Cancer Care Providers' Knowledge and Attitudes Towards Women's Cancer in Peru

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Abstract

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In Peru, cancer is the second leading cause of death with an expected increase in new cases. Women comprise 64.4% of new cases with breast and cervical cancer having some of the highest prevalence, mortality, and morbidity. This study utilized mixed-methods to analyze cancer care providers' knowledge and attitudes during a 2015 Pan American Health Organization's conference on women's cancers. Surveys measured knowledge, stigma, and fear as potential barriers to quality of cancer care before and after conference participation. In focus group discussions, providers identified barriers and facilitators to breast and cervical cancer detection and treatment. Paired t test analyses demonstrated an increase in knowledge after conference participation. In addition, providers identified individual (fear, shame, anticipated stigma), interpersonal (gender norms, marital relationships, and lived experience of social network), organizational (structural health system barriers and community based communication), community (stigma), and policy (Plan Esperanza) level barriers and facilitators. Thus, our study showed that educational conferences could be an avenue to increasing provider knowledge. Also, the providers highlighted the importance of social networks, family and social support when strengthening and developing efforts to engage women in care.

Introduction

Cancer has become the second leading cause of death causing 8.7 million deaths globally with breast cancer being the most common and leading cause of cancer related deaths for women [1]. Peru is also experiencing urbanization [2, 3], decrease in fertility rate [4], increase in median age [5], and a doubling of population in the last half-century [2]. Along with this epidemiological profile transition, limited health care resources are expected to be further strained by an expected increase in cancer incidence [1].

In 2012 cancer was estimated to cause 26,165 deaths annually in both sexes in Peru with an expected 72% increase in new cases from 2012 to 2030 [6]. Women comprise 64.4% of new cases [7] with breast and cervical cancer as some of the most common cancers with a cumulative risk of 3.4 and 2.9 [6]. In Peru, cervical cancer is the leading cancer-related cause of loss of Disability Adjusted Life Years (DALYs), with breast cancer being the second [8].

When cancers are detected early, diagnosed correctly, and prompt treatment is provided, better health outcomes are achievable. In Peru, breast cancer mortality rates in 2013 stood at 10 per 100,000 (age-adjusted), and of those, 50% were detected in advanced stages [9]. Plan Esperanza, national cancer control plan, was implemented with the aim to reduce the burden and incidence caused by various cancers including breast and cervical cancer [10]. This initiative is a step forward in decreasing the high mortality-to-incidence ratio of female reproductive cancers that persist.

To aid the process of decreasing breast cancer burden, the Breast Health Global Initiative has developed guidelines for early detection, diagnosis, treatment, and health systems based on resources available [11]. The CDC's adapted National Breast and Cervical Cancer Early Detection Program's Social Ecological Model (SEM) describes how a multi-level approach is necessary in addressing breast and cervical cancer [12]. As programs, campaigns, and interventions have been planned and implemented health knowledge has been explored. Studies conducted in Peru demonstrated that women had little knowledge of cervical cancer [13, 14] and wanted more knowledge regarding breast cancer [15]. A study conducted in Iquitos concluded that approaches to increasing this knowledge in public education must aid women in understanding prevention and treatment [16]. Women have expressed that ideal interventions to increase knowledge are education programs with medical providers in the lead, as they have the most potential to be influential [13].

An integral part of cancer care and service delivery are well-trained health care workers. Not only do health care workers diagnose and treat cancers, but they are also an essential part of effective patient-provider communication and patient education about cancers [17]. Limited research has been conducted that is focused on providers. In this mixed-methods study, we assessed cancer care providers' knowledge of and attitudes towards women's cancers and how their knowledge and attitudes are influenced by participation in the First International Cancer Survivorship Conference (Conferencia Plan Esperanza) in Peru.

Methods

Mixed methods data collection occurred at the 2015 First International Cancer Survivorship Conference in Lima, Peru. The mixed-methods design provided triangulation of data, in which we examined knowledge and attitudes both quantitatively and qualitatively. We held focus groups with health care providers and surveyed them before and after participation in the Conference.

