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Community Engagement for Identifying Cancer Education Needs in Puerto Rico

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Abstract

Cancer is the leading cause of death in Puerto Rico, suggesting a need for improved strategies, programs, and resources devoted to cancer prevention. Enhanced prevention needs in Puerto Rico were initially identified in pilot studies conducted by the Ponce School of Medicine (PSM) in collaboration with the H. Lee Moffitt Cancer Center (MCC). In the current study, we used community engagement to identify specific needs in cancer prevention and education and strategies to create culturally attuned, effective cancer prevention education programs. A total of 37 participants attended a community forum and were assigned to one of 3 discussion groups: patients/survivors (n = 14); family/caregivers (n = 11); or healthcare providers (n = 12). Most participants were women (73%), over 35 years of age, and a majority were married (58%) and had a university education (81%). The sessions were recorded and transcribed and analyzed for key themes. Participants wanted improved awareness of cancer prevention in Puerto Rico, and believed cancer prevention education should start early, ideally in elementary school. Participants also stressed the importance of creating partnerships with private and government agencies to coordinate educational efforts. Suggested strategies included: outreach to communities with limited resources; incorporating the testimony of cancer survivors; and utilizing social media to disseminate cancer prevention information.

Keywords

Cancer Prevention; Community Forum; Community Engagement; Qualitative; Cancer Education; Outreach; Puerto Rico

INTRODUCTION

For Puerto Ricans living on the island, cancer causes more premature deaths than any other illness (nearly 5,000 per year) [1]. In 2010, approximately 13,300 Puerto Ricans developed some type of cancer [2]. These statistics highlight the need for improved cancer prevention programs, strategies, and resources [3]. Several studies have examined lifestyle choices, health-seeking behaviors, and access to healthcare among Puerto Ricans living in the United States, but there is a lack of knowledge of these same factors for Puerto Ricans living on the island [3].

This dearth of culturally relevant cancer information must be remedied to improve cancer prevention education programs and outcomes in Puerto Rico. One approach to addressing the lack of information is the development of research through community engagement. This process involves creating collaborative community-academic partnerships to improve knowledge and create change through the scientific process [4, 5, 6]. Understanding the tremendous potential of community engagement, King et al [7] delineated these benefits. King surmised that community engagement helps build legitimacy for a research project, creates human infrastructure for research, and, most importantly, demonstrates respect for the stakeholder community. The integration of culturally adapted educational strategies as a way to increase cancer knowledge and prevention has proven to be an effective and respectful method of reaching underserved communities [8, 9]. Community engagement is the key for facilitating the development of culturally adapted educational strategies via the implementation of diverse data gathering methods. One of the methods that could be employed to acquire the information needed for the construction of these strategies is Community Forums. Diverse authors have identified that this is a useful tool to develop an open conversation with community members, increase their knowledge of a particular health condition and to integrate them in the scientific process. Also, Community Forums can propitiate the identification of barriers, needs, resources and priorities of the community in relation to a health care dilemma and can also help to develop interventions directed to the community in ways that could benefit them directly [9, 10, 11].

The Ponce School of Medicine in Ponce, Puerto Rico (PSM) and the Moffitt Cancer Center of Tampa, FL (MCC) have established a unique partnership via this National Cancer Institute (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. The primary goal of this collaboration is to improve cancer health outcomes among Hispanics in Florida and Puerto Rico and to decrease existing cancer health disparities through cancer education. Previously, a community forum was developed as a strategy to identify barriers related to cancer care and prevention services. The community forum consisted of cancer patients, cancer survivors, healthcare providers, community leaders, and members of faith-based organizations. Findings from previous focus groups and surveys, showed consistent concern in the community that there was a great need for improved cancer prevention and education services [3, 4]. We used the community forum platform as a way to explore what the improvements should be and strategies to develop them.

