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The Faces on Our Educational Materials: Real Stories behind the Messages

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As university-based faculty members, our daily routine usually involves some mix of teaching, research, and service. While we are busy with activities such as correcting a student's rough draft, responding to critiques from a manuscript that needs to be revised, peer reviewing a manuscript, or preparing a grant proposal, we seldom stop to think about the lives we have affected or been part of because of our chosen specialty in cancer education research. Faculty have different motivations for becoming involved in cancer education – both personal and professional, and many may have even been personally affected by cancer. As a researcher who primarily works in cancer prevention and screening with healthy individuals, I usually do not encounter research participants who actually have cancer. It is a worthwhile self-reflection exercise to consider how our research programs have affected the lives of our research participants, so in this vein, and in the spirit of the *Reflections* column, I offer the following vignettes from cancer education research projects we conducted in rural Georgia, USA and the Peruvian Andes.

Rosa's Story

In our 2011 promotora (lay health advisor) training program for cervical cancer education, *Salud es Vida* ("Health is Life"), Rosa Mendoza (pseudonym) was one of the seven promotoras in our region [4]. In her exit interview following the training, she was very knowledgeable about the Pap test, the HPV vaccine, and the importance of early detection. In terms of receiving cervical cancer screening, she believed the largest barrier for her to seek routine health care was transportation. During the time of the study, police were implementing roadblocks to intercept undocumented immigrants who were driving without licenses as a result of Georgia immigration enforcement legislation that was passed in the state legislature [3]. She also said what would help her the most to receive a routine Pap test was to have a friend or family member who knew about the importance of the test and to encourage her to get screened. She said it was important to have peer support, such as could be provided by a promotora, because many women were afraid to be screened and needed

some encouragement. Two years after the promotora training project grant, Rosa died of cancer. My project coordinator, Claudia Reyes-Garcia, and I attended Rosa's funeral in October, 2013 at the Catholic Church in Statesboro. We found out that she was treated and cleared for cervical cancer in 2009, but later developed breast cancer and died at the age of 51.

Rosa was born in 1962 in Michoacan, Mexico. She first came to the U.S. in 1989 from Mexico City to work in the agricultural fields in Bulloch County, Georgia. She then worked in a chicken factory for several years until she developed some health issues. She then switched jobs and worked as a seamstress in a textile factory to earn a living until she was diagnosed with cancer. She was a single mother, and left behind three children - an older daughter, and two teenagers, a son and a daughter. We interviewed her oldest daughter following Rosa's death to find out more information about her life.

In 2009, Rosa was diagnosed with early stage cervical cancer and received a hysterectomy in 2009. Despite being undocumented and uninsured, she was able to qualify for a special program to assist with the medical costs at one of the major hospitals in Savannah. Her workplace provided her with some unemployment assistance. She returned to work, but then she was diagnosed with breast cancer in October, 2012. She sought treatment at the other major hospital in Savannah and was receiving chemotherapy. Unfortunately, the cancer spread to her lymph nodes and then to her kidneys. Rosa's daughter said that at first, she tried to hide the cancer from the family, but later explained her diagnosis to the family. Despite her illness, she continued to help her family and tried to keep working, but in the end the chemotherapy took its toll and she was too weak to leave home. Rosa's daughter reflected that her mother loved being a promotora. After being trained as a promotora in the *Salud es Vida* program, she started providing healthier fresh foods for her family and less canned goods. She also emphasized drinking a lot of water. Rosa's cancer experience had a profound experience on her daughter, and she expressed to us that she thought she would also like to work as a promotora to educate others about cancer prevention.