Participants and Procedures

At the 2015 Pan American Health Organization's conference on Women's Cancers (Conferencia Plan Esperanza) in Lima, Peru, cancer care providers from Peru, Bolivia, Colombia, and Ecuador (e.g. nurses, physicians, patient navigator/advocates) took part in workshops, focus groups, and surveys. During the plenary sessions, conference organizers recruited health care workers to participate in focus group discussions by broad announcement at the start of sessions. In the plenary sessions, conference organizers distributed four-page Knowledge Summaries (KS) and discussed guidelines from the Breast Health Global Initiative (BHGI) [11]. Conference speakers also provided informational talks on detection and treatment of cervical cancers affecting women in Peru and neighboring Andean countries.

Focus Groups

Two focus groups (14 and 13) were facilitated by two Spanish-speaking Peruvian investigators, which Holcomb recommends for data saturation to be achieved for each type of participant (e.g. health care workers) [18]. Discussions were held during the lunch hour of the conference in nearby conference rooms and lasted approximately one hour. The focus groups were audio recorded and transcribed in Spanish verbatim. The investigators used a moderator's guide that covered topics of barriers and facilitators to women's cancer testing and treatment. Participants were asked to give their perspective on barriers that women in their practices faced that may prevent and delay the detection and/or treatment of cervical and breast cancer. In addition, they were asked to give their perspective on facilitators that women faced that may enable, encourage, and lead to the detection and/or treatment of cervical and breast cancer.

Surveys

At the start of the conference, all conference attendees were given the opportunity to complete a conference survey in order to obtain an understanding of providers' knowledge and provider attitudes (including stigma and fear) around women's cancers before and after the conference. The conference attendees were given a pre-conference, paper-based survey to complete immediately, and then a post-conference survey to complete at the end of the conference. The pre- and post- conference surveys were matched such that each participant had a unique identification number on both surveys. This study protocol was approved by the Institutional Review Boards at the University of Washington, Fred Hutchinson Cancer Research Center, and Universidad Peruana Cayetano Heredia.

Analysis

Focus Groups

LR, the primary coder, used open coding techniques to analyze the Spanish Language transcripts. After reading transcripts several times to develop familiarity with data, the primary coder constructed a start-list based on the topics covered in the pre/post quantitative surveys. After the start-list was overviewed by the second coder (PN), the first coder completed both inductive and deductive coding. Utilizing the start-list to apply codes and further expanding them based on themes and ideas that arose in the transcripts to create a final codebook. Using Atlas.ti, both coders conducted paragraph coding in order to identify themes. Both coders are Spanish speakers. We analyzed agreement in codes and themes the two coders developed and discussed the few disputes that came up between codes with a third party present (DR).

Survey Measures

Knowledge. We assessed knowledge of breast cancer with a questionnaire that included 27 true/false questions on topics of breast cancer risk factors, detection, and treatment. The questions were statements that came directly from the KS workshops. We coded correct answers as 1 and incorrect answers as 0 and summed all 27 responses to calculate a summary knowledge on scores from 0 – 27, with a higher score corresponding to higher knowledge.

Stigma. We used the Livestrong/RAND Cancer Stigma Index to measure stigmatizing attitudes in 12 items inquiring about feelings (e.g. fear), thoughts, and behaviors about people with breast cancer [19]. The total stigma score ranged from 0 to 26 with higher scores corresponding to higher stigma. We mean-imputed responses in cases of missing data, and calculated a total score for stigma from the sum of all the item scores.

Fear. To analyze recognition of fear as a barrier to detection and treatment for women, providers were asked if they felt women in their community wouldn't participate in screening because they are afraid of being diagnosed. All items used Likert type responses (strongly agree (4) to strongly disagree (1)). The total fear as barrier score ranged from 1 to 4.

Pre/Post conference survey results were stored, cleaned and analyzed using STATA. Preliminary analysis consisted of descriptive statistics, including frequencies, means, and standard deviations. We used paired t-tests to look for significant differences in our knowledge, stigma, and fear outcomes of interest between pre- and post-conference.