As a next step towards addressing this issue, and with the objective of exploring the ideas, concerns, expectations, and possible experiences related to the issue of cancer prevention education, key questions for discussion groups were developed, and discussion groups were conducted in a community forum. These groups included: cancer patients and survivors; caregivers and family members of cancer patients; and healthcare providers. The goal was to identify specific needs in cancer prevention education and to identify strategies that could be used to create culturally attuned, effective cancer prevention education programs. This study exemplifies one approach that the PSM-MCC outreach core utilizes to facilitate community engagement in an effort to reduce cancer health disparities.

METHODS

Recruitment of Participants

The PSM-MCC outreach core includes a Community Advisory Panel (CAP) composed of four groups: cancer patients/survivors (n = 3), family members/caregivers (n = 2), representatives of community/faith-based organizations (n = 2), and healthcare providers (n = 2). The CAP participated in the design of semi-structured interview guides, planned the agenda, and provided guidance in recruitment of participants for the community forums.

For this study, recruitment for the community forum utilized two approaches. The professional community was invited through letters mailed to healthcare providers (oncologists, family medicine physicians, etc.), government agencies, and community/faith-based organizations. Community leaders in the southern region of Puerto Rico aided in the recruitment of cancer patients, survivors, caregivers, and family members. These community leaders used a snowball sampling technique, a strategy whereby participants nominate peers with similar backgrounds, and contacted community members from a list of those who attended previous forums and were interested in participating in events related to research and cancer education. In addition, a community liaison (a professional educator and active community leader) participated in the recruitment process using a word-of-mouth strategy with the community representatives.

Data Collection

All community forum participants provided written informed consent, with all procedures and forms approved by the Institutional Review Board (IRB). During the registration process, demographic information was collected from the participants regarding the following: occupation, age, gender, monthly income, highest level of education, city of residency, marital status, whether they are cancer patients/survivors, family member or caregiver, or healthcare provider. The latter information was utilized to assign the participants to their corresponding discussion group, with the intent of acquiring the perspective of different components of the community. Throughout the initial portion of the forum, the moderator provided information about the PSM-MCC Partnership, described the forum's objectives, and addressed all of the participant's comments and questions. Three discussion groups were then conducted with the objective of exploring the perception of participants toward cancer prevention education needs and strategies to address their community's needs. Each discussion group was led by a research team member with

experience in conducting focus groups, using a semi-structured focus group guide. Examples of questions that guided the group discussions included 1) “*What do you think are the needs in education for cancer control and prevention?*” 2) “*What strategies in education should be used?*” 3) “*What educational resources do you know in relation to cancer prevention?*” and 4) “*Have you participated in activities of cancer control and prevention?*”

During the group discussions, one member of the research team served as moderator, and the other took notes. Also, audio recordings were made of each session. All meetings were conducted in Spanish, the participant s native language, and took place in private rooms with seating arrangements that allowed the participants to maintain eye contact with the facilitators. Each group lasted about 90 minutes. In each session, a leader was selected to represent their discussion group and share a summary of the discussion with the larger group. At the end of the discussion groups, the assembly was gathered to present and integrate information obtained during the three individual discussion groups.

Analysis

All recordings were transcribed verbatim and content analysis, using the constant comparative method, was performed to identify key themes. Content analysis is a systematic interpretation of data to identify patterns, themes, and meanings [12]. A thematic framework was established to classify and organize data according to key themes, concepts, and categories [13]. The thematic frameworks were synthesized from the complete review of all transcriptions. This step was completed individually by research team members (AR, FR), who then subsequently classified the findings into broad categories (e.g., create awareness about cancer prevention, cancer preventive education should start early, provide appropriate educational information, and disseminate information about relevance of acquired health behaviors) within that cancer needs framework. To ensure reliability, members of the research team (JJ, EC) separately coded the material using the same process. Each coded transcript was compared to certify that the codes selected reflect the opinion of the participants. Any disagreements were discussed and resolved through expanded definition of the code books.

RESULTS

Participants and Discussion Groups

Thirty-seven participants attended the community forum. They were distributed among 3 discussion groups: patients/survivors (n = 14), family/caregivers (n = 11), and healthcare providers (n = 12). The demographics of participants are shown in Table 1. All participants were more than 35 years of age, and most were female (73%), married (58%), and had a university education (81%).

