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Barriers and Challenges of Cancer Patients and Their Experience with Patient Navigators in the Rural US/Mexico Border Region

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Abstract Patient navigation is a widely used approach to minimize health disparities among socioeconomically marginalized cancer patients. Although patient navigation is widely used, there is a dearth of studies exploring patient experience with navigators among rural cancer patients. This qualitative study explores the challenges and barriers to cancer care faced by cancer patients living in a US/Mexico border region in Southern California. We individually interviewed 22 cancer patients, most of whom were Latino. Data were analyzed using constant comparison with a reiterative analysis method. The main themes relating to barriers to care and experiences with patient navigators include the following: (1) removing financial barriers, (2) coordinating services, and (3) providing therapeutic interventions. The cancer patients highly valued the navigators for their knowledge about community resources, support, and advocacy. This study suggests that it is imperative that navigators know the regional and binational health care utilization issues that impact patients' access to cancer care.

Keywords Rural · US/Mexico border · Cancer care · Challenges/barriers · Health care disparities

Background

Addressing and eliminating health care disparities in minority populations is a growing focus of research in public health [1]. Cancer is the second leading cause of death in the USA, and cancer care disparity for certain racial/ethnic groups is a concern [2]. Racial/ethnic minority individuals living in rural areas face unique challenges related to health care access including limited health care facilities, physical distance, low socioeconomic status, and rural cultural practices associated with dietary or health beliefs [3–5]. Moreover, the stage of cancer at diagnosis differs by region, with individuals who live in rural areas more likely to be diagnosed with cancer at a later stage [6] and less likely to utilize cancer screening [7] than people residing in urban regions.

The Patient Navigator Program (PNP) model aims to minimize the barriers that prevent cancer patients from accessing and utilizing health care prevention, diagnostic, and treatment services and thus ensure that these services are received in a timely manner [8]. While the concept of patient navigation developed from case management, the role of patient navigation is somewhat different from traditional case managers, as patient navigators mainly assist underserved populations (e.g., racial/ethnic minority, low-income patients) [9]. Cultural competency is a key component in PNPs which enables the practitioner to develop a strong alliance with patients. This is achieved by gaining in-depth knowledge and understanding of the hardships and challenges the patient experiences [5, 10].

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The hardships and challenges may be especially great for members of socioeconomically marginalized populations and those in rural areas.

Recent large-scale studies [11, 12] examining the effectiveness of patient navigators on cancer care among underserved populations, including Latinos, found that PNPs positively contribute to initiating cancer treatments in a timely manner. Previous studies exploring the barriers cancer patients confront and the ways that patient navigators help overcome these barriers include the provision of emotional support [10, 13, 14], cancer-specific information [14], assistance with financial difficulties [10, 15], and communication with health care providers [15]. A number of qualitative studies report positive outcomes associated with a PNP including increased patient cancer knowledge and understanding of medical information [16, 17], decreased emotional distress [17, 18], increased emotional support, [10, 17], enhanced communication between health care professionals and patients [16, 19], and improved logistical tasks such as scheduling appointments with clinics [16].

These previous studies provide insights and broaden our understanding about the barriers cancer patients' confront and the role patient navigators can play in reducing disparities in caring for cancer patients. However, most of these studies were conducted with English-speaking participants in urban settings. Rural cancer patients may face different kinds of barriers, partly because of the limited health care resources available. In particular, those living in the rural US/Mexico border region may encounter more complex and unique issues that pertain to binational health care utilization. Although PNPs are relatively heterogeneous and are often tailored to the specific needs of cancer patients and the available regional resources, little is known about how a PNP adapts to the needs and issues of Latinos in a rural, medically underserved area. Because cancer occurs within the context of personal circumstances and environments [20], implementing a PNP that can address the cultural needs of the Latino population in a medically underserved, rural area with binational health care options is important and central to the promotion of public health and reducing health disparities. The aims of this qualitative study were to (1) describe the challenge and barriers of accessing cancer treatment among a group of cancer patients in a US/Mexico border region, and (2) illustrate the ways the services provided by patient navigators were or were not helpful.

Methods

Study Design and Recruitment Process

This was a qualitative study using an in-depth individual interview. Cancer patients recruited from a local cancer organization located in Imperial County, Southern California along the US/Mexico border region were administered face-to-face interviews at the study site. The study site is the sole organization providing a patient navigation program in this area of the US/Mexico border region.

