completed written consent forms. For the current study, we focused on a subset of this sample who identified as Peruvian in order to obtain country-specific patient and provider perspectives.

Four Spanish-speaking investigators (AB, MCG, MB, YM) subsequently conducted audio-recorded semi-structured individual interviews with survivors and focus groups with providers. Given the potential for cancer-related stigma, individual interviews were conducted with survivors in closed rooms within the conference venue to obtain in-depth, private information (Gill, Stewart, Treasure, & Chadwick, 2008). Conversely, focus groups were considered appropriate for providers, given the interest in understanding the perspectives of local healthcare communities as a collective in terms of cancer care. Thus, two focus groups (13 and 14 providers) were conducted. Interview and focus group guides, with probes, were used to elicit responses on a broad range of aspects related to cancer care in Peru. All participants received $3 compensation for their time.

Analysis

Interviews and focus groups were transcribed verbatim in Spanish by a professional transcriptionist and uploaded into ATLAS.ti version 7 (Berlin, Germany). We utilized a combined deductive and inductive analysis approach, in which themes from different samples were explored and new themes were identified from the raw qualitative data (Bernard & Ryan, 2010). Two co-authors (YM, PEN) adapted a codebook from previous analyses of similar interviews with US-based Latinas and other US-based women (Hohl et al., 2016; Y. Molina et al., 2015; Yamile Molina et al., 2014). The original codebook included codes pertaining to different types of provider support and communication styles associated with patients' satisfaction with care. Salient themes important to the current study's sample of Peruvian women (e.g., multiple types of support needed) were identified and included in the codebook. The coders worked independently and met regularly to address coding disparities, cluster similar concepts together into categories representative of themes, and discuss findings.

Results

Table 1 depicts the demographic characteristics for the 11 patients and 27 providers who participated in the study. When patients described positive cancer care experiences, their focus was on interpersonal communication with their providers and specifically providers' roles as agents in facilitating positive experiences. Providers described similar aspects of positive cancer care experiences and the importance of patient-provider communication; however, their focus concerned systematic factors.

Patient perspectives: the importance of individualized, empathic care for positive cancer care experiences

Participants emphasized individualized, empathic care as paramount to a positive cancer care experience. This theme generally emerged when describing providers' numerous experiences with cancer in contrast to patients' unique experience with their own cancer, as depicted by Respondent #109:

> I think doctors should remember that every patient is a world apart from the other. If you have cancer, your cancer is very important, for the patient. [Providers] should not take it j, as if all [patients] are the same…care should be individualized…because in those moments, one is very sensitive, very concerned –

> and you want the support of a person supposedly has the task to heal…the doctor that gave me my diagnosis gave it nonchalantly. I guess they're used to telling people who have cancer and do not realize that for one [the patient], it is not normal…that they give you the diagnosis in such a cold way.

Other patients emphasized that informational support without emotional support may have an unintended deleterious impact, as exemplified by these respondents:

> He just told me, it's cancer of a third grade and I'll send for the doctor…at least it will be about five chemotherapies. I mean, I got scared. I left there. I said, but why did this doctor talk to me like that, instead of telling me-giving me more encouragement…'yes, do not worry.' He did not meet my expectations, that doctor, because instead of giving me security, he gave me fear and mistrust. –#104

> I did not like his treatment…he told me, 'I'm going to operate – come back.' I did not come back because I did not like it…I did not like how he told me. The manner in which they can tell you says much – in a way that patients have to take it. It's decisive…He told me, 'You have cancer.'…and in that moment, I decided not to cry because he thought I would cry…how the doctor told me – without anything of kindness or humanity. – #107

In contrast, patients who experienced individualized, empathic cancer care highlighted its effects on their optimism during a frightening experience, as illustrated by Respondent #121, "They wanted to support me…I was in good hands. It was a team I also knew well. They operated on me. I received the treatment calmly – not worried at all." Further, providers' empathic communication and encouragement enabled some patients' self-advocacy in the context of information seeking, as exemplified by Respondent #108:

> He gave me a response and it gave me tranquility. He said, calm yourself, because here in Peru there are good treatment options…stay calm, seek treatments and procedures and everything will go well. So, I listened to him like someone who knows, learned about this issue [cancer], welcomed the protocol, did the treatment, and outside of the time, I learned all about the issue [cancer]."

Provider perspectives: the importance of systems to ensure individualized, empathic care and positive cancer care experiences

While understanding the importance of individualized, empathic care, providers often discussed the difficulty of providing such a service. First, they described how healthcare system requirements inhibited them from being able to provide personalized care, as exemplified by Respondent M11 (Obstetrician/Hospital Leader in Strategic Cancer Plans):

> I do not want to miss the opportunity to mention what is always commented... [which is] to sensitize health personnel – all health personnel…to feel and tell them that we are working with people…not numbers... [but] if we are asked to increase our coverage in terms of tests…I have to achieve that objective and not do my job well…we leave quality work that is part of quality treatment – good treatment – left by the side for those 'sacred' numbers. For those 'sacred' numbers, we ignore how to care for the consumers [patients].

