

“And, then there are the lines”: Crossing the Border for Cancer Care; Not

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Abstract: This interpretive phenomenological study explored breast cancer health care-seeking experiences of documented Mexican immigrant women living on the US-Mexican border. Interviews, observations and Photovoice were conducted with 7 Mexican immigrant women utilizing patient navigator services in California who had been diagnosed with breast cancer and received health care services on either side of the border. Both structural and social barriers to care exist for immigrant women with breast cancer. Participant narratives revealed that their health care seeking experiences were often characterized by long waits for care and language barriers. Patient navigator services and state health care coverage specifically provided for breast cancer help alleviate some of these barriers. Modifying current policies to encourage greater communication between the health care systems on either side of the border could contribute to reduced wait times, language barriers and suffering of patients.

Introduction: Latino cancer patients in the United States, particularly those residing in medically underserved areas, face health disparities associated with social, economic, and cultural barriers resulting in poorer health outcomes and lower quality of life.¹⁻³ In Mexico, where breast cancer is the second leading cause of death among women aged 30–54, the need for attention is considered a “pressing priority” by medical authorities.⁴ The rural Imperial County, in southern California, is located on the US-Mexico border directly across from the city of Mexicali, the capital of Baja California, Mexico. It has been estimated that up to half the residents on the Texas-Mexico border have crossed into Mexico to utilize some form of health care, yet little is known about this phenomenon for women with breast cancer in California.^{5,6} Agricultural workers from Mexicali, Mexico move to Imperial County, CA in search of work and may seek health care on either side of the border, thus providing an optimal location and situation in which to study immigration and cross-border utilization of health services. We used a mixed-methods approach to examine access and barriers to health care and cross-border utilization of services among immigrant women with breast cancer on the

US-Mexico border. By combining qualitative and quantitative methods we aim to provide a holistic, patient-centered perspective of breast cancer on the border and the experience of cross-border cancer care. The techniques entailed in photovoice enabled a small group of selected participants to share their lived experiences visually with policy makers, while ethnographic interviews with patients and key informants allowed for a culturally rich and deeper exploration of the care seeking experience and barriers to care. Following the ethnographic methods, we used validated survey instruments to measure quality of life, access and barriers to care and utilization of cross-border health services.

Background: Health disparities in accessing cancer treatments have been persisting in the United States, particularly for cancer patients who reside in medically underserved areas, have limited or no health insurance coverage and were born outside the US.^{7,8} A study conducted with residents on the US-Mexico border by Bastida, et al., reported that 60% of respondents under the age of 65 had no health insurance.⁹ Residents with cancer in underserved areas suffer from a lack of access to appropriate treatment, lack of knowledge about cancer and, consequently, worse treatment outcomes. These patients face extensive social, economic, and cultural barriers that hamper health outcomes and lower their quality of life.^{10,11} In the United States, individuals who reported that they had “ever been diagnosed” with cancer were likely to be considered uninsurable in the current private non-group market (until 2014, when parts of the Affordable Health Care Act became effective).¹²

Imperial County, California, is a poor rural county with the highest unemployment rate (26.9%) in California.¹³ Based on 2008 U.S. Census data, approximately 76% of residents are Hispanic, 70% speak languages other than English at home and 24% of families are

living below federal poverty level.¹⁴ Among the Imperial County population, Hispanics had a higher breast cancer mortality rate (20.96 per 100,000) compared with the statewide average (17.71 per 100,000) based on state cancer registry data, 2000-2007.¹⁵ Nationally, in 2006, 34% of Latinos were uninsured, compared with 11% of non-Hispanic whites and 21% of African Americans.¹⁶ Patient Navigation Programs (PNPs) were designed to assist cancer patients with overcoming such barriers and accessing cancer treatment in a timely manner.¹⁷ The PNP program in Imperial County has been serving cancer patients since 2006 and contributing to the improvement of cancer treatment access and health outcomes for immigrant families.

Study objectives: The study explored personal agency, border identity and social agency as seen through the eyes of Mexican immigrant women living with breast cancer on the US-Mexico border. It examined some of the significant social actions that breast cancer patients and their advocates take and the complex series of processes required to attain life-saving procedures on either side of the border in the face of cultural, political and economic barriers. The specific aims for this project included to:

- 1) understand the phenomenologically rich 'lived experience' of breast cancer among low-income immigrant women using patient navigator services on the US-Mexico border;
- 2) gain an understanding of the process of seeking and utilizing health services on the Mexican side of the border by breast cancer patients living on the US side;
- 3) promote reflection and discourse about the health care experiences, reasons for the underutilization of services, and the types of services needed by this population,
- 4) and reach key local policy makers through the voice of the participants.

Result summary: The research setting is located within close proximity to the Mexican border and daily border crossing for commercial purposes is a common occurrence.

Health care seeking history, we initially expected, would have a direct bearing on seeking breast cancer treatment on the Mexican side of the border by immigrant patients living in the U.S. Our *a priori* expectations based on the literature and research experience were that more patients would seek chemotherapy and radiation treatment in Mexico. Our results show that patients receiving patient navigation services prefer to receive their cancer treatment in the U.S., although they continue to seek general health care and pharmaceutical services in Mexico.

