



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 as advocates in advancing science. However, there is a lack of representation of Hispanics in scientific review panels, and clinical studies increasing the need 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** 1) in research proposal reviews, 2) as part of key personnel within research studies, 3) in patient recruitment from clinical studies, and 4) in cancer research information dissemination in Puerto Rico and abroad. By increasing minority populations trained, this project ensures that everyone, including Hispanics, will have an equal opportunity to live long, 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 review research process. The participants were recruited through word of mouth, email, social media, and flyers. After the initial contact, the potential candidate had to complete an application, and a telephone interview was conducted. Once the participant was chosen, a written agreement was signed by each of them. The training began with an intensive three-day curriculum. Follow up sessions are conducted every other month to increase and reinforce scientific advocacy knowledge as well as hand on activities **Results:** Preliminary evaluation suggests that participants acknowledge the need of this project, and demonstrate significant increase in knowledge in 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. Data in progress. **Conclusion:** This innovative project is unique in addressing the needs for bigger voice of Hispanics as scientific advocates. To our knowledge this is the first advocacy training to Hispanics.



Introduction

The **purpose** of this project is to create a scientific advocacy group that will be trained in **cancer research, health policy, experimental design, 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

- Women
- Age 18-65
- Diagnosed with breast cancer for at least two years
- Be bilingual (written and spoken, English and Spanish)
- Have an interest in the science of cancer and peer review research process

Study advertisement

- Flyers
- Email blasts
- Facebook
- Word of mouth

Application process

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

FIRST EDUCATIONAL TRAINING

- Three day weekend training
- Twenty contact hours
- Lodge, meals, and materials included
- Program topics:

- The 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 Proof Film – Herceptin's discovery
- Mindfulness sessions



FOLLOW-UP EDUCATIONAL SESSIONS

- **August-** three hour face-to-face session
 - Revisiting H-IDEAS agenda
 - Oncotype Dx test
 - Advocates and scientists working together
- **September** – Scientific Posters
 - Each participant received via email scientific poster materials regarding: the purpose of presenting a scientific poster, sections that should be included, how to evaluate one, examples, and guide questions.
- **January** – Scientific Posters follow up
 - Three hour session to discuss the scientific poster materials and for the participants to present the possible poster they will develop.



STATISTICS

- Data were entered to SPSS statistics version 19 for analysis. Data rechecking accuracy was performed on the database. Descriptive analyses (frequencies, means and standard deviations) and non-parametric analyses were run and interpreted.



Preliminary Results

Fig 1. Recruited participant profile. A total of fifteen women ages 40-64 ($M=52$, $SD = 11.2$) were successfully recruited. **A.** Years since first diagnosis shows that the majority are within 2-5 years of being diagnosed. **B.** The academic degree level is equally distributed across the cohort.

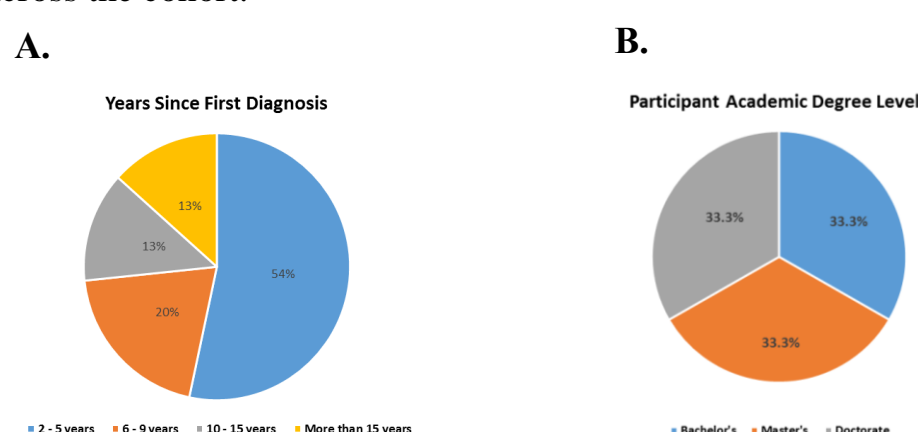


Fig 2. First Educational Training Results. Participants were required to participate in a 3-day intensive training session. The majority of women expressed increased knowledge gain in genetics and its role in breast cancer, phases of clinical trials, impact of advocacy in science and bioethics in research.