Cancer Education Needs

Theme 1: Create Awareness About Cancer Prevention—In the patient/survivor discussion group, some participants highlighted that knowing risk factors such as family history of cancer was not sufficient to motivate them to search for information about cancer. For specific quotes, see Table 2.

Most of the participants in both the patient/survivor group and the healthcare provider group echoed the need to encourage the community to recognize and consider the physical symptoms associated with cancer when promoting awareness about cancer prevention (Table 2). Likewise, both groups acknowledged that early detection was associated with the opportunity to increase the likelihood of survival.

Theme 2: Cancer Prevention Education Should Start Early—All participants among all groups agreed on the need for cancer prevention education to start at an early age (Table 2). Participants of every group also agreed that conversations about cancer should start at school age because of the possibility of being diagnosed with this disease in childhood and because of the many environmental factors related to cancer development. They acknowledged that discussing these risk factors during childhood can promote a better understanding and awareness of cancer prevention strategies.

Many participants felt that ideas related to general healthcare, as well as methods for detecting cancer at early stages, should be taught to children and adolescents in school (Table 2). Members of the family/caregiver group pointed out that information about the importance of early cancer detection is exclusively directed to adults. They suggested this subject should also be directed to a younger population.

One member of the patient/survivor group suggested the need to raise awareness about self-care from an early age. Education about the importance of recognizing the signs and symptoms associated with different health conditions was identified as a point to consider when raising awareness about self-care. Participants also stressed the importance of teaching children to acquire healthy habits, such as eating correctly, to prevent cancer (Table 2).

Theme 3: Provide Appropriate Educational Information—The majority of participants recognized that, although cancer prevention information exists, it is not easily accessible by all. Participants of both, the healthcare provider group and the family/caregiver group identified the need to have clear, detailed, and accurate information that helps educate adults and the youth about cancer prevention. They stressed that adequate and factual information can help diminish negative emotions and fears associated with disease (Table 2). One participant in the patient/survivor group highlighted the importance of educating in a clear and simple manner: “people like it when you talk to them in colloquial language, avoiding medical jargon...”

Theme 4: Disseminate Information About Relevance of Acquired Healthy Behaviors—Another topic of discussion was the need to disseminate information about the relevance of incorporating healthy behaviors associated with self-care, especially among family and caregivers. Healthy behaviors, nutrition and physical activity were highlighted topics (Table 2).

Strategies for Cancer Prevention Education

Theme 1: Schools as a Forum for Educating and Disseminating Information About Cancer Prevention—The majority of participants among all 3 discussion groups suggested that incorporating education about cancer prevention in schools would be useful

because of the numerous community members who could be reached, including children, parents, and teachers. Specifically, a participant of the family/caregiver group emphasized that “*we have to go into public schools to do this effort*” (Table 3).

Participants in both the family/caregiver group and the healthcare provider group indicated that schools would be an ideal place to provide information regarding early detection and screening. They also highlighted the possibility of impacting parents when informed children and adolescents go home and talk to their parents about cancer prevention.

Theme 2: Create Partnerships With Private and Government Agencies—The majority of participants indicated that support from government and private agencies may be an effective strategy for the dissemination of information related to cancer prevention. Many of the participants agreed that discussions about cancer prevention should occur through sponsorship of the Departments of Family, Health, and Education (Table 3). Participants in the healthcare provider group underscored the need to integrate efforts in a coordinated manner, driven by a common goal, even while including different government and private agencies.

Theme 3: Consider Specific Cultural Factors When Preparing and Sharing Cancer Education Information—When planning strategies for disseminating information about cancer, about half of the participants in the patient/survivor and healthcare provider group expressed the need to consider the culture of the target population. Specific to Puerto Rican culture, the participants of both of these groups stressed the importance of keeping in mind the cultural and social implicit and explicit norms and values of Puerto Rican men, as expressed by the quotes in Table 3.