Care in the US may be delayed due to (1) a wide-spread perception that patients need health insurance in order to access diagnostic care, (2) tissue samples from biopsies not allowed to be transported across the international border, (3) written results of biopsies not accepted by the U.S. health care system and (4) language barriers and lack of professionally trained translators.

Care in Mexico may be delayed due to (1) emigrants from Mexico not being eligible to access Mexican public health system, (2) long wait times for appointments for services, including, ultrasound and mammogram.

Care on both sides of the border may be delayed due to (1) excessive waiting times for medical appointments, (2) transportation issues, (3) out of pocket expenses not covered by health insurance.

Patients living in the contested border space between the first and third worlds describe situations in which lifesaving care was delayed for months. While the results of our study are not representative of the general population, the great majority of participants

preferred to receive their treatment on the U.S. side, because of advancement of medical science and higher quality of care. They expressed a lack of confidence in health care systems and facilities in Mexico, particularly technology; rather than in individual physicians. Participants showed strong willingness to be involved in community activities to support cancer patients through more opportunities for them to be engaged and advocate for community action to receive better cancer care.

Whitaker Manderson and Cartwright (2010: 336) right that:

although the trade carries economic benefits for countries receiving foreign medical patients, it comes at a cost to the provision of public health, through distortions in the health workforce and the development of of two-tiered health systems. Inequalities and failures in the health systems of sending countries largely drive the need to travel for care. [CITE]

Design and Methods

Interpretive phenomonology or phenomonography

Data Collection

This research was approved by the Committee on Human Rights at San Diego State University and the Colegio de la Frontera Norte. Each participant signed a sepearte written consent for interviews and Photovoice. Pseudonyms are used in publications and transcripts stored and locked in a secure location.

Patient navigator program

The study was conducted at the office of a patient navigator program located in a rural California town within close proximity to the Mexican border. The program provides navigagator services to

The participants

A purposive sample of study participants was recruited through the patient navigator program, where participants were assisted in accessing health insurance and referred to local oncological services. Participants were paid \$20 for each interview.

Inclusion criteria required that participants....

Eight immigrant Mexican women were recruited from the navigator program by the director of the program. Each woman was over the age of 40. Each woman was interviewed once for approximately two hours. Seven participated in the Photovoice sessions.

Data were collected by the first and third authors using ethnographic methods, including interviews, participant observation, and reflexive field notes (which were discussed by all three authors). Interviews were audio recorded and followed an open-ended, semistructured guide to explore (a)....(b)

All one-to-one interviews were conducted in Spanish by the first author and Photovoice interviews conducted in Spanish with first and third author, who is a native Spanish speaker. Interviews were transcribed verbatim and translated into English by local multicultural and multilingual translators and the first author.

Data Analysis

Iterative in nature.

Three levels of analysis: thematic; exemplars; paradigm cases.

Methodological Rigor

Triangulation: Open-ended interviews; Photovoice; drawings; survey. Reflective memoranda

Findings/Themes

Living on the border
Wanting to live (Rosalba)
Waiting
Goes to Mexicali for everything except cancer care
Transition

Then there are the lines:

That for them there was nothing, they said there was no cancer, because they touched me and nothing was felt. But as I say the mammogram said other thing. That is why they did other tests more profound but that was here in this side. When cancer came out they said that it was cancer and my daughter was the one who told me "no mom we should go there, there to the house, because we have to think that you need surgery, the surgery any way, but the chemo, you are going to need daily later and we can't be coming daily because everyone works," and I don't know how to drive. That is another problem. Then there are the lines, you see that two or three hours of like to come here, and other two hours to go out, and my daughter said,

“when.” And if it is daily they told me to think. And we went here, and thanks God everything was faster, and like I told you better. For me the treat was better.

N. In what way? How is it better?

Y. well how I can tell you... just saying you go there and... no, I can't explain how

N. but it is different

Y. yes it is different

N. but different in what way?

Y. like I said, to me is the way they treat you, the attention is better here.

N. they pay you more attention. What type of attention do they give you here that not... what is the difference?

Y. how can I tell you...

N. take your time, it is a really hard question. I try to understand the differences.

(Silence)

Y. well it may be that it is slower on the other side, like I say with my mom they last a lot of time, after they detected it they last a lot of time

N. a lot of time during the appointments, or a lot of time waiting...

etc.

Discussion

Strengths and limitations

Implications for practice (?)

Implications for policy

References to include:

Husserl

Chandler, Juliet

Results Iterative process

- Waiting
- Translators
- Insurance
 - Blessed because I had breast cancer
 - and not another form of cancer
- Cost: don't pay anything

- Rosalba . Had to pay about \$1000 for the first exam. The hospital where she was diagnosed cost \$336.
- Confidence in doctors
 - Here it is the money and time

Rosalva describes how she was delayed in the US by two months because of the bureaucratic system: “In the US it is the time...because you have to meet requirements to see an oncologist. That is to say, you don't go to an oncologist. I go to Mexico and I say that I want to see an oncologist and they immediately let me. Here no. Here is a process. They have to send papers, demonstrate that I had cancer. I was delayed by 2 months.”

Discussion