Participants were recruited using a convenience sampling method. Cancer patients who were scheduled for an intake at the study site were approached by a research assistant after their intake, and the purpose and procedures of the study were explained. Thirty-one patients were invited to participate in the study and nine declined. All participants signed an informed consent form, and study protocols were approved by the San Diego State University Institutional Review Board (#691078). Participants who agreed to participate in the study were scheduled for an interview to be conducted at a time convenient for them. Eligibility criteria included being 18 and older, currently diagnosed with cancer, and cognitively competent. Eligibility of cognitive ability was determined by the organization's staff members who have direct contact with the patients. Of the total of 31 participants approached for an interview, nine declined due to frequent hospitalizations, multiple medical appointments, and physical discomfort. All nine patients that declined to participate were of Mexican descent, and their average age was 54.3 years old. The majority were female ($n=8$), five were diagnosed with breast cancer, and four patients had stage 2 cancer at the time of diagnosis. The final sample size was 22.

Data Collection

Data were collected via face-to-face interview from June 2012 to August 2013 by one bilingual/bicultural trained graduate research assistant. All but five participants were individually interviewed at the private office of the study site. Among these five participants, three were interviewed in the presence of their spouses at their request because of their concerns about memory recall, and two were interviewed at their home due to transportation issues and limited mobility because of physical weakness. Interviews were conducted either in English or Spanish using a semistructured interview guide which was created based on the existing cancer literature [10, 14, 17] on this topic. Interview questions included the following: what were the barriers or concerns in accessing cancer treatment? What were the things that navigators did for you that were the most helpful? In what way, were they helpful? What were the least helpful? Are there any specific ways/services that you felt the navigators could help you with? Each interview lasted from 40 min to 1 h, and each interview was tape-recorded, transcribed, and translated to English from Spanish. Unclear words or phrases in translation were discussed and clarified by the authors.

Data Analysis

Data were analyzed within a grounded theory approach using constant comparative method [21]. Two researchers (EK and SW) reviewed the transcripts independently and conducted an initial coding of the content. While developing a coding scheme, the researchers went through an iterative process to identify any codes that were not noticed in the initial coding process. The two researchers then met and compared the codes developed for each transcript. For inconsistent coding, the two researchers jointly worked to reach consensus. Codes were then grouped into a set of categories. Then, the researchers identified emerging themes in response to interview guide questions. Subthemes were merged into a broader theme when appropriate. For example, "insurance conversion" and "financial support" were merged into the broader theme "removing financial barriers."

Results

Participant Demographic Information

As shown in Table 1, the average age of the participants was 52.1 years and slightly over half were female (n= 12, 54.5 %). The majority of the participants were Mexican or Mexican American Latino (n=20, 90.9 %), and over two thirds (n=15, 68.2 %) were interviewed in Spanish. Approximately 41 % were married (n=9, 40.9 %), followed by never married (n=6, 27.3 %), and separated/divorced (n=6, 27.2 %). Fifty-nine percent of the participants (n=13, 59.1 %) had full health insurance coverage, 13.6 % (n=3) had partial insurance coverage, and six (27.3 %) were uninsured. Over a third, 36.4 % (n=8) reported having breast cancer, followed by lymphoma (n=3, 13.6 %) and lung cancer (n=3, 13.6 %). Over one third of the participants (n=8, 36.4 %) reported to have stage 4 cancer, followed by stage three (n=6, 27.3 %), two (n=6, 27.3 %), and one (n=2, 9.1 %). While two thirds were diagnosed with cancer in the USA, 32 % (n=7) were diagnosed in Mexico.

Table 1 Participant's sociodemographic and cancer-related variables (N=22)

Variables	Number (%)	*M* (SD)
Age		52.10 (15.94)
Female	12 (54.5 %)	
Race/Ethnicity		
Latino	20 (90.9 %)	
White non-Latino	1 (4.5 %)	
Filipino	1 (4.5 %)	
Language interviewed		
Spanish	15 (68.2 %)	
English	7 (31.8 %)	
Marital status		
Married	9 (40.9 %)	
Separated/divorced	6 (27.2 %)	
Widowed	1 (4.5 %)	
Never married	6 (27.3 %)	
Insurance status		
Full insurance	13 (59.1 %)	
No	6 (27.3 %)	
Partial coverage	3 (13.6 %)	
Types of cancer		
Breast	8 (36.4 %)	
Non-Hodgkin lymphoma	3 (13.6 %)	
Lung	3 (13.6 %)	
Prostate	2 (9.1 %)	
Other	6 (27.3 %)	
Stage of cancer		
1	2 (9.1 %)	
2	6 (27.3 %)	
3	6 (27.3 %)	
4	8 (36.4 %)	
Place of cancer diagnosis		
USA	15 (68.2 %)	
Mexico	7 (31.8 %)	