Theme 4: Outreach to Communities With Limited Resources—The majority of participants in the family/caregiver and healthcare provider groups echoed the need to pay attention to the underserved population living in municipalities distant from bigger towns or cities. Lack of transportation and limited economic resources were both mentioned as reasons for delivering cancer education information through community outreach activities.

Many members of each group suggested disseminating educational information in health fairs as a strategy to reach members of these communities. One participant also expressed that, in scheduling such a community outreach effort, the unique characteristics and resources of the members of each community need to be explored and taken into consideration.

Theme 5: Include Testimony of Cancer Survivors—Members of the family/caregiver and the healthcare provider discussion groups highlighted the importance of survivor testimony. Integrating the individual testimony of cancer survivors in talks and/or orientations could be a beneficial and effective strategy for increasing awareness of the importance of cancer prevention and treatment adherence (Table 3).

Theme 6: Utilize Online Social Networks and Media to Disseminate Cancer Prevention Information—In the current culture, online social networks have become a

dominant medium for the dissemination of information. Given the ever-growing availability and popularity of online information, social media has become a common way of communicating. Given this awareness, most participants in the family/caregiver group identified social media, specifically as Facebook and Twitter, as a viable and useful tool for sharing information about cancer prevention education (Table 3).

DISCUSSION

Prevention remains the leading strategy to reduce the incidence of cancer and associated morbidity and mortality [14]. Educational programs have been developed to promote healthy lifestyles, reduce cancer risk factors, and encourage compliance with recommended cancer screenings. However, these initiatives will only succeed if the population has access to them and they are culturally relevant. Previous exploratory studies conducted in Puerto Rico under the PSM-MCC Partnership have identified the need for increased education about cancer prevention [3]. In the present study, we used discussion groups in a community forum to identify specific needs with regard to cancer prevention education and explore strategies to create culturally attuned, effective cancer prevention education programs in the southern region of Puerto Rico. Our results showed that most participants believe it is necessary to increase awareness about the importance of cancer prevention in their community, and they discussed a variety of strategies to achieve that goal.

A common strategy among many cancer prevention programs is educating the population about the importance of committing to a healthy lifestyle, which involves maintaining a healthy diet, practicing a regular exercise regimen, not smoking, and controlling body weight. These programs underscore that a healthy lifestyle will reduce the risk of cancer. However, research has also shown that behavioral changes related to reducing cancer risk will only emerge when there is an association between having knowledge about cancer prevention and believing that knowledge to be true [15].

The majority of participants in all three discussion groups emphasized the necessity of introducing cancer prevention education programs at an early age, preferably in schools. Specifically, they felt it would be beneficial to educate children about the importance of recognizing the physical signs and symptoms related to cancer, acquiring healthy habits, and participating in cancer screenings. Several studies and programs have considered the importance of improving health by educating and promoting healthy habits at early ages. In a randomized controlled trial targeted at Hispanic children, Peñalvo et al. [16] reported positive results that included improved knowledge, a more positive attitude, and adoption of healthy habits related to diet, exercise, and the human body. Younger children and families with higher socioeconomic status seemed to benefit most from this program [16]. This strategy has also been successfully employed in other areas. Studies have shown that intervention programs aimed at young populations are most effective. For example, childhood obesity programs are most successful if started at an early age [17].

A variety of different strategies can be used to teach children about cancer prevention. Often, the most successful programs take a holistic approach. One strategy is to demonstrate the psychosocial impact of the disease [18]. Educational programs designed to improve sun

protection behaviors among children and adolescents from 6th to 8th grade have been successful in producing behavioral changes by teaching facts about skin cancer combined with protective behaviors [19]. Other examples include health prevention education related to chronic conditions such as diabetes, with the objective of preventing type 2 diabetes mellitus in adults. A positive impact was observed when the program increased understanding of both general health and diabetes [20].