Results

Focus Groups

Twenty-seven providers participated in the two focus groups (FGs), with 13 participants in one focus group and 14 participants in the other. Table 1 describes the demographic composition of participants. Throughout the FGs, providers discussed the barriers and facilitators they perceived their patients faced when seeking and achieving detection and treatment for breast and cervical cancer. In both FGs, providers described barriers and facilitators that occur on an individual, interpersonal, organizational, community, and policy level. These five levels comprise the Social Ecological Model [12], which we used to organize the provider-identified, multiple levels that impact and interact with women's ability to engage in care. As described by providers, when it comes to detection and treatment all five levels of the model are present and interact with one another.

Individual level barriers and facilitators

Providers in both FGs reflected on patient interactions that identified various barriers to detection and treatment at an individual level. Through these stories providers further highlighted the perceived individual barriers of: fear, shame, and anticipated stigma. In addition, providers described how these three barriers interacted with each other as well as barriers that occur in other aspects of the social ecological model.

An often-discussed barrier was *fear,* which was identified as the fear a woman has around obtaining a cancer diagnosis. The fear a woman experiences are a result of various factors and perceptions such as fatality, negative impact of disease on various aspects of their life trajectory, and side-effects.

> "…. one of the barriers is the fear that the patient has to the result that she will obtain, many are afraid of knowing that they have cancer and think that by not knowing they are going to be able to cope with it much better…. "

The *shame* of exposing such an intimate part of the body can be a barrier in seeking and completing detection and treatment. Shame, as described by providers, was not a shame of being diagnosed but shame of exposing their body, particularly parts of their body that are highly recognized as private.

> "I also consider, apart from what my colleague is mentioning, [the element of] shame because obviously these are the intimate parts, as you mention, a woman's intimate parts, so they have a bit of shame to do the exam.

In facing the shame of exposing one's body, the providers described that there are *differences* in the level of shame experienced for cervical and breast cancer. Depending on the community culture, one body part may be perceived as more private than the other.

> "… In the mountains women do not readily expose their breasts, it is the opposite, you have to explain it to her very well to be able to, for them to expose their breasts so you can check them. It is a bit more difficult than cervical cancer, why? Because everyone talks about cervical cancer in publicity..."

Providers discussed stigma as a barrier and further touched on *anticipated stigma.* As described by providers, anticipated stigma, interacts with the individuals knowledge and understanding of breast and cervical cancer, fear, and community level attitudes. Stigma is a barrier that providers stated occurred for both for breast and cervical cancer. Providers also discussed that although it occurs for both types of women's cancer it is shaped by different factors and manifest in different ways.

> "… with cervical cancer, if their life with their partner will be limited, what will happen, the husband will leave her, or won't leave her, will she be able to have kids, or won't be able to have kids. She asks herself all those questions…."

Interpersonal-level barriers and facilitators

In both focus groups providers discussed how interpersonal interactions functioned as both barriers and facilitators to detection and treatment. As highlighted by providers, interpersonal interactions and relationships shape social structures and are an avenue of communication of knowledge.

One of the social constructs that provider's discussed are *gender norms* and how these norms can become barriers. Providers highlighted how gender norms influence relationship structure/power, familial obligations, and ultimately impact if and how woman seek and fulfill detection and treatment. As described by providers, women play an integral part of family well being which shape the roles and responsibilities they fulfill. These roles and responsibilities may become barriers to completing detection and treatment.

> "Another important thing that I have dealt with is women who don't seek care because their husband doesn't want them to, there's a lot of machismo/sexism, because the husband [would have] to take care of the food, the kids, so the aspect of women's health is left until the very end, the last priority is the mother's health."

Providers also discussed how husband-wife relationships under these social constructs place power in the hands of men to shape and play a role in the decision making when it comes to women's cancer screening and treatment. They shared stories of times where patients abandoned or delayed diagnosis and treatment due to the opinion of their husband.

> "….The patient will do her cryotherapy if her husband authorizes it... the husband comes, asks questions, and only then the woman will have her cryotherapy…."