Qualitative Themes

Results of qualitative analysis yielded multiple themes highlighting the navigators' roles in structural, cultural, and emotional assistance. Patients' barriers/challenges for accessing cancer care reflected unique circumstances in the rural border area, such as geographic distance and binational health care compatibility when transfer or coordination issues arose for treatment. These themes highlight the importance of culturally competent PNPs in bridging the gaps in health care delivery for underserved populations. The major themes and subthemes are presented in Table 2.

Major Theme 1. Navigation as Removing Financial Barriers

1. Navigating health insurance system

   The most common and profound barrier in accessing cancer care was financial insecurity, primarily in the form of inadequate health insurance. Participants reported that resolving a health insurance issue was an obstacle where the navigators' assistance was crucial. "She (navigator) helped me with the insurance and everything because we don't know anything about this, nothing" (ID #1). Inadequate health insurance coverage imposed financial

Table 2 Barriers and challenges in cancer treatment: the role of PNP (N=22)

Themes	Subthemes	Number
Navigations removing barriers: financial navigation	Navigating health insurance system with expertise	10
	Financial assistance to accessing cancer care outside of the community	10
Navigation as coordinating services	Providing guidance in transitioning cancer care	6
	Providing logistic assistance	7
Navigation as therapeutic intervention	Providing emotional support	6
	Advocacy	5

burdens which may have delayed treatments without the navigators' financial navigation.

"It was complicated and really expensive for the treatments such as biopsy, fee for oncologist, the doctors, everything…and we barely could pay it. I was working here (USA) and had health insurance benefits from my employer that I could only use in Mexico. So I went to the doctor (in Mexico) with the insurance but it only covered the general doctor. It didn't cover any more things… like specialists and that. And everything else we had to pay it. And yes it was really hard to be able to…it was here with a navigator who helped me to get MediCal" (ID #14).

Health insurance application or conversion processes are considered complicated and confusing by participants. Completing these processes was deemed to be challenging. A participant referred the navigator's work in securing proper health insurance as "life-saving." "Figuring out the [health insurance system]…it's, it's a labyrinth, you know. They (navigators) took me over to the county (office) and fixed up for the, uh, MediCal… I think there are a lot of people who have already died because they didn't have people like that" (ID #6).

2. Financial assistance when accessing cancer care outside of the community

   Meeting basic needs in order to access cancer care was a struggle for some participants. "A lot of times, I had a lot of problems with the gas, going to the doctors and from here to there" (ID #22). Providing emergency cash assistance such as reimbursement for gas mileage was perceived as essential for the patients, in particular for those who receive treatment outside of the community. For those who travel outside of the community for their cancer treatments, financial assistance for transportation related expenses was extremely useful. "They have helped me to get in a part of the program where they pay my gas bill, and in case I have surgery or something there in San Diego or wherever well they will help me" (ID #10).

   Another patient who struggled paying his phone bill shared his experience with emergency cash assistance that helped him maintain communications with health care providers.

   "They ended up cutting my cell phone like three times. No communication was available. One time I asked the navigator if there was any way I could get help with my phone and she helped me. You know, I felt bad taking it but I needed it" (ID#9).

Major Theme 2: Navigation as Coordinating Services

1. Providing guidance in transitioning cancer care

   Finding an appropriate cancer treatment facility and coordinating cancer care emerged as a major challenge. The navigators' knowledge of community resources (e.g., treatment facilities) in both what was available and what was unavailable expedited the cancer care transition process. "There were no available oncologists here which was the first obstacle I encountered. The navigator noticed the lack of medical attention at the first hospital I went to and advised us to go to another hospital. If it wasn't for her we would still be struggling looking to get where we are now" (ID #20).

   Making a cancer care transition was more complicated and burdensome for those who used the binational health care options. Navigators were the first and perhaps the most helpful resources in making cancer care transition for those utilizing binational health care services. A participant, originally diagnosed with cancer in Mexico who sought further diagnostic work in the USA, shared his experience with navigators and stated, "I came here (USA) in the dark knowing nothing. And here is where they helped me a lot. They (navigators) were the ones who sent me there to the hospital. I didn't grow up here well I didn't know where to go. They told me go to that place, and to start off you know. Because of their recommendation we went to that hospital and it was where we were welcomed" (ID #14).