A number of studies have attempted to identify alternative strategies for more effective cancer prevention educational programs. As a result of those efforts, programs like *Partners in Health Sciences*, which contains information about the biology of cancer and prevention of the disease, have been developed. The results of this program, developed at the University of Arkansas, indicated that topics related to the biology of cancer can motivate kindergarten to 12th grade teachers and students to learn about normal cell growth and cancer. Although the majority of studies report the effectiveness of cancer prevention programs, data from pre- and post-tests illustrate a dearth of information regarding the amount of time dedicated annually to cancer prevention education for students and teachers [21].

In our current study, the majority of participants in each group identified schools as a promising place to conduct cancer prevention education, considering its reach not only to children, but also to parents and teachers. This suggestion is supported by the National Health Education Standards (NHES) and the American Cancer Society (ACS), both of which promote and support the development of healthy lifestyles in children starting in preschool. Both NHES and ACS consider schools to be an ideal place to start educating children about health from early ages. The NHES promotes healthy behaviors in children with the goal of extending those habits to their family and community. The standards include students having the ability to advocate for personal, family, and community health [22]. This idea is supported by the social-ecological model developed by Bronfenbrenner, which contends that the impact and benefits of educational programs may extend beyond the individual level (the child) to family and peers (microsystem level), to the extended family, neighbors, parent's work environment (ecosystem level), and to health policies and the education system (macrosystem level) [17, 23].

Narrative forms of communication such as entertainment, literature, and testimonials have proven to be important tools for cancer prevention education. Kreuter et al. [24] identified four distinct functions of narrative communication: (1) overcoming resistance; (2) facilitating information processing; (3) providing surrogate social connections; and (4) addressing emotional and existential issues. The authors concluded that narrative forms of communication might be useful in addressing cancer prevention objectives by helping overcome resistance to both prevention behaviors and health messages and by facilitating processing of cancer information [24]. Consistent with this, a strategy recommended by the majority of the participants in the family/caregiver group was the use of online social networks and social media to disseminate information about cancer prevention. Currently, the vast majority of individuals use social media, especially young people. Every day, more people and institutions are using online social networks to share information about health, and these channels are effective in developing health-related interventions. For example, social media-based interventions have been developed with the goal of modifying unhealthy

lifestyle choices, such as the use of tobacco, unhealthy diet, lack of physical activity, and unsafe sexual practices [25].

This study's findings showed the need to educate beginning at an early age; therefore, schools should be considered as an appropriate place to raise awareness about health care. The participants' view suggests that using school settings and the educational process as platforms to inculcate education about healthy habits could be an effective strategy.

If we consider schools as a cornerstone of an integral foundation for children, public policies should be established to implement school health programs. These policies would include strategies for the integration of cancer prevention education into the curricula of public and private schools in Puerto Rico, including the involvement of stakeholders such as teachers, parents, and school administrators.

Efforts to establish partnerships should promote the inclusion of public and private organizations, such as universities, as well as Health and Education departments. For example, universities that have public health programs could provide health educators as resources for the dissemination of healthy habits and cancer prevention education.

In summary, the participants in this study identified many important needs for improved cancer prevention education in Puerto Rico. They also discussed meaningful strategies to achieve better health literacy and encourage healthy lifestyle choices that may someday reduce the burden of cancer in our community. Future studies should be focused on exploring the best mechanisms and pathways to implement the concept of a healthy school program in accordance with the educational system of Puerto Rico.

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References

1. Puerto Rico Department of Health. [Accessed September 24, 2015] Informe de Salud de Puerto Rico. 2014. Available at: <http://www.salud.gov.pr/Estadisticas-Registros-y-Publicaciones/Pages/Estadisticas-Vitales.aspx>
2. Centro Comprensivo de Cáncer, Universidad de Puerto Rico. [Accessed September 24, 2015] Boletín del registro central de cáncer. 2013. Available at: http://www.estadisticas.gobierno.pr/iepr/LinkClick.aspx?fileticket=XNd4xX_dMjg%3d&tabid=186
3. Simmons VN, Jimenez JC, Castro E, et al. Initial efforts in community engagement with health care providers: perceptions of barriers to care for cancer patients in Puerto Rico. *Puerto Rico health sciences journal*. 2011; 30:28–34. [PubMed: 21449495]
4. Gwede CK, Ashley AA, McGinnis K, et al. Designing a community-based lay health advisor training curriculum to address cancer health disparities. *Health promotion practice*. 2013; 14:415–424. [PubMed: 22982709]
5. Meade CD, Menard JM, Luque JS, et al. Creating community-academic partnerships for cancer disparities research and health promotion. *Health promotion practice*. 2011; 12:456–462. [PubMed: 19822724]

