

Initial Efforts in Community Engagement with Health Care Providers: Perceptions of Barriers to Care for Cancer Patients in Puerto Rico

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Objective: Cancer health disparities are evident among Puerto Rican Hispanics, both for those on the island and in the mainland United States. Less is known about cancer care services available on the island. Through the Ponce School of Medicine and Moffitt Cancer Center partnership, focus groups with health care providers (HCP) were conducted to explore needs and barriers related to cancer care services with an ultimate goal of developing a cancer control and prevention program for the southern area of Puerto Rico.

Methods: To engage the community in outreach efforts to identify barriers to cancer care in Ponce, Puerto Rico, we conducted two focus groups with HCPs from a variety of settings, including general hospitals, private clinics, pharmacies, and government agencies. These 90-minute focus groups were conducted in Spanish and moderated using a semi-structured interview guide that explored the needs and barriers related to cancer control and prevention services.

Results: We analyzed content using the emergent material for identifying patterns, themes, and perceptions. Our qualitative analysis indicated that providers had significant concerns about unmet patient needs and system factors, which served as barriers to quality cancer care delivery. Key barriers included unmet practical needs, such as transportation, treatment affordability, lack of resources, and unmet needs for social support and education services.

Conclusion: Future research will examine other key informants' (e.g., patients, caregivers) perspectives and identify which issues can be addressed by the partnership grant and which must be addressed by policymakers. [*P R Health Sci J* 2011;1:28-34]

Key words: Hispanic, Cancer, Health Care Providers, Focus groups

Cancer health disparities are particularly evident among Hispanics. Although the overall incidence and death rates for all cancers are lower in Hispanics than in non-Hispanic Whites, Hispanics are more likely to be diagnosed later in the course of the disease when the cancer has reached a more advanced stage (1). However, the majority of cancer health services research has examined Hispanics as a homogenous group rather than exploring variations by sub-ethnicity. Hispanics are a diverse population with individuals from multiple origins such as the Caribbean, Central or South America, and Spain (2). The majority of the U.S. Hispanic populations are of Mexican, Puerto Rican, and Cuban origin (3).

To reduce cancer health disparities, it is important to consider individual cultural and system factors that may impact perceptions of cancer and health seeking behaviors

(4). For example, there are differences in cancer rates and access to services between Puerto Ricans living in the United States (mainland) and those living on the island. Island Puerto Ricans appear to have different rates of cancer compared to

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other Hispanic groups and non-Hispanic whites. Rates of breast, colon/rectum, lung, and prostate cancer are lower in Puerto Rico than in the mainland United States, whereas rates of cervical, liver, and stomach cancers are higher (5). In 2000, the total US Puerto Rican population reached over 7.2 million, with approximately equal numbers living on the island of Puerto Rico or the mainland US (2). Mainland and island Puerto Rican Hispanics differ by several factors that may impact health status, including lifestyles and health behaviors, the environment, and access to health services. With respect to access to health services, in the 1990s the Puerto Rican legislature approved Health Care Reform legislation intended to increase access, lower costs, and improve health outcomes for individuals who had previously been covered under Medicaid and Medicare and whose incomes are below 200% of the poverty level (5). This Reform (known as “the Reforma”) shifted the care of these individuals, who comprise nearly half the island’s population, from the public sector to the private sector via the creation of the Puerto Rico Health Insurance Administration (in Spanish, ASES). However, there has been little published research on the effectiveness of Reforma or the perceptions of its value among Puerto Ricans. Due to the research emphasis on mainland Puerto Rican populations; additional research is needed to ensure that cancer prevention and control activities are relevant to Puerto Rican populations on the island.

The National Cancer Institute (NCI) provides funding to pair minority-serving institutions and NCI-designated cancer centers for the purpose of fostering research and outreach collaborations aimed at reducing cancer-related disparities in minority populations. The Moffitt Cancer Center of Tampa, FL (MCC) and the Ponce School of Medicine in Ponce, Puerto Rico (PSM) have established a unique partnership via this NCI grant mechanism. The PSM-MCC Partnership provides support for programs and research cores in the following areas: Cancer Research, Cancer Training, and Cancer Outreach. As the Cancer Outreach program of this partnership, we have developed a research agenda to understand and address factors that may impact cancer care or cancer prevention services for Puerto Rican Hispanics, with an ultimate goal of developing a cancer control and prevention program for the southern area of Puerto Rico.