An additional interpersonal interaction discussed by providers is the exchange of *lived experience of social networks*. This exchange of lived experiences, as discussed by providers, can become both barriers and facilitators to detection and treatment. Further, providers touched on the importance of acknowledging the role lived experience plays to increase the exchange of positive lived experiences.

> "Many times they say, "No, if my family received chemotherapy and in two weeks they died," or "If they were operated on and then the cancer advanced, you know? Then that also will happen with me, therefore why should I be like that if I can live longer having the disease before they operate or do the biopsy or something, and then I end up dying within a month or two,"

In contrast, providers also shared experiences in which their patients were encouraged to seek treatment and detection based on the lived experiences of their social network.

> "There are some patients with cervical cancer and her neighbor and everyone knows she has been bleeding. And out of fear they go get a Pap."

As providers discussed how lived experiences were both barriers and facilitators to detection and treatment they highlighted the importance of knowing the role lived experience plays. As stated by providers it is important to utilize this avenue of interpersonal communication to share positive experiences and education that may further facilitate woman to seek detection and treatment.

> " “When a dog bites a man, it’s not news, but a man who bites a dog is news,” right? So, regarding those things for example, why don’t we disseminate the positive aspects of mammography”

Organizational- level barriers and facilitators

Providers discussed the organizational structure of the healthcare system. Providers discussed *healthcare system structural barriers that may lead to delay or abandonment of detection and treatment.* As providers shared stories they touched on geographical, referral, and resource barriers the healthcare system contained.

> “You refer, they don’t give you an appointment, or if they give you one, they want another reference, and the patient gets bored with going and coming and then they don’t go. And so definitely the process gets paralyzed there.”

> “… for breast cancer we have no staff that is trained even to do a biopsy. Then, for cervical cancer, for treatment they need to be referred, either to Arequipa, which is by flight, or to Lima, which is by flight, in other words by plane….”

In addition, providers discussed the importance of *community-based communication* and the role it plays on an organization level. Providers’ further discussed how some of the current communication strategies become a barrier. In addition, they further discussed the utilization of communication skills and strategies that are tailored to each individual community as a facilitator. their communication plays an essential role in provision of services and an avenue for increasing education.

> “Many times we arrive in the communities with a patronizing attitude, we know everything, they don’t know anything, we are repressing them…“the people don’t know,

> the people don't understand" and that is not true. The problem is that we have not developed the appropriate communicational strategies for each community."
>
> "That is also why it is important to incorporate the community health workers and the leaders of the community because through them we can create, over there, we have created of a type of flip-chart with the population's local language so we can do our counseling."

Community- level barriers/facilitators

Along with internalized stigma providers also discussed *community level stigma* that is a barrier to detection and treatment. Providers discussed how community knowledge and understanding of women's cancer shaped how they perceived the illness and construct stigma regarding diagnosis.

> "...it's like they isolate her from the community meetings….or the community makes her isolate herself because of the feeling of "embarrassment". They start to isolate themselves from daily community activities, which finally ends up as stigma."

Policy – level barriers and facilitators

Along with discussing the healthcare system, providers further discussed current policies in place and how they interact with the provision of services. Both focus groups discussed Plan Esperanza and how the cancer control program further increased treatment. Providers further discussed how the goals of the new cancer control plan interacted with the current healthcare system structural barriers that may lead to delay or abandonment of detection and treatment and accessibility. Providers shared stories that described how policy implementation occurred in different clinical settings.

> “Now, in relation to treatment. Maybe our reality is a bit different because we are in Lima, and because we have Plan Esperanza in place.”
>
> “It is different, let’s say, for another type of cancer like Leukemia lymphoma which are emergencies and they are transferred as an emergency and the SIS public health insurance pays for it all, transportation, food for her and her family, everything when they are referred as an emergency condition, unlike for this group of women’s cancers like cervical cancer and breast cancer.”