6. Valente TW, Fujimoto K, Palmer P, et al. A network assessment of community-based participatory research: linking communities and universities to reduce cancer disparities. *American journal of public health*. 2010; 100:1319–1325. [PubMed: 20466964]
7. King KF, Kolopack P, Merritt MW, et al. Community engagement and the human infrastructure of global health research. *BMC medical ethics*. 2014; 15:84. [PubMed: 25495054]
8. Sudarsan NR, Jandorf L, Erwin DO. Multi-site implementation of health education programs for Latinas. *Journal of community health*. 2011; 36:193–203. [PubMed: 20652382]
9. Gonzalez-Guarda RM, Lipman DG, Cummings AM. A community forum to assess the needs and preferences for domestic violence prevention targeting hispanics. *Hispanic Health Care International*. 2012; 10(1):18–27. 10p. [PubMed: 23268109]
10. Dulin MF, Tapp H, Smith HA, Urquieta de Hernandez B, Furuseh OJ. A community based participatory approach to improving health in a Hispanic population. *Implementation Science: IS*. 2011:638.
11. National Institutes of Health, National Institute of Environmental Health Sciences. Community forums. 2011. Retrieved January 26, 2016, from <http://www.niehs.nih.gov/about/community/communityforums/index.cfm>
12. Berg, B. *Qualitative Research Methods for the Social Sciences*. Boston, MA: 2006.
13. Ritchie, S., O'connor, W. *Carrying Out Qualitative Analysis*. Thousand Oaks, CA: 2003.
14. Umar A, Dunn BK, Greenwald P. Future directions in cancer prevention. *Nature reviews Cancer*. 2012; 12:835–848. [PubMed: 23151603]
15. Vidrine JI, Stewart DW, Stuyck SC, et al. Lifestyle and cancer prevention in women: knowledge, perceptions, and compliance with recommended guidelines. *Journal of women's health*. 2013; 22:487–493.
16. Peñalvo JL, Sotos-Prieto M, Santos-Beneit G, et al. The Program SI! intervention for enhancing a healthy lifestyle in preschoolers: first results from a cluster randomized trial. *BMC public health*. 2013; 13:1208. [PubMed: 24359285]
17. Lee A, Ho M, Keung V. Healthy school as an ecological model for prevention of childhood obesity. *Research in sports medicine*. 2010; 18:49–61. [PubMed: 20391246]
18. Morse LL. Let schools do it! Helping schools find a role in cancer prevention. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*. 2013; 52:S89–92. [PubMed: 23601617]
19. Buller DB, Reynolds KD, Yaroch A, et al. Effects of the Sunny Days, Healthy Ways curriculum on students in grades 6 to 8. *American journal of preventive medicine*. 2006; 30:13–22. [PubMed: 16414419]
20. Dodge C, Chino M. Type 2 diabetes science and American Indian/Alaska native culture: creating a national K-12 curriculum prevention strategy for native youth. *Diabetes Spectrum*. 2012; 25(1): 23–25.
21. Summerfield, L. *Preparing classroom teacher for delivering health instruction*. Washington, DC: ERIC Clearinghouse on teaching and teacher education; 2001.
22. Anonymous Center for Disease Control and Prevention. *Healthy schools*. National Health Education Standards; Available at: <http://www.cdc.gov/healthyschools/sher/standards/index.htm>
23. Lohrmann DK. A complementary ecological model of the coordinated school health program. *Public health reports*. 2008; 123:695–703. [PubMed: 19711650]
24. Kreuter MW, Green MC, Cappella JN, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 2007; 33:221–235. [PubMed: 17600449]
25. Cavallo DN, Chou WY, Mcqueen A, et al. Cancer prevention and control interventions using social media: user-generated approaches. *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*. 2014; 23:1953–1956.