As an initial step in engaging the community in Puerto Rico, we chose to conduct a series of forums/focus groups with health care providers (HCPs) to initiate dialogue surrounding cancer care needs and barriers to care [future forums will be held with other key stakeholder groups (e.g., patients, clergy)]. Our discussion with HCPs was consistent with Andersen’s Behavioral Model of Health Services Use. Specifically, Andersen’s model posits that cancer health services use is determined by both population characteristics and health care system characteristics (6-7). Importantly, Andersen’s model includes components that are relevant for vulnerable populations including ethnic minorities

and has been applied to Hispanic populations in prior research (8-10). In the current study, attention was paid to examining enabling factors, defined as personal and community resources that impede or facilitate utilization of health services. HCPs are in an ideal position to discuss the current state of cancer on the island of Puerto Rico from this framework as their responses offer unique insights on both healthcare system and population/community perspectives (11). Previous research stresses the importance of including HCPs as well as patient perspectives in the analysis of a healthcare system because HCPs can influence “both process and outcomes of service delivery as well as compliment efforts to address unmet needs” (12). HCPs serve as a “critical link between the healthcare system and patient” (13). Not only are they in a position to influence policy, design, and evaluation of healthcare systems, but, given their immediate interaction with patients, HCPs also have the opportunity to directly observe the barriers preventing patients from accessing available resources (13). Furthermore, the importance of the patient-provider relationship, including reciprocal influences, on the delivery of quality health care services, and the health-enhancing effects of “relationship-centered care” is increasingly recognized in health services research and policy (14-15). HCPs have also been shown to be instrumental in identifying when barriers to health care fall in the category of a policy issue, patient characteristic (such as low literacy) or healthcare system issue (available appointment slots) (16).

Community needs assessments that include key stakeholders are an important tool to identify and address health disparities and provide a foundation for developing interventions. Moreover, a participatory approach that includes community input increases the likelihood of the development of sustainable interventions that will be relevant and promote community engagement. In particular, we were interested in using community approaches to identify barriers to care experienced by Puerto Ricans living on the island and ultimately using this information to improve services there as well as in Tampa, Florida, where one of the largest majority of Hispanics are of Puerto Rican sub-ethnicity. Increased awareness and examination of perceived barriers can greatly improve and direct community outreach efforts. Importantly, this line of research can help determine which barriers to cancer care may be addressed via the development of outreach programs (e.g., education about cancer risk) and which barriers (i.e., structural issues such as transportation) can only be addressed through policy change.

In this study, we present results from a series of community forums with HCPs who serve patients with cancer as an example of effective community engagement for the purpose of developing successful community outreach programs. These forums, directed by the MCC-PSM partnership grant, represent an initial step to explore, in a broad manner, the needs and barriers related to cancer care services in the southern part of Puerto Rico, in line with the ultimate goal of the partnership.

Materials And Methods

Participants

All HCPs serving the cancer patient population in Ponce, Puerto Rico were identified via a medical directory and represented providers from general hospitals, private clinics (oncologist, family medicine, gynecologist, and urologist), cancer registry offices, pharmacies, and medical laboratories. Invitation letters were mailed to inform potential participants about the main objectives of the community forum and to request their participation in focus groups. Importantly, this effort represents the first attempt to engage HCPs in Ponce in a cancer needs assessment. Two HCP focus groups (N = 17, with 7 and 10 participants each) were conducted with HCPs from the following professions: physician (n = 6), nurse (n = 2), pharmacist (n = 2), medical technologist (n = 3), psychologist (n = 1), pharmaceutical representative (n = 1), and cancer registry official (n = 2).

Data Collection

During the first part of the forum, HCPs participated in a brief presentation to inform them about the MCC and PSM partnership. Prior to the focus group sessions, the lead interviewer/facilitator described the purpose of the study and the forum. Written informed consent was obtained. All procedures were approved by the Institutional Review Board (IRB) of the Ponce School of Medicine.