Some providers discussed a nuanced interplay between norms and personality types among healthcare professionals that affected relationships with patients. They also discussed their lack of systemic training to promote empathetic, individualized care:

> The other thing I always see as a barrier is the attitude of health professionals… who often arrive at communities with a paternalistic attitude. We know everything…they know nothing...what happens is that we have not developed the appropriate methods for communicating to each community.-- Respondent M12 (Hospital-based Health Promotion Worker)

> I shall refer the personnel…most are temporary and their instability does not allow the community to engage and trust them…the problem is the overload of administrative work the staff has in relation to time that should be given in guidance and counseling to the patient…there is also a lack of training, because not everyone has the personality to be [empathic] counselors…at times, we obligate ourselves to meet an [administrative] objective, but the problem is that the attention should be to the patient. –Respondent M21 (Cancer Control & Prevention Surveillance Technician)

Finally, providers noted that patients may misattribute delays in care to individual providers' lack of concern, instead of attribution to limited facility resources. Such misattribution would, they believed, might impact patients' perceptions about care experiences and decisions regarding future care utilization.

> What we have also seen is the delay of the Pap test result. Three months pass, then six months…[patients] go to the facility continuously and the result does not arrive. So, they think to themselves, "Why am I going if they won't give me the result or will tell me there is nothing [wrong]?." – Respondent M15 (Regional Cancer Control Program Coordinator)

> I would divide [the blame] into two parts: one that is the patient and the second the healthcare professional. The healthcare professional will create an [administrative] barrier, then that hinders the patient…the patient themselves has beliefs...the other is a lack of interest in the patient, because they delayed the result by so much time, that the patient believes it is not important…it took three months-four months – so it can't be so important, because it didn't interest the healthcare professional. – Respondent H11 (Oncology Surgeon/ Hospital Leader in Strategic Cancer Plans)

Discussion

At the same time that many HICs are seeing decreasing rates of cancer deaths, cancer mortality is increasing in LMICs (Torre, Siegel, Ward, & Jemal, 2016), including in Peru (PAHO, 2013; Zelle et al., 2013). To complement efforts to address this public health priority, we examined what was associated with positive cancer care experiences within the Peruvian context from patient and provider perspectives. We sought to address two gaps in past literature. First, we examined if Peruvian patients were similar to other patients in terms of what contributed to positive cancer experiences. Second, we explored what interpersonal and institutional factors patients and providers discussed in relation to positive cancer care experiences.

Our study suggests that Peruvian patients find individualized, empathic care a facilitator to utilization of cancer care services. Such data align with existing literature concerning positive cancer care experiences among US-based Latinas and other ethnic minorities with similar sociocultural norms, practices and values (Arora, 2003; Hohl et al., 2016; Y. Molina et al., 2015; Y. Molina et al., 2014). Our data thus support that perhaps there is some overarching overlap in sociocultural contexts among US-based Latinas and Latinas within other countries. This work further supports the increasing popularity of patient-centered care (Epstein & Street, 2007; McCormack et al., 2011; Venetis, Robinson, Turkiewicz, & Allen, 2009), which emphasizes the importance of empathy and understanding care from patients' unique, potentially singular, experiences with cancer. Although primarily studied in the US and other high-income countries (HICs), these results confirm the international applicability of patient-centered care, including in low- and middle-income countries (LMICs). Our work thus aligns with recent efforts to expand access and utilization of patient-centered care approaches. For example, the International Consortium for Health Outcomes Measurement (ICHOM) recently assembled an international working group of providers, advocates, and patients to develop standardized value-based, patient-centered breast cancer outcomes (Ong et al., 2017). There are two potential theoretical reasons regarding why empathy may be important internationally (Gagan, 1983; Halgren 2003; Lorié, Reinero, Phillips, Zhang, & Reis, 2017; Nelson-Jones, 1983; Rogers, 1957, 1975). First, empathic communication may reflect that providers are actively considering patients' unique situations, including their individual frames of reference about the diagnosis (e.g., family history, cultural attributions of disease), preferences, emotional affect, and behavioral responses. Under this scenario, empathic communication may be universally important in that patients may prefer to have providers who are tailoring their communications and interactions to their specific circumstances. Second, empathic communication may be important in that providers' cognitive, emotional, and behavioral responses to patients may reflect providers' accurate perceptions of patients' cognitive, emotional, and behavioral responses to a major traumatic event. Under this scenario, empathic communication may be important as it reflects providers' shared identities or awareness of how to understand when to provide and how to convey kindness in a culturally accurate manner. Future work is warranted to explore these hypotheses further and advance our understanding of culture, empathy, and cancer care.