2. Providing logistic assistance

   The extensive amount of paper work required in cancer care transition was considered burdensome by participants. The participants considered the navigators' logistic assistance (e.g., communication with other service providers, paper work) crucial to moving forward in receiving cancer treatment. "Fill out forms, make phone calls, uh, direct us with what forms that we needed to send, what medical records we needed to get you know and uh, especially she (navigator) pretty much deals with us" (ID# 20).

Such logistic assistance was particularly invaluable for the patients using binational health care options. Navigators' bilingual and bicultural expertise enabled the participants to make a transition in a timely manner.

"She (navigator) helped me to fill out the papers and send them through fax and everything when… they (the US oncologist) couldn't help me because of the fact that the cancer diagnosis was in Mexico and not here…So when I got the diagnosis here (USA), I went immediately with the navigator who had already filled out the papers and everything so I could apply (for MediCal). In 24 h, they gave it to me" (ID #12).

Major Theme 3: Navigation as Therapeutic Intervention

1. Providing emotional support

   Emotional distress emerged as an important barrier to cancer treatment. Participants experienced a deep sense of feeling overwhelmed and sad. "I mean there have been times when um you know I cried you know or I have to let it out and then I just have to keep going" (ID #20).

   Navigators' emotional support eased anxiety and renewed hope for life. Navigators' presence and availability to talk and listen heightened the participants' sense of relief.

   "You come here and think it's the end of your world but when you talk to them you walk out calm, and you feel stronger with their (navigators) words of encouragement. They help you a lot emotionally. Each time I would come here I would cry… as soon as I would walk in, it was something I felt over me and they would give me strength. I would come here to relieve my emotions, to listen to them, and I would walk out feeling better" (ID #11).

2. Advocacy

   Some participants identified challenges they encountered in their communication with physicians regarding their cancer information. The navigators' advocacy for assertiveness in the decision-making process was considered by the participants to empower them to actively seek information.

   "When I got here [study site], I told them I had a lot of frustrations that I had a lot of questions and that nobody was supporting me. And they told me I had the right to ask questions, and express everything I felt to the doctors, and that's what I did. It was great help because they motivated me to have my voice heard even if it's not heard, but for them to know that we count" (ID# 4).

   While the majority addressed the positive aspects of services by PNP, two participants suggested that PNP needs to provide more transportation services and education on diet/nutrition. Several participants considered transportation service as helpful although one patient expressed a wish that more transportation services be provided. While addressing the lack of information about the effects of diet/nutrition on cancer, a participant stated, "They tell me not to eat anything very greasy, not very spicy but in reality I don't know what it is that provokes nausea if is it the chili or the grease…. they can tell me if this is what affects my cancer so I know definitely what I should not eat anymore" (ID#15).

Discussion

This study explored the challenges and barriers to accessing cancer care among the cancer patients in a rural US/Mexico border region and their experiences with cancer navigators. Barriers/challenges patients encountered encompassed structural, cultural, and individual characteristics such as health insurance coverage, geographic distances from care providers, and the lack of resources for cancer care. Our findings indicate that navigators play various roles in assisting the participants accessing cancer care which includes navigating health insurance requirements, coordinating services, and providing therapeutic interventions. The findings from our study were similar to other studies, yet the context and extent of the challenges and needs were unique which amplifies the importance of patient navigators in a rural region.

As found in other studies [15, 22], our participants identified a lack of financial resources, particularly inadequate health insurance coverage. Among the study participants, about half of them reported having either no insurance (n=6) or partial coverage (n=3). The participants with inadequate health insurance coverage were not able to arrange for specialists or necessary follow-up care. They were concerned their lack of health insurance caused delays in treatment and left them with a narrow range of treatment options. Because securing health insurance is a complicated process involving multiple steps in applications and requiring close contacts with financial personnel [23], the navigators' expertise in the health insurance system was highly valued and considered by some to be literally life-saving.