Each focus group was moderated using a semi-structured interview guide that explored the needs and barriers related to cancer control and prevention services for the southern part of the island of Puerto Rico. The following are examples of questions that guided the focus group discussion: *“What has been your experience as a health care provider helping a person with cancer?”* and *“What (factors) could have helped your patients have a better experience?”*

The focus group discussions took place in a private room and were approximately 90 minutes in length. The discussions were guided by a facilitator and an assistant previously trained by the investigators. Both HCPs’ focus groups were conducted in Spanish. Advanced psychology doctoral students were in charge of note-taking and audio-recording each session.

Analysis

Focus groups’ discussions were audiotaped, transcribed, and translated into English by a certified translator. Content analysis was conducted using the emergent material for identifying patterns, themes, and perceptions (17). A thematic framework was used to classify and organize data according to key themes, concepts, and categories (18). Main themes and subtopics were selected from the entire transcription based on our study objectives and interview guide questions. The thematic framework helped develop a codification system

for researchers to follow. Researchers at both institutions (MCC and PSM) individually evaluated the document for a comprehensive review, categorization of responses, extraction of major concepts, and synthesis of themes. These findings (key themes, concepts, and categories) were arranged into categories of structural vs. cognitive/individual barriers, facilitated by the Andersen Model. That is, the findings fell into the broad categories of structural (transportation, financial, policy or cognitive/individual (social support, education) and we present the findings within that barrier framework (19). Disagreements were discussed and resolved. To maintain qualitative reliability, individual content analysis was completed by each researcher. Then, investigators held a series of meetings for the discussion of the categorization process and to generate a consensus on the findings to be presented.

Results

The focus group facilitator asked participants to consider what the barriers were to delivering quality care to cancer patients in Puerto Rico. Eight key themes, displayed in Table 1, emerged that focused on HCP perceptions of unmet needs of patients and health care system issues on the island.

Table 1. Key barriers

Barrier	Example
Transportion needs	Lack of coordination between transportation services and medical appointments
Financial concerns	Inability to pay for optimal treatment
Family and social support needs	Families’ fears not adequately addressed
Education needs	Lack of education regarding cancer care
Cancer prevention needs	Lack of prevention education
Quality of healthcare services	Cannot obtain second opinion
Health insurance concerns	Government plan has limited coverage
Need for professional support services	Lack of providers and support groups, time constraints

Patient Needs

Transportation needs

Transportation issues were mentioned frequently among the HCPs as being a barrier to receipt of appropriate and timely cancer care for patients. All respondents discussed the issue of lack of adequate transportation as being part of the larger issue of inadequate cancer care services.

“The truth is, it’s very unfair for a person in his 60’s to receive chemo treatment at 9 AM. He’s been recommended to rest, and then has to wait under a tree at the clinic for the bus to pick him up at 3 PM.”

“There is a real need to present the transportation issues (of cancer patients) to our legislators... It’s urgent.”

Issues of transportation also overlapped with concerns about wait times in the clinics for cancer care or treatment. Most participants expressed both lack of transportation and long waits for services as issues because of the lack of coordinated services and the shortage of cancer care specialists.

“They have to travel so far to get the services they need. One day it is radiation, the next chemotherapy, and there are not enough doctors and not enough clinics or places that offer the services to accommodate all these cancer patients.”

Financial concerns

The issues related to financial need and the lack of financial resources were a significant problem noted by all participants in the focus groups.

“Pre-medication is not accessible to patients so these (with state sponsored or no insurance) experience ... the pain, nausea—everything chemo entails. For those who can afford the medications, their suffering is less.”

“They can’t pay for deductibles... they have small children and no one to care for them... they cannot afford to miss work... the financial situation is a stress... people cannot afford cancer care in many ways.”

The inability to afford cancer care services and treatments was far-reaching. The majority of respondents told of situations with patients whose extenuating circumstances caused them to receive sub-optimal care or, in some cases, to refuse care.

“There are patients who refuse treatment because of this issue (health plan will not pay for all required treatment) – they cannot afford some or all of the treatment they need. They are concerned with finances and they imagine ... ‘at least I can save my house for my children.’”