In sum, focus groups discussed barriers and facilities that occur on an individual, interpersonal, organizational, community, and policy level. Throughout the discussion providers’ analyzed barriers and facilitators in each category, how they interact with one another, and how they could be utilized to increase detection and treatment.

Survey Results

A total of 54 cancer care providers participated in the surveys. Data was analyzed from participants who completed both the pre- and the post- surveys. After pre and post responses utilizing a responded specific code, those that did not contain both responses were excluded. Figure 1 describes the educational composition of the sample and how many participants completed each measure. Figure 2 provides a graphical depiction of all analyses.

Knowledge. The overall breast cancer knowledge scores increased from a mean of 21.56 (standard deviation [SD= 1.9]) pre-conference to 22.54 (standard deviation [SD= 1.8]) post conference. The paired t-test demonstrated an in increase in knowledge scores ($p < 0.01$)

Stigma. The overall woman's cancers stigma scores increased from a mean of 4.7 (standard deviation [SD= 3.4]) pre-conference to 6.3 (standard deviation [SD= 5.0]) post conference. The paired t-test demonstrated a statistical trend ($p= 0.05$).

Fear. The overall recognition of fear as a barrier to detection and treatment decreased from a mean of 2.37 (standard deviation [SD= 0.82]) pre-conference to 1.95 (standard deviation [SD= 0.70]) post conference ($p < 0.01$).

Discussion

We examined how knowledge and attitudes changed before and after an educational conference on women's cancers and in focus group discussions with health care providers. Our participants demonstrated an increase in knowledge about cancer, but did not show a decrease in stigmatizing attitudes. Healthcare workers' discussed fear as a barrier to women's engagement in detection, but agreed less that it was a barrier to detection in the post survey.

Healthcare workers demonstrated an increase in knowledge, suggesting that audience members benefited from discussions of Knowledge Summaries (KS) and informational sessions on cancer care. These findings are consistent with research that has shown educational forums are a good avenue for disseminating information to health care providers [13].

With respect to stigma and negative attitudes towards cancer, the results suggested a slight increase in stigmatizing attitudes. The increased knowledge attained may heighten healthcare worker's concerns around women's cancers. Although stigma reduction was not the ultimate purpose of the Conference, these data suggest that education may not be the best route to reducing negative attitudes around cancer. The work of Corrigan and colleagues suggests that in addition to education, contact and interaction with cancer survivors may be a more effective method of reducing cancer-related stigmatizing attitudes [20].

Qualitative results also suggested that healthcare workers were aware of their patients' fears of diagnosis and treatment and its impact on their patient's willingness to engage in care. Other studies have found similar results, as fear has been identified as a factor that impacts cervical cancer service utilization in low-resource settings.[13, 21] In addition, one study suggested that women worry that a cancer diagnosis will be life changing and fatal [22]. These data show that health care providers and women conceptualize and discuss how fear of diagnosis is experienced by women. As we move forward in efforts focused on women's cancers, it is important to discuss and develop strategies to decrease the fear experienced by women. Healthcare providers also provided information on barriers and facilitators on various levels of the health care system. On an individual level, providers described their patient's shame of exposing oneself in the process of medical care and treatment for cancers.

On the interpersonal level, providers discussed how marital relationships shape and impact cancer detection and treatment. Studies have shown that some women chose not to disclose a cancer diagnosis in order to reduce stress on the family [22]. On the other hand, supportive husbands can also serve as a reason for continuing care. One study conducted in Peru found having a husband who was supportive of screening participation was a predictor for program completion [23]. Analyzing the role of gender norms and marital relationships it is essential to develop efforts that efforts to increase community level knowledge including that of spouses. Developing a community level awareness will shift some burden off the women.

Participants described instances where their patient's previous experiences with cancer diagnosis and treatment both deterred or engaged women into care. Their patients are part of larger social networks in which information on quality of care is shared, and negative experiences discussed by peers can prevent women from completing care. In contrast, positive experiences and social support can strengthen women's chances of completing care. A study found that female family members and neighbors have been found to be an important source of support in completing a cervical cancer screening [14]. Understanding the role social networks have in knowledge, understanding, and support it is important to develop strategies to utilize them as tools. Providers discussed how social networks could be utilized to share positive experiences that may lead women to participate in detection and treatment.

