Formative Research to Inform the Development of Innovative Communications to Improve Health Literacy among Hispanic Migrant Farmworkers with an Abnormal Pap Test Result

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October 24, 2014

“I, or an immediate family member, including spouse or partner, have NO financial relationship(s) relevant to the content of this educational activity.”
Research Team

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Outline

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• Purpose
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Background

Cervical Cancer Disparities Persist

- Hispanic women have the highest **incidence** (11.8 per 100,000) of cervical cancer when compared to all other racial/ethnic groups (National Cancer Institute, 2013)

- Hispanic women have the third highest cervical cancer **mortality rate** (3.0 per 100,000) (National Cancer Institute, 2013)

- Within the Hispanic population, **farmworkers are at increased risk** for cervical cancer, and have elevated rates of cervical cancer mortality (Mills, Beaumont, Nasseri, 2006).
Background (cont’d)

Barriers to Cervical Cancer Screening and Follow-up Care Exist among Hispanic Women

– Above barriers are exacerbated among those predominantly low-income, employed in the agricultural sector, and who are migratory (Hispanic migrant farmworkers)

Background (cont’d)

Building on Previous Work

• Cervical Cancer Patient Navigation Program – access and logistical barriers

• Low literacy cervical cancer educational intervention delivered by a patient navigator (PN) – cervical cancer screening and HPV

• Technology intervention (avatar - Spanish) to deliver cervical cancer screening and HPV education to augment PN activities

• Gap: No systematic and formalized method of providing education to women who have experienced a cervical abnormality detected by a Pap test – health literacy gaps unknown
Purpose

• Identify leverage points that can improve health literacy skills and increase the capacity of women to engage in follow-up care following an abnormal Pap test result

Specific Aims:
- Determine the level of understanding and the psychosocial impacts among women who have received abnormal Pap test
- Identify assets and barriers that facilitate and/or hinder the necessary follow-up care
- Elicit women’s educational needs and communication preferences, including channels and methods for receiving information
Methods

• Guided by **community-based participatory research methods**

• **Recruitment site:** Faith-based community clinic who provides healthcare to this population

• **Sampling:** Non-probability, convenience, purposive sampling
  – Stratify by length of time since receiving test result

• **Inclusion criteria:** (1) female; (2) 21-70 years; (3) Hispanic; (4) history of receiving an abnormal Pap test result; (5) able to speak Spanish or English; (6) able to provide Informed Consent; (7) seek services in rural Hillsborough County
Methods (cont’d)

**Instrument:**
1) Semi-structured in-depth interviews guide
   a) Study Aims; b) Social Cognitive Theory (SCT); and c) Health Literacy (HL) domains
      – SCT: Outcome expectation; Outcome expectancies; Behavioral capability; Facilitation and incentives
      – HL: Access; Understand; Evaluate; Communicate
2) Participant profile sheet

- Translation, back-translation of instruments
- Pilot-testing and role-playing

Methods (cont’d)

- **Procedure**
  - Informed Consent; Incentive
  - Quite location of convenience to participant
  - Trained research assistant fluent in Spanish/English
  - Interview guide; Participant profile sheet
  - Detailed interviewer notes; Audio-recorded discussion
  - Transcription & translation of data

- **Analysis:**
  - Systematic coding (open, axial and selective)
  - A priori and emerging themes
  - Inter-coder reliability established
Findings

Participants (n=18)

• All participants were originally from Mexico

• Mean age = 39.6 years (range 22-50 years)

• Marital status: 50% married; 39% single/never married; 11% divorced

• Years in the U.S.: 33% 5-10 years; 39% 10-20 years; 28% > 20 years

• Current employment: 44% employed full-time; 11% employed part-time; 44% unemployed
Understanding

• Feelings of confusion
  – Thinking it’s cancer at initial diagnosis
  – Due to the unknown
  – Death sentence

“At first I was scared, I thought maybe... that it could be the beginning of cancer and that I had to do what I could to cure myself or I could die. So I got scared because I thought I don’t have the money, what am I going to do? what if I die, I could die because the nurse said that there is a risk that I might die.” – Participant 12
Psychosocial Impacts (Initial)

• Feelings of fear, shock, depression, upset, worry
  – Due to the unknown, thinking it’s cancer at initial diagnosis

• Social support from family and friends (specifically females), partners and providers
  – Informational
  – Emotional
  – Appraisal
  – Instrumental

“I was worried that if I had an advanced cancer, my family is in Mexico and I'm here alone. My worry, I told the doctor, “I don’t have resources for a surgery; I know that treatments are expensive, I don’t have resources and maybe you put me in the surgery room and I can die in the there. Who will send me to my country? How will that be done?” All those were my worries when I talked to the doctors. I worried a lot and I thought “when they give me another result I'll leave”, I'll leave but I said “the solution isn't to leave because if I'm in a country of advanced science and I'm going to go to a country where they're going to tell me to just wait there” But I was very scared that I had an advanced cancer and that I would stay here forever. That was my fear.” – Participant 15
Psychosocial Impacts (Now)

- After being diagnosed, some still worry about their next results, but most women report being *fine, calmer, and happy*
- Many attribute not having worries because they know they can get the healthcare they will need
- Getting inspiration from children, God