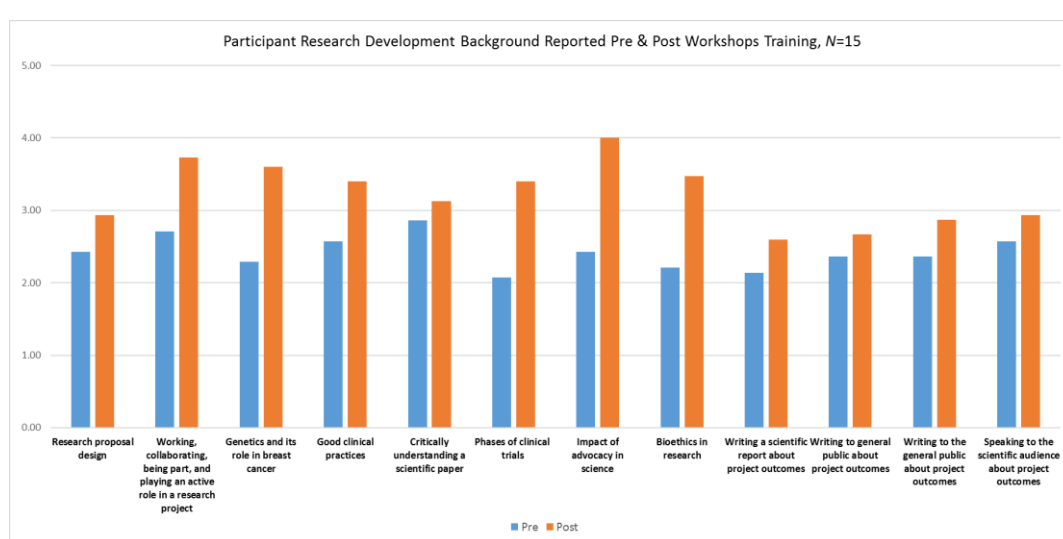
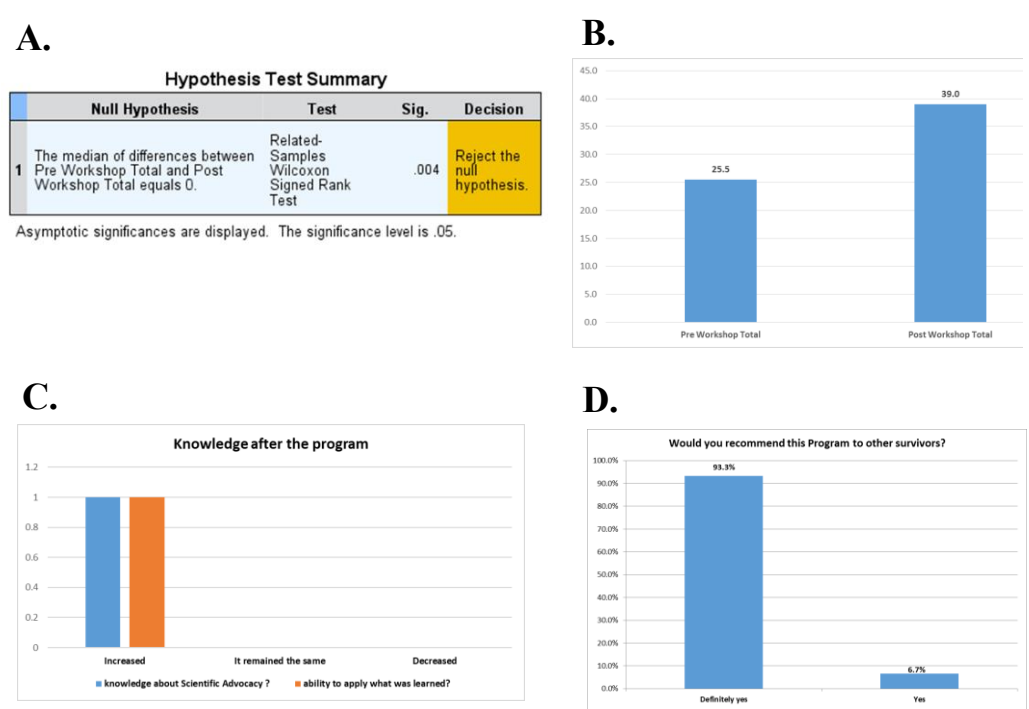
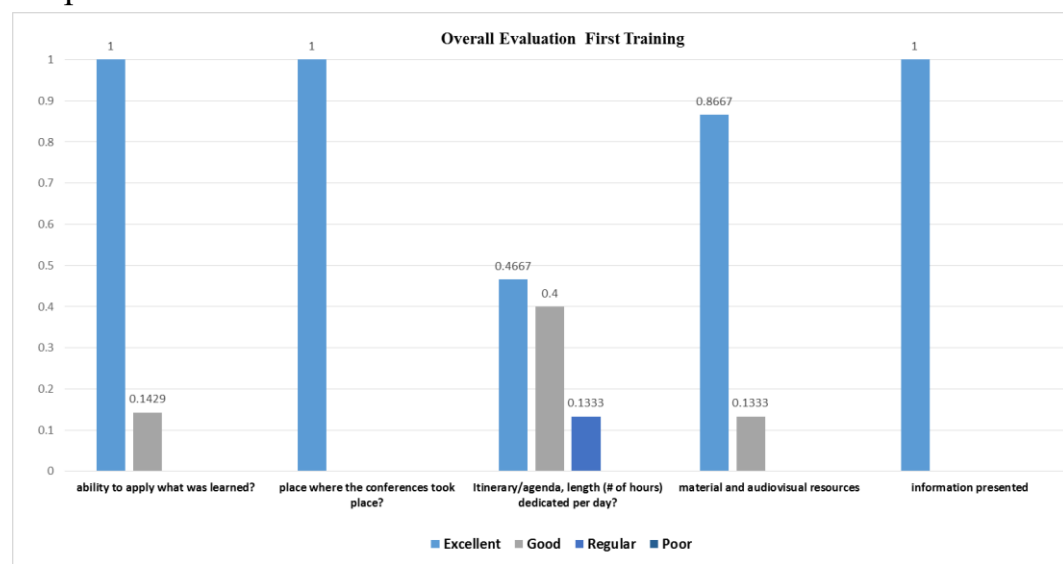


Fig 3. The initial workshop significantly increased their overall knowledge. **A.** Hypothesis testing on pre/post knowledge. **B.** Overall post knowledge significantly increased by 1.3 fold. **C.** 100% of women said their knowledge increased. **D.** 100% of the women would recommend the HIDEAS training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



- A Wilcoxon Test indicate that the post-test was statistically significantly higher than pre-test, $p < .004$

Fig 4. Overall initial training program evaluation. The majority of the participants reported excellent overall experience. The only criteria that they expressed concern is in the agenda and time available to complete the material.



"I really loved this experience and the passion of the PIs that had a dream to develop this group of survivors and injected in us the spirit to be part of this dream" quote by one of the participants.

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 ($p < .004$).
3. This bilingual project can be a model for other groups to address the lack of Hispanic research advocates.
4. The progress has been delayed 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 activities. The next trainings will include hands on experience such as: poster development and evaluation, research proposal evaluations, and patient engagement with researchers.

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