At the organizational level, providers discussed structural barriers at a health care system level that may lead to delay or abandonment of detection and treatment. Although studies have found that those with private insurance receive faster diagnosis and treatment, participants in our study discussed barriers in the Seguro Integral de Salud –Peruvian public insurance. Location of services, financial, and organizational reach have been found to shape detection and treatment [13, 21]. Within the public insurance system, providers discussed challenges with geographical location and access, resources, and referral mechanisms. Similar barriers have been identified by Peruvian women as barriers that shape their care [22]. Although the public insurance system offers resources, women often times are unaware of these resources that may aid in their access to care [22]. In addition to improving health systems, studies show that it is also important to develop mechanisms in which individuals can become informed on the services and resources that are available.

This study had several limitations. First, these results were obtained from health care workers from Andean countries at an educational conference on women's cancers, and thus, may not be generalizable to other populations. In addition, the conference was not designed to reduce stigmatizing attitudes or decrease fears around women's cancers, and thus, these results are exploratory in nature, and do not reflect results from an intentionally designed intervention program.

Conclusion. Exploring knowledge and attitudes creates an avenue of understand through which further interventions, programs, and policies can be tailored. Our quantitative data demonstrates the potential of conferences as a tool to increase knowledge. Providers are a source of knowledge for all their patients, further efforts must work to ensure they communicate with their patients in a non-stigmatizing manner. Further exploration of stigma reduction efforts could focus on contact-related methods to reduce fear and decrease other negative attitudes around cancers.

The qualitative data allow providers to communicate barriers and facilitators women face when seeking detection and treatment. This consistency highlights the importance of exploring the impacts of behavioral intervention on women’s engagement in care. When constructing interventions programs to increase knowledge about women’s cancers, our data show that it will be essential to recognize the importance of social networks, family, and social support to engage women in care.

Tables/Figures

Table 1: Socio-demographic characteristics for focus group participants

Variable		**Mean (SD) / Frequency (%)**
Gender		
	Female	23 (88%)
	Male	3 (12%)
Profession		
	Physician	20 (74%)
	Nurse	2 (7%)
	Nutritionist	1 (4%)
	Surgeon	4 (14%)
Age		
	28 – 35	6 (23%)
	36 – 40	7 (26%)
	41 – 48	10 (36%)
	49 – 62	4 (16%)
		Total Participants: 27

