Spanish Language Personas Inform the Development of Healthcare Websites

Silvia Inéz Salazar, MPA, Health IT
Audience Research and Informatics Laboratory Manager
Analytics and Audience Research Branch

Jennifer Romano Bergstrom, Ph.D.
User Experience Research Leader