Photo Story Meets Reality in Peru

In a different research project from 2013 to 2015, I led a team to conduct an evaluation of cervical cancer outreach campaigns and develop patient education materials (*fotonovela* - pamphlet with pictures telling a story - and radio ads) to be disseminated through social networks in the Cusco region of the Peruvian Andes [5]. This research was completed in partnership with CerviCusco, a Peruvian registered nongovernmental organization located in Cusco, which improves the health and quality of life of Peruvian women through the primary and secondary prevention of cervical cancer using both a stationary clinic and outreach campaigns [2]. The first step in creating educational materials for the screening campaigns was to recruit and conduct a focus group of seven Quechua women (30-49 years old) in the small community of Quiquijana 90-minutes drive south of Cusco to provide ideas for the *fotonovela*. Participants discussed how the Pap test was an exam that was necessary to receive every year and how the doctors came from CerviCusco to conduct the campaigns. One woman explained that a neighbor had contracted cervical cancer and went to Cusco for treatment, but unfortunately, the cancer had already progressed and she died. After

transcribing the focus group discussion from Quechua to Spanish, a storyline was scripted of two women attending one of the campaigns to receive a Pap test. I took pictures at one of the campaigns in a small community and asked two women in line to volunteer to be featured in the *fotonovela*. Community participants and health workers at two campaigns in other small rural communities reviewed drafts of the *fotonovela* to ensure comprehensibility, likability, and reading level.

We titled the *fotonovela*, “*Salvando Vidas*” (Saving Lives). The *fotonovela* begins with two women meeting in a pharmacy and discussing that there is a screening campaign in town. They engage with a pharmacist who explains about what cervical cancer is and how the Pap test can prevent cervical cancer (see Figure 1). One woman talks about remembering one of her friends who contracted cervical cancer and died because it was discovered too late, even though she went to the city for treatment. Next, the scene switches to the clinic where a number of women are waiting to be screened. The nurse explains that the Pap test will not cause pain and illustrations in the *fotonovela* describe the procedure. The nurse explains that the women can return in two weeks to receive the results of their Pap test. The final page of the *fotonovela* lists important facts and has contact information for CerviCusco. On the back of the *fotonovela* is a copy of the campaign poster so it could be used for advertising the date, time and place of the campaign. Each of two women in the story is at a different stage of change regarding the screening. In terms of stages of change theory, one woman is at the “contemplation stage” (considering the possibility of attending the campaign) and the other woman is at the “action stage” (engaged to go and receive her Pap test) [6]. After completing the health promotion project to distribute the *fotonovelas* in two communities prior to scheduled outreach campaigns, our project coordinator, Wendy Guevara, communicated to me that one of the women featured in the *fotonovela* had received an abnormal Pap test result. She was able to travel to the CerviCusco clinic in Cusco and was successfully treated for a precancerous lesion.

Conclusion

In summary, as cancer education researchers we should be willing to share these stories with our colleagues and funders that the real impact of our work cannot always be captured in our standard final reports and research publications. The qualitative value that our work contributes to the lives of our community participants in research and practice provides us with a wealth of stories to tell and creates meaning in people’s lived experiences. In particular, in Rosa’s example, it is evident that her experience of learning about cervical cancer and volunteering as a promotora was an empowering experience [1]. These two vignettes provided here are but a snapshot of a larger narrative that needs to be shared about the impact that cancer education can have on empowering women and saving lives.

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Condorhuaman (study coordinator for CerviCusco), and Dr. Daron Ferris, M.D. (President and Founder of CerviCusco and Professor at Augusta University).

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English Translation

Later in the Health Department, Isabel and Rosalia wait to receive their Pap test.

Isabel: You know my friend Juana, right?

Rosalía: Yes!

Isabel: I ran into her the other day and she told me she had cervical cancer.

Isabel: She said that she went to the clinic to get her Pap test and the result came back as positive.

Rosalía: And what did she have to do?

Isabel: She returned to the clinic and they told her she needed to get a colposcopy, which is a specialized exam.

Isabel: And then they did the treatment and she is better!

Rosalía: How great!

Nurse: Mrs. Rosalia!

Rosalía: I am afraid of the exam. Will it hurt?

Figure 1.

Page 4 (of 8) of the Fotonovela “*Salvando Vidas*” or Saving Lives