Family and social support

The majority of HCPs reported that attending to the needs of the patient’s family is an integral part of the culture of the community and to providing quality care to their cancer patients.

“So then, we have to work multiple roles with the patient and now-a-days more than with the patient, with the family, because the family is also included in the healing process and in the therapeutic process of the patient.”

“So then the time for decision making, our help at that time is very important and we can’t just think about speaking briefly with a cancer patient because he is part of a family with cancer, because their relatives are also a part of the situation.”

Many providers reported that the family members of patients often experienced a great deal of fear and sadness surrounding a cancer diagnosis. Family members experience fear for the patient and for themselves in terms of their own future cancer risks.

“The whole world thinks that cancer equals death, and this has repercussions because some people don’t even dare to mention

it. ... There are many patients who feel they are in crisis ... they isolate from their family, because the families respond with such strong fears.”

“We need personnel that can work on the emotional side... that can help them cope with the fear of a cancer diagnosis for the patient and for the family.”

A few providers reported that patients may not tell their families about their cancer diagnosis to protect them from suffering. Providers noted the need to protect the family can result in the patient attempting to isolate themselves from the family.

“And if the patients go alone ... and I give them a cancer diagnosis, with the tests results we have received... if that patient does not communicate that to his family, the only thing I can do is consult with a social worker to get them involved in that process. In the mean time, while all that takes place, the patient possibly continues to conceal this information from his family.”

Education needs

Some of the HCPs echoed the need to educate the patients regarding different aspects of cancer care.

“I understand about the educational aspect of helping a patient. It consumes the provider, so that is one of those things that maybe should be incorporated in educational groups at the same time of the process of diagnosis.”

Lack of education about cancer was also mentioned as a precursor to avoiding talking about cancer.

“Why is there such a fear?” [Referring to fear of talking about cancer] “The information does not reach them? Is there not enough advertising? Is it cultural? I don’t know.”

One physician suggested community presentations as a strategy to provide educational information.

“One of the things that can be done is to incorporate educational ‘charlas’ (presentations or talks) at the same office to take advantage of that time with the patients ...”

Cancer prevention

The majority of HCPs agreed there is a need for prevention education among the Puerto Rican population.

“... I feel we are missing orientation with regards to making the populations aware that medicine is more than healing and should be preventive. Because in the ER we see many patients who wait to be very ill to go to the ER...”

“... medical insurance is unfortunately regulating that part of prevention of the diagnosis... because actually, the medical insurances limit the possibilities that a healthy patient receives an early diagnosis that may save his life or may provide a better quality of life...”

System Factors

Quality of health care services

Issues about the quality of cancer care services were described by the majority of respondents. These issues often centered

on the state health insurances rules for the provision of care. The majority of HCPs felt that they could not offer what they knew to be the best quality of care because of constraints with insurance.

"A patient has the right to... a second opinion... doctors used to be Gods... now a patient has the right to look for alternative treatments. But if you cannot pay for it, you do not get it. The insurance will not pay for second opinions."

"I have seen patients who cannot get the tests they need because they do not meet age requirements. If you have a mass in your breast, but you are not old enough by the insurance company's rules to get the test – you will not get the test. I will have to send you away. As a doctor, I should be able to decide when a patient needs a test."

In addition, some of the HCPs believed that bureaucracy of health care in Puerto Rico is a cause for concern.

"... medical insurance (Reforma) governs our practice and they tell the doctor how to practice, they tell them what medications to prescribe. It's not on the list I recommend - that we have to justify. It has to go through a couple of evaluations so that you can justify the use of certain medications."

Need for professional support services

A desire to address the emotional needs of their patients was expressed by the majority of the HCPs. Providers expressed a great need for additional professional support services from social workers and psychologists. Many providers felt that time constraints, a lack of social support programs, and limited resources prevented them from providing patients with the type of emotional care they felt their patients needed and deserved.

"I think that developing a counseling program, like support groups, where we can be more actively involved with the patient, it would help them during this process"

"We still have needs, transportation needs, education needs, of the previous concept of public health, the need to broaden support groups, activate and captivate support groups, make professionals aware of health."