“Well, now like I said I don’t really worry because first, I know there are doctors, and second I trust in God that everything will be fine. Yes, like I said the first time it really hit me but not anymore” – Participant 10
Barriers

- Cost (of appointments, medications, no insurance)
- Transportation
- Embarrassed to get seen by male practitioners (stops them from getting Pap to begin with)
- Not knowing the severity of an abnormal Pap, having other health issues to worry about
- Information regarding what they need to do, where to go

“The money was what concerned me because I don’t have the resources; I thought ‘Where am I going to get the money to pay the doctors?’ I don’t have money, what helps me to survive here in the US is our weekly paycheck (my husband’s and mine), that we earn with my partner, that was my main concern because I didn’t have the money”

– Participant 5
Assets

• Living in a country that they can get care

• Low cost at the clinic

• Knowing someone else (girlfriends) who has gone through something similar

• Taking care of themselves and their families, especially children as a motivator
  – In order to be able to do the things they want to do or be with (either in the U.S. or in Mexico)

P - “Having found this clinic... God bless them as I have told Sister Sara and my friend who... how do you say? Who...

I- Facilitated the...?

P- Yes, who helped me finding them here, and God Bless you and I hope she provides much knowledge to people from USF because all that facilitated it for me; it was like a new hope when they said ‘everything is fine’ and the checkups were no longer needed, and also as I said its very easy because its not too far away and they treat us very well”

– Participant 2
“I- And what motivates you to stay healthy? P- My children’s wellbeing. My family is the reason I have to keep going because if it wasn’t for them you will just give up but thinking that you have a family and have to keep going” – Participant 7

Educational Needs

• Need information on:
  – Actually needing a Pap, what it’s testing, specifics regarding the Pap, how long it will take to get ‘cured’, what their result means now and in the future, how often they should get a Pap

• Want initial information on what their diagnosis means immediately, but also want more detailed information following the initial diagnosis

• Want to know long term effects, if it can come back, what it means for their sexual lives, what it means if they want to get pregnant
“Firstly to know that we need to have a Pap regularly because you can’t just get it and say that it’s fine, then not go for 3 - 4 years without doing it again, so you have to know that you have to do it every time the doctor tells us we need it because I used to do it not very often but every 2 - 3 years, and it was never abnormal, so just because it didn’t come up before doesn’t mean it won’t later...” – Participant 7

“**It’s important to give them the information** when something is abnormal, **telling them what it means**, for example when they tell you that there is something abnormal the doctor **explain** to you what they found and what is means, like ‘Look, we found this in your pap, you have this, it mean that you have cells, I don’t know, maybe cancerous cells or we **saw some bad cells** that we need to study so we need to repeat the exam because it could be something bad or it means this, or could be that so we need to do it to rule out that is something bad’, but not just say ‘we found something bad’ and not explain to you what is it.” – Participant 3
Participants wanted information from different sources:
- From media (pamphlets, internet, radio, etc) for general information
- From face-to-face interactions (doctors, nurses) for follow-up on any questions

For face-to-face interactions: want info to come from other women providers and other women who have lived through the same diagnosis (testimonials) and in a group setting (group education talk)

“...I mean like the pamphlets you are saying, the internet I also think helps a lot but many people don’t know how to use it; on TV is also good because when they show something about cancer or results like that, well the first thing you do is turn on the TV when you hear that they are going to talk about it or at least that’s what I do now when I know they are saying something about cancer or anything like that...then you already have it in your head when you go see your doctors and you tell them about it ‘doctor I heard this and that’, that’s when you ask them and the pamphlets you said also; it would be good that when you come to your appointment they can put them up and you grab one out of curiosity, and take them home to read them or even to take them home ...

...Yes that’s [nurse/another person] good but sometimes there are questions that you don’t exactly want to ask just anyone like the nurse because you are embarrassed and think ‘I am not asking because its embarrassing or you don’t want to talk to them about that’ but when you read it by yourself or when you talk to the doctor, even if you’re embarrassed you feel like you have to talk with him about it” – Participant 7
Limitations

Findings not generalizable, but can be illustrative

• From one healthcare organization

• All women interviewed were originally from Mexico

• Only a few women that had been recently diagnosed with an abnormal Pap – most participants had received their diagnosis prior to one year to the interview

• Reached data redundancy with sample size (n=18), but might not have reached saturation

Discussion

• Psychosocial impacts and facilitating and hindering factors influencing follow-up to an abnormal Pap test result were identified

• Detailed description of issues related to health literacy needs and assets
  – Specific information and recommendations (e.g., no waiting periods)
  – Social support – providers and family
  – Multiple communication channels

• Need to understand unique demographic, social, economic, cultural and political experiences that influence health literacy and subsequent illness behaviors
  – Lived experiences critical

• Findings essential to guide the development of culturally and linguistically-relevant intervention that empower rural, low-income Hispanic migrant farmworker women to maintain/regain health and well-being
Acknowledgements

• Gloria Arroyo – Patient Navigator at San Jose Mission

• All the women who participated in the study

This project is supported in part by the Tampa Bay Community Cancer Network (TBCCN) training core, a National Cancer Institute’s Center to Reduce Cancer Health Disparities Community Network Program Center (5U54 CA153509)

Thank You!

Questions?