Our study highlights the importance of multi-stakeholder qualitative inquiry for assessing women's cancer care programs throughout the world. Local, context-specific program evaluation is essential for cancer care programs, particularly when assessing strategies and methods developed in HICs for implementation in LMICs. Promising, international collaborative breast and cervical cancer control programs are being piloted in low-resource settings throughout the world, but need rigorous evaluation using implementation and social science methods to inform policy (Ginsburg, 2013). Obtaining stakeholder feedback from patients and providers to guide program implementation is a central component of an implementation science research framework for cancer prevention and control programs in LMICs (Sivaram, Sanchez, Rimer, Samet, & Glasgow, 2014). Our work further highlighted distinctions between patients' and providers' lens of understanding and lived experiences.

Patients focused on the on the interpersonal aspect of patient-provider communication. Providers agreed with this perspective and provided concrete strategies for facilitating such communication and positive cancer care experiences. Certain suggestions aligned with previous qualitative research with US-based providers, including system issues such as a lack of time designated for individual patients and administrative aspects of care (e.g., payment, protocols, coordination and care policies) (Prouty et al., 2014). Other emergent themes, including professional norms and awareness of patients' interpretations about delays, support aforementioned frameworks (Mead & Bower, 2000).

Given our participants' suggestion that the patient-provider dyad is strengthened and providers mentioned their lack of training in empathic communication, these results suggest the need to develop training programs in Peru for providers around empathic communication and patient-centered care. Plan Esperanza provides training to health care personnel in the continuum of cancer care and has built some infrastructure to provide such trainings (Vidaurre et al., 2017). Prior to this, an environmental scan that assesses provider's willingness to participate in these trainings would also be welcome. Such a scan would be crucial, given providers in our study emphasized limitations to providing such care due to systemic requirements and a lack of resources. Our participants noted that in order to enable providers to provide such care, there must be supports at organizational and healthcare system levels. Such facilitation of trainings may be operationalized, depending on the extent to which the workforce has been expanded under the Plan Esperanza, resulting in reduced administrative burden for individual providers. On the other hand, administrative burdens may be potentially increased through requirements associated with safety and quality indicators under Plan Esperanza (Vidaurre et al., 2017). In this case, the prioritization for such trainings and capacity to do so may be limited for providers. Altogether, our findings provide some suggestions for future research and development of strategies to promote positive cancer care experiences for Peruvian breast cancer patients: nonetheless, it is crucial to situate these recommendations within the unique Peruvian era of Plan Esperanza.

Our study had limitations. First, we used a convenience-based sample of patients and providers attending a cancer conference. Thus, the generalizability of our findings is limited. Future studies with probability-based sampling are warranted to confirm our work. Second, although these patients and providers experience cancer care from a similar health system, further research should focus on shared perspectives from more acutely focused settings, such as clinics in rural settings. Future studies should generate purposive sampling that enables within-hospital comparisons of patients and providers in the future. Third, in the present study, we conducted secondary data analysis of qualitative data. It was not our original objective to examine patient-provider communication when we first set out to conduct the study. In fact, the themes of interpersonal communication were prominent and ripe for suggesting future directions, and thus we have brought out these themes in this paper.

Conclusions

In conclusion, our study highlights important venues by which providers can contribute to growing multi-sectoral efforts to reduce cancer burden in Peru. We highlight the importance of future provider trainings in clinical empathy and patient-centered care. Simultaneously, our work highlights the importance of systemic solutions for cancer education, such as Plan Esperanza, to ensure that such training results in feasible and sustainable adoption of evidence-based practices. Future research is warranted to address limitations described above. Our work provides important baseline data in the era of Plan Esperanza – a new landscape for oncology practice in Peru. In the coming years, researchers should explore how providers' roles in positive cancer care experiences change, including through the perspectives of patients as well as in terms of the ability to do so through the perspectives of providers. Such work along with collaborative efforts with practitioners, patient advocates, community leaders, and policy makers will help to characterize and optimize cancer care experiences in Peru. Such work may further be helpful for understanding patient-centered care in other low-resourced oncology practice settings.

Acknowledgements:

The authors would like to acknowledge JoAnne Zujewski for technical assistance and support of the larger project and Silvia Lara for her assistance with.clinical empathy literature. Partial support for this research came from a Eunice Kennedy Shriver National Institute of Child Health and Human Development research infrastructure grant, R24HD042828, to the Center for Studies in Demography & Ecology at the University of Washington. YM was also supported through the National Cancer Institute under grant numbers K01CA193918 and R25CA92408. MB was also supported by the Fogarty International Center through grant 1R25TW009710–01.

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Table 1.

Study sample characteristics.

	Patients (n = 11)	Providers (n = 27)
	M (SD)	**M (SD)**
Age	55.60 (8.86)	41.70 (7.85)
Years since diagnosis	5.50 (2.46)	--
	N (%)	N (%)
% Female	11 (100)	23 (88)
% Married	6 (55)	--
% With children	6 (55)	--
% early stage diagnosis	7 (64)	--
Profession	--	
Surgeon	--	4 (15)
Obstetrician	--	17 (63)
Primary Care Doctor	--	3 (11)
Other	--	3 (11)
% Affiliated with INEN[1]	55 (5)	2 (7)

[1] Instituto Nacional de Enfermedades Neoplásicas, a major cancer care hospital located within Lima, Peru.