Figure 1: Information on Survey Participants

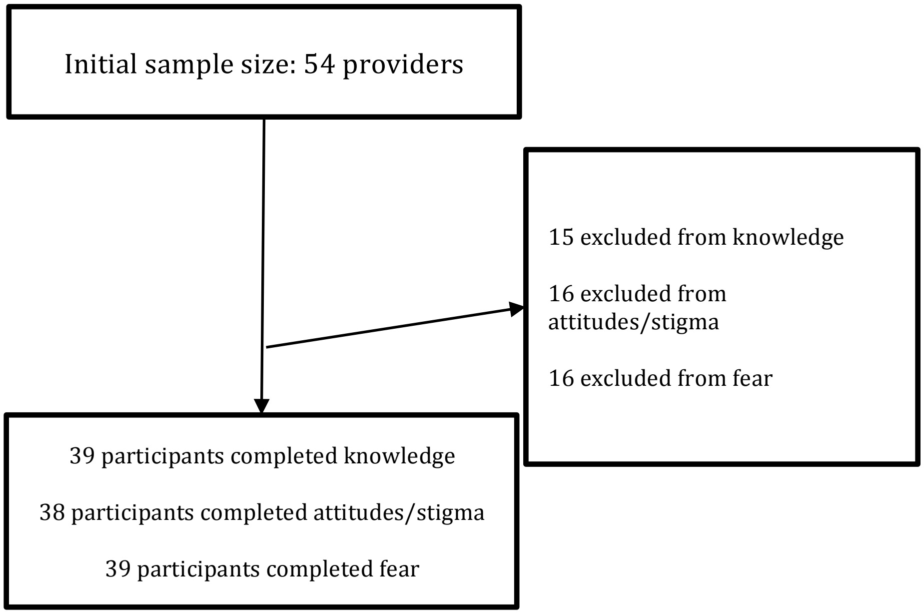
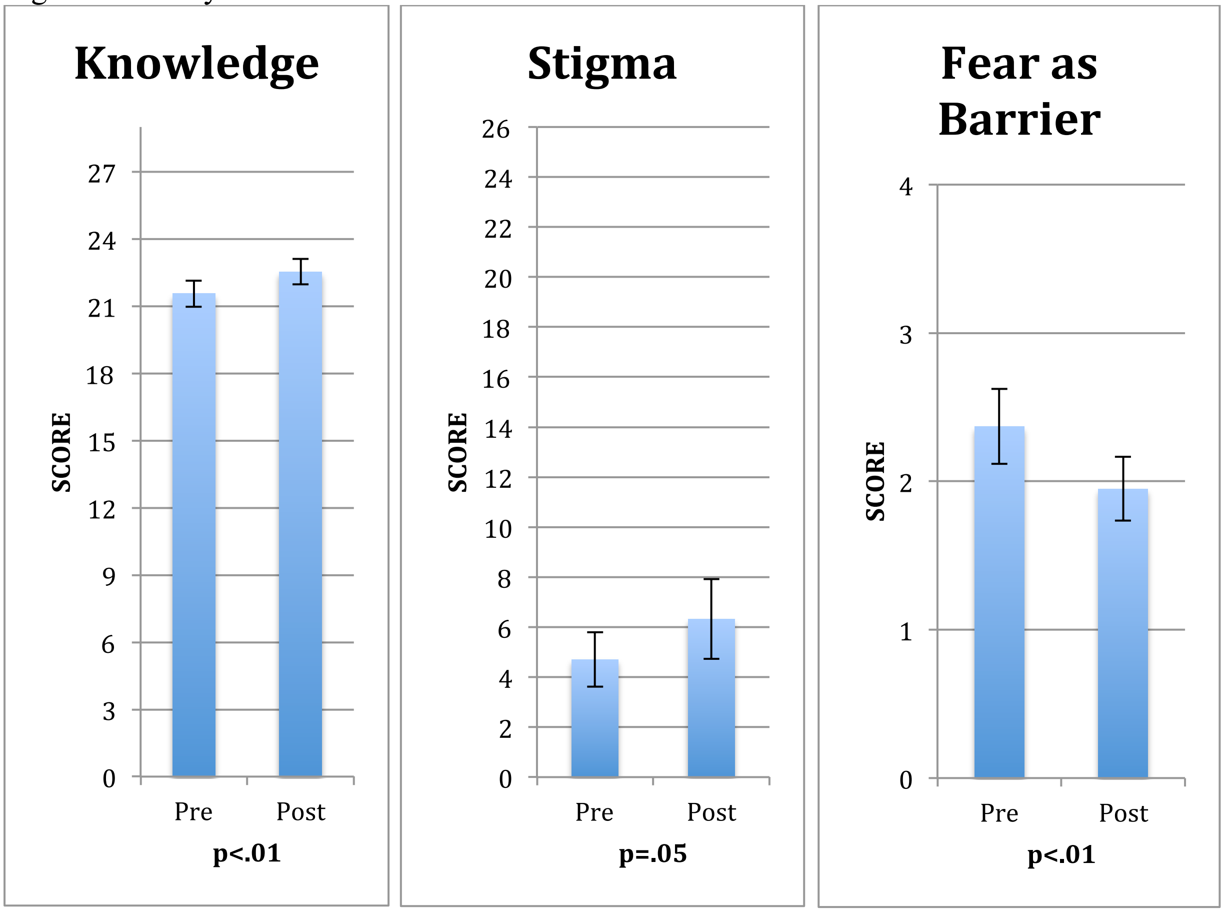


Figure 2: Survey results



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