"We are not enough, but like I was telling the intern that we have from the psychology program of Ponce School of Medicine, I think that developing a counseling program, developing a program, maybe, like support groups, or developing programs, were we can be more actively involved with the patient, it would help them during this process."

Provider Suggestions

The Health care providers' discussion led to various suggestions aimed to address some of the identified barriers.

"... and basically I think a suggestion would be that schools incorporate an educational club, like the chemistry and biology clubs, where they educate, not only about cancer but all diseases."

"I don't know much about politics but we can propose a legislation, right, but we have to get to legislators, we as a group."

"Then we have to get there because they are not going to come to us and as a group we should present immediate, structural, actual needs of cancer patients and get them to legislators."

"I think that developing a counseling program, developing a program, maybe, like support groups, or developing programs, right, were we can be more actively involved with the patient; it would help them during this process."

One of the healthcare providers talked about developing a system to save for the person's health as a way to alleviate the economical burden.

"Sometimes for a minimal amount, right, you say... why do they have to do it and I would say that instead of a Christmas Club, a Cancer Club and since you are a child you would teach to save for you to become a lawyer or consider a disease."

Discussion

Needs assessments have been used to identify the specific concerns and needs of cancer patients and to provide a foundation for developing interventions (20-22). Due to cultural and political idiosyncrasies such as the passage of recent health care reform legislation (the Reforma), little is known about the cancer control and prevention needs or barriers faced by Puerto Ricans living on the island. In this study, through a partnership established between MCC and PSM, we conducted focus groups with HCPs in Ponce, Puerto Rico. These focus groups served as an initial exploratory step in identifying patient needs with respect to cancer care, toward a larger goal of developing a cancer control and prevention programs for the southern area of Puerto Rico.

According to Andersen's behavioral model of health services use, community (available facilities, health personnel) and personal enabling resources (income, travel and wait times) are important considerations for health care service use to occur. HCPs participating in the focus groups had consistent concerns about patient needs and system factors that served as barriers to the delivery of quality cancer care as well as those they perceived enhanced the experience for patients and families. The most frequently mentioned area of unmet needs involved practical needs, including transportation needs and affordability of treatment, and a general lack of cancer care resources. Consistent with Andersen's model, these concerns fit within a broader theme of system factors that HCPs identified as barriers to receipt of quality health care services. For example, HCPs indicated that lack of access to reliable transportation is compounded and complicated by the structure of service delivery, which typically requires long, unpredictable wait times and multiple appointments in different locations that may not coordinate well with bus schedules or doctors' recommendations for rest. Notably, transportation problems on the island are a significant barrier to accessing health care, mental health services, and job opportunities and have been affected by the worsening economy

in the past 2 years (23-25). More generally, and similar to needs endorsed by underserved mainland US Hispanics (20), HCPs noted that patients receiving care did not have funds to pay for deductibles, child care, medications, and other expenses often associated with cancer treatment. HCPs expressed that financial concerns were a barrier to care, particularly among those with government-sponsored insurance plans (i.e., Reforma).

In addition to financial needs, the majority of HCPs also identified professional support services and education for both patients and their families as areas with significant unmet needs. Consistent with theoretical models that suggest that the three dimensions of physical, mental, and social health constitute quality of life as it relates to health in cancer survivors (26), HCPs hoped that increased and improved mental health services would become available to cancer patients and their families. Importantly, the Multinational Association of Supportive Care in Cancer (MASCC) recently published a position statement that emphasizes the importance of adequate and integral supportive care, defined as management of both physical and psychological symptoms from diagnosis through the entire survivorship period (27). Regarding education, HCPs felt that most patients were not educated about cancer and needed more information about their disease and treatment than they had the time to provide. The need for cancer prevention education was also identified as a lacking service on the island.