Financial navigation enabled the participants to access cancer treatments outside of the community when necessary. Study participants considered financial assistance, in particular gas mileage reimbursement, as important. Some cancer patients receive treatments outside of their home communities due to the lack of treatment facilities or specialists or concerns about quality of care in a rural region [24]. Given the limited number of cancer treatment facilities (only two) and cancer specialists in Imperial County, some participants commute over a hundred miles to San Diego for their treatments. According to Baldwin and colleagues [24], the median travel distance for cancer care to outside of community (urban cancer care provider) was 47.8 miles or more. The majority of participants receiving treatment out of the community traveled to San Diego which is about 120 mi. away. As consistent with the findings from previous studies [22, 24, 25], traveling long distances for medical treatments may impose financial burdens on patients and families. Navigators' ability to secure financial assistance such as gas mileage reimbursement was helpful in reducing financial burdens and accessing appropriate medical care. These findings suggest that navigators assessing the types of financial barriers within the patient's unique social and cultural contexts and mobilizing the available resources in the system in a timely manner is critical.

A second major theme taken from the study is the importance that navigation plays in the coordination of the multiple elements of services. Participants expressed a lack of knowledge about cancer-related resources (e.g., treatment facilities, specialists) and indicated that the difficulty of cancer care coordination was a challenge, especially for the patients using binational health care options. Due to its geographic proximity, it is common for cancer patients to seek medical treatments in Mexico. In this study, about one third of the study participants reported having the cancer diagnosed in Mexico. Coordinating cancer care which requires gathering medical records, finding cancer specialists, and treatment facilities can be challenging for those who make a treatment transition to the USA. Consistent with the results from a previous study [10], participants considered navigators as "insiders" who were knowledgeable of community resources, binational health care options, and the administrative procedures for coordinating cancer treatments. This finding highlights the importance of training navigators on regional, cultural, and binational health care issues and their impacts on the patients' access and utilization of cancer care. This in turn, will effectively address the needs of cancer patients in the border region and minimize delays in cancer treatments.

Another major theme may extend beyond coordinating services to therapeutic intervention. Consistent with other studies [13, 19], emotional distress for cancer diagnosis was a significant stressor for which the participants needed emotional support. Similar to the finding from a previous study [10], our participants viewed the navigators' presence and availability to listen to them positively contributed to their coping with illness. The navigators' responses and welcoming attitudes channeled the participants' frustration and the navigators' advocacy was perceived as a core element for strengthening the participants' ability to cope with their cancers. Navigators also became a voice for the participants seeking their rights and expressing their opinions which is consistent with the aims of PNP's empowerment. Patient navigators are considered more than service providers for the participants. Rather, they are considered the "experts" who are fully aware of the participants' hardships and are able to identify and initiate the steps that could ameliorate their issues. While the navigators understand the closeness as a vital component to build trust, there has also been an increasing emphasis on maintaining relational boundary between patients and navigators [26]. Navigators need to clearly assess the patients' expected roles of navigators and be mindful of the relational impact on the services.

The results of this study highlighted the positive aspects of PNP; however, two participants suggested ways to improve services in transportation and nutrition/education. Transportation is critical for those who travel to outside of the community for their treatments. Organizing proper transportation services will prevent delays in cancer treatments. Health care professionals' suggestion regarding food and diet was found by the cancer patients to be an important area of service needs yet unmet [27]. The navigators' provision of education and/or advocacy for patients to consult with their physicians on diet and nutrition can address the patient's concerns about how the foods she eats and the ways the foods are cooked impact her cancer treatment.

Limitations

This was the first study to explore the barriers and needs of cancer patients on the US/Mexico border in Southern California. This study yielded findings that are unique to rural and US/Mexico border region which may broaden our understanding about the challenges and needs these patients face, yet there are several weaknesses that need to be acknowledged. Because the findings of a qualitative study are not intended to generalize, applying these results to a larger population should be undertaken with caution. Participants were recruited from only one study site, and the sample size is relatively small. Future study needs to include more samples from multiple sites in rural regions to replicate findings and enhance generalizability. Another limitation is the potential social desirability bias. Face-to-face interviews were conducted at the study site. Given that participants are the service recipients, they may not feel comfortable talking about their unmet needs. This may explain that the majority of the participants addressed positive aspects of PNP, not commenting on the areas of improvement in PNP services. Future study might consider interviewing at other places (e.g., participants' home).

Conclusion

Barriers and needs of cancer patients in underserved areas were multilayered, from lack of personal knowledge and financial means to structural barriers in navigating a health insurance system and binational health care utilization. Navigators fill the gap in accessing health care services by addressing the patients' psychosocial and medical needs. The importance of navigators' work is even greater in a rural region where increasing the number of patient navigators who are knowledgeable about local and binational health care utilization will be important.

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