Table 1

Participants Characteristics

Variable	Patients and Survivors: n	Families and Caregivers: n	Healthcare Providers: n	Total: n
Age, years	n = 14	n = 11	n = 12	n = 37
< 18	0	1	0	1
18 – 24	1	2	0	3
25 – 34	0	0	2	2
35 – 44	2	3	3	8
45 – 54	2	4	3	9
55 – 64	6	1	3	10
65	3	0	1	4
Gender	n = 13	n = 11	n = 11	n = 35
Male	3	4	3	10
Female	10	7	8	25
Marital status	n = 13	n = 7	n = 12	n = 32
Single	1	2	4	7
Married	10	3	7	20
Living with partner	0	1	0	1
Divorced/separated	1	1	1	3
Widower	1	0	0	1
Monthly income, \$	n = 12	n = 11	n = 12	n = 35
< 500	1	4	0	5
501 – 1000	4	1	2	7
1001 – 1500	1	2	0	3
1501 – 2000	0	0	1	1
2001 – 2500	1	1	3	5
2501 – 3000	1	1	3	5
3001	4	2	3	9
Highest level of education	n = 14	n = 11	n = 12	n = 37
High school not completed	1	1	0	2
High school completed	3	2	0	5
Associate degree	3	3	1	7
Bachelor degree	4	4	5	13
Master degree	2	0	5	7
Doctorate degree	1	1	1	3

Table 2

Participant Statements Regarding Cancer Education Needs

Statements	Discussion Group
Theme 1: Create Awareness About Cancer Prevention	
“(We) have to spark the interest, because the information exists, but we don’t worry (about it) until we have a family member or it happens to us, and then we begin to look, because there is information, little, but like she says, you have to keep searching and searching, but people are not interested, until it doesn’t happen to that person.”	Family/caregivers
“A lot of times despite that we have family members, for example in my case, it happens that my father died of cancer, however it never crossed my mind that I too could have the condition. So, in that sense, also create that conscience.”	Patients/survivors
“A lot of us could not prevent the cancer or take early care of it simply because we could not read our body’s own message. We did not decode the messages, the body is a living being that is telling you “help me!” but you are (refractante) and don’t listen...”	Patients/survivors
Theme 2: Cancer Prevention Education Should Start Early	
“In school, they shouldn’t only teach general subjects, we should teach children and adolescents to take care of their body. They have to teach the youth and the children how to prevent, how to eat right, how to focus on themselves and maintain themselves healthy. Right now, people do not focus on keeping healthy, they only focus on developing for the future to sustain you economically and it’s not like that. We have to teach our youth to prevent, to have health, which is what is most important.”	Patients/survivors
“There isn’t any direct information for young people, so that since young they can start preventing, the younger you are, you don’t give it importance.”	Family/caregivers
“One of the things we should teach the youth since they are young is to listen to their body. Your body is constantly giving messages, constantly. That your head hurts, that your stomach hurts, that this and that sort of stuff appeared, a blemish.”	Patients/survivors
Theme 3: Provide Appropriate Educational Information	
“There is a lot of incidence, in young adults as in adults, but there are so many diseases that lead to that condition, for example there is that among ladies that is the Papilloma. There are one hundred Papillomas, and of those one hundred, ten are transmitted by sexual relations. There is a lot of misinformation in the media to indicate to which type of population the prevention has to be done.”	Family/caregivers
“We have to eliminate the fear, because a lot of times one is scared of facing difficult situations because we all think: “I am going to suffer, I am going to feel pain, I am going to die”, you see, that is what occurs when you have bad information.”	Family/caregivers
“I think there is misinformation. My opinion is that people should be spoken in terms of (how they speak in) the street, how it would be said. Not in medical terms, because there are a lot of people that come up and say “we have to do you a PET scan”. And if I have not studied that and don’t know what a PET scan is, well I don’t think I am going to understand.”	Patients/survivors
Theme 4: Disseminate Information About Relevance of Acquired Healthy Behaviors	
“I think that nutrition, the information regarding the meals and chemicals, well we have to educate more so than us or the next generation...”	Family/caregivers
“Exercise is something that liberates toxins, and when you liberate toxins, well you have less chances of becoming sick. It is important to educate the people. It’s doing it for health, not for you to lose weight, not so that you can look better, which is true, right, but rather a matter of prevention, which is important, it makes the difference.”	Family/caregivers