Results from this initial step of community engagement have already served fruitful in directing community outreach efforts associated with the MCC-PSM partnership. Although providers identified several system barriers that we are unable to directly influence; our data also suggest potential educational avenues for improving the quality of cancer care among Hispanic patients living on the island of Puerto Rico. For example, the majority of providers reported a lack of availability of cancer prevention education materials. Thus, the development of culturally and linguistically appropriate cancer education materials will be an important goal of our outreach partnership. As informed by our findings, additional strategies to be utilized by our partnership for addressing barriers to cancer care include developing culturally acceptable approaches for conveying cancer education information (e.g., charlas), developing family-focused educational materials, and facilitating the development of cancer support groups in Ponce akin to those readily available to patients at NCI-designated cancer centers, such as Moffitt Cancer Center.

Importantly, the generalizability of the findings from these initial focus groups with providers is unknown. For instance, we do not know whether these results would apply to other regions of Puerto Rico, to Puerto Ricans on the mainland, or to other Hispanics. These findings however are similar to those of a recent needs assessment study that targeted an ethnically diverse low SES population in the Bronx, New York (20). Moadel et al. reported that cancer patients generally endorsed the most

need for information (e.g., on treatment side effects, diet) and support (e.g., stress management, coping with sadness), followed by moderate endorsement of practical needs (e.g., finances, transportation), and the least endorsement of spiritual needs (e.g., finding meaning in life, finding hope). A “needs disparity” was also found in that Hispanic patients when compared to non-Hispanic whites, endorsed significantly greater levels of need in all four categories, with the greatest discrepancy in the area of spiritual needs.

A limitation of the current study is that data were collected solely from the health care providers’ perspectives. We chose to interview HCPs because of their unique position in having direct knowledge of the health care system and observing barriers preventing patients from accessing resources. Nevertheless, future research must validate these findings with other sources of data and should include the perspectives of individual patients and caregivers. Indeed data from additional forums conducted with cancer patients and their caregivers will also be examined to further direct cancer outreach activities.

Despite Reforma, HCPs had consistent concerns about patient needs and system factors that served as barriers to the delivery of quality cancer care. Unmet needs such as transportation, affordability of treatment, and lack of social support and education services were key barriers to cancer care. A lack of these resources may directly contribute to disparities in cancer-related outcomes in Puerto Rico. The current research has helped to delineate which issues can truly be addressed by our partnership and which should be brought to the attention of policymakers and others who are in a position to create change.

Resumen

Objetivo: Las disparidades de salud en cáncer son evidentes entre hispanos de Puerto Rico, tanto aquellos que viven en la isla como en los Estados Unidos. Poco es conocido sobre los servicios de cuidado en cáncer disponibles en la isla. A través de la asociación de la Escuela de Medicina de Ponce (Ponce School of Medicine) y el Centro de Cáncer de Moffitt (Moffitt Cancer Center), fueron desarrollados grupos focales con proveedores de cuidados de salud para explorar las necesidades y las barreras relacionadas a los servicios de cuidados de cáncer, con la meta final de desarrollar un programa para el control y prevención del cáncer en la región sur de Puerto Rico. **Métodos:** Para incluir a la comunidad en actividades de alcance comunitario dirigido a identificar barreras para cuidado de cáncer en Ponce, Puerto Rico, nosotros condujimos dos grupos focales con proveedores de cuidados de salud de una gran variedad de escenarios, incluyendo hospitales generales, clínicas privadas, farmacias y agencias de gobierno. Los grupos focales tuvieron una duración de 90 minutos, fueron conducidos en español y moderados usando una entrevista semiestructurada que exploró las necesidades y barreras relacionadas con servicios de prevención y control del cáncer. **Resultados:** Analizamos el

contenido usando el material emergente identificando patrones, temas y percepciones. Nuestro análisis cualitativo indicó que los proveedores tenían importantes preocupaciones acerca de las necesidades insatisfechas del paciente y factores del sistema, los cuales actúan como barreras para proveer servicios de calidad en pacientes con cáncer. Barreras claves incluyen necesidades prácticas no satisfechas, tales como transporte, disponibilidad económica para el tratamiento, falta de recursos, necesidades de apoyo social y servicios de educación. Conclusión: Investigaciones futuras examinarán las perspectivas de otros informantes claves (ej., pacientes y cuidadores) e identificarán cuáles temas podrían ser abordados mediante consorcios de investigación o políticas públicas.

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