Introduction

The purpose of this project is to create a scientific advocacy group that will be trained in cancer research, health policy, and patient recruitment for clinical studies and science dissemination. This project addresses the lack of participation of minority scientific advocates in cancer research, a significant issue that needs to be resolved.

Methods

RECRUITMENT

Inclusion criteria

- Age 18-65
- Diagnosed with breast cancer for at least two years
- Be bilingual (written and spoken, English and Spanish)

Exclusion criteria

- Intoxicated in the science of cancer and peer review research process

Study administration

- Flyers
- Social media
- Facebook

Application process

- Participants had to complete an application and state availability for the dates of the training.
- Each participant was interviewed by one of the principal investigators to assess interests and availability to complete the project

FIRST EDUCATIONAL TRAINING

- Twenty contact hours
- Forty percent face-to-face contact
- Program topics
  - Introduction to science of cancer
  - Breast cancer overview
  - Introduction to genetics and immunology
  - Research and study design
  - Evidence Based Medicine
  - Ethics in Research
  - Good Clinical Practices
  - Clinical Trials in Puerto Rico
  - Patient’s testimony as a clinical research participant
  - Living with Pubic - Hispanic’s discovery

Mindfulness sessions

FOLLOW-UP EDUCATIONAL SESSIONS

- August: three-hour face-to-face session
  - Oncotype DX test
  - Cancer care and treatments working together
- September: Scientific Poster
  - Distribution of a scientific poster via email scientific poster materials regarding the purpose of representing a scientific poster, sections that should be included, how to evalue one, examples, and guide questions.
- January: Scientific Poster follow up
  - Three-hour session to discuss the scientific posters materials for the participants to present the possible scientific poster they will develop

STATISTICS

- Data were entered to SPSS statistics version 19 for analysis. Data including age, race, and education were strata by type of cancer, sex, social analysis (frequencies, means and standard deviations) and non-parametric analysis were run and interpreted.

Preliminary Results

Fig. 1. Recruited participant profile. A total of fifteen women ages 40-64 (38.5%) 32.3±12.2) were successfully recruited. A. Years since diagnosis shows that the majority are within 2-5 years of being diagnosed. B. The academic level is equally distributed across the cohort.

Fig. 2. First Educational Training Participants. Participants were required to participate in a 3-day intensive training session. The majority of women expressed increased knowledge gain in genetics and its role in cancer treatment, illustrate the trend, impact of advocacy in science and biosciences in research.

Fig. 3. The initial workshop significantly increased their overall knowledge. A. Hypothesis testing pre/post knowledge. B. Overall post knowledge significantly increased by 1.3 fold. C. 100% of women said their knowledge increased. D. 100% of the women would recommend the HIDEAS training program to other survivors.

Conclusions

1. The recruitment process was successful by enrolling fifteen female breast cancer survivors.
2. Evaluations demonstrate the participants’ satisfaction with the trainings offered and an increase in knowledge. A Wilcoxon Test indicate a significant increase in knowledge from the pre test to the post test (p<0.004).
3. This pilot training project can be a model for other groups to address the lack of Hispanic research advocates.
4. The process has been delivered approximately four months due to the hit of Hurricane Maria which affected all the island.

Future Directions

The first part of the project has been focused in the development of knowledge and skills needed to participate in research activations. The next training will include hands on experience such as poster development and evaluation, research proposal evaluations, and patient engagement with researchers.

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A Bigger Voice: Hispanics Increasing Diversity to Enhance Advocacy in Science (H-IDEAS)

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Abstract

Breast cancer is the most common cancer type and the number one cause of cancer death among women in Puerto Rico. Breast cancer survivors have played an important role in advocating for advancing science. However, there is a lack of representation of Hispanics in scientific review panels, and clinical studies lacking the number of representation in important forums to advocate for studies in Hispanics with breast cancer. The specific aim for the project is to create a scientific advocate group of trained Hispanic cancer survivors that will participate in research proposals, 2% of the key personnel within research studies, 5% in patient recruitment from clinical studies, and 4% in cancer research information dissemination in Puerto Rico and abroad. By recruiting minority populations trained, this project ensures that everyone, including Hispanics, will have an equal opportunity to live, learn, healthy and productive lives. Methods: This educational project will be conducted in a one-year period. A group of fifteen breast cancer survivors were recruited. The inclusion criteria included being a woman between the ages of 18-65, resident of Puerto Rico for at least 10 years, being diagnosed with breast cancer: be bilingual (written and spoken, English and Spanish) and have an interest in the science of cancer and peer research review. The project initially included being a woman between the ages of 18-65, resident of Puerto Rico for at least 10 years, being diagnosed with breast cancer: be bilingual (written and spoken, English and Spanish) and have an interest in the science of cancer and peer research review. Data were entered to SPSS statistics version 19 for analysis. Data and project outcomes were compared using Wilcoxon test, a non-parametric test for independent groups. Results: Preliminary data suggests that participants attend and gain knowledge in scientific advocacy which allows them to be proactive in their role as advocates. Also, they have demonstrated to be highly engaged and motivated to continue their journey as scientific advocates. In data progress: This innovative project in unique in addressing the needs of bigger voice of Hispanic scientific advocates. To our knowledge this is the first advocacy training to Hispanics