Table 3

Participant Statements Regarding Strategies for Cancer Prevention Education

Statements	Discussion Group
Theme 1: Schools as Forum for Educating and Disseminating Information About Cancer Prevention	
"We have to go into public schools to do this effort"	Family/caregivers
"We have to give guidance, talks about cancer prevention in school, start early."	Patients/survivors
"You know, maybe information can be offered in high school regarding the mammogram, the PCA test which is a blood test to detect changes in the prostate, and maybe those same adolescents can be the influence for their parents."	Healthcare providers
Theme 2: Create Partnerships with Private and Government Agencies	
"To speak of cancer prevention, you have to do it through the Department of Family, Department of Health and the Department of Education."	All
"I think of taking the resources, maybe to the Department of Education and in public and private schools of the country, where there is not only a direct communication with the students, but also with the parents, and focus all that information that is recollected about what is prevention and cancer education, more so, bring (health fair) clinic."	Family/caregivers
"There are a lot of boats rowing at different places and we are going to get to the same place and we are going to get to the point, but I understand that the orientation about cancer prevention is very disseminated among the agencies and that they are not looking to reach a point in which they can all take part and can all benefit."	Healthcare providers
Theme 3: Consider Specific Cultural Factors When Preparing and Sharing Cancer Education Information	
"Try to orientate and educate, eliminating the taboo there is about cancer, because a lot of times there is ignorance and that same taboo makes people not educate themselves (and), not visit the doctors."	Patients/survivors
"The Puerto Rican idiosyncrasy has to be taken into consideration. A lot of times, if we are speaking of colorectal cancer, a man will not go get his digital rectal test because "that is not manly" nor screen the reproductive area because of machismo and I don't know what other things, represent a limitation for the masculine sex. That is, that in that sense we would also have to explore how we can surpass that type of fear, shame, whatever it is."	Healthcare providers
Theme 4: Outreach to Communities with Limited Resources	
"(Health fair) Clinics shall be taken to the communities, because there are a lot of people of limited economical resources and that live far, and the message has to be taken to them of what is cancer prevention and guide them."	Family/caregivers
"It is important not to focus only in the Metro area, but also focus in the smaller cities. My city, how you would say, nobody sees it, take the information there to the people of those small cities, in the center of the island..."	Family/caregivers
"It is very important to know what are the necessities of the community that we are interested in studying, because no matter how many help clinics we try to create, of awareness, of prevention, if those patients and those people do not have a way to get there, if they don't have transportation, they can't go because they have their children in schools or they arrived and cannot go past the afternoon. Find out why they can't get the help we are trying to provide and let that lead our efforts and decide how we can help them."	Healthcare providers
Theme 5: Include Testimony of Cancer Survivors	
"The testimonies are very shocking. When another person has passed through a situation and shares it, you then understand that this is real, that it's happening, because when you share things with another human being like you, that is going through the same thing, the message, the message is taken (understood) better."	Family/caregivers
"The survivor is very important it is the key to any type of prevention event that we want to take to the community."	Healthcare providers
Theme 6: Utilize Online Social Networks and Media to Disseminate Cancer Prevention Information	
"We have to utilize the media and the online social networks to share the subject of cancer prevention."	Family/caregivers

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Statements	<i>"We also have to put advertisements on the television, for children, for doctors also, that the same doctor gives the information to the patient."</i>
Discussion Group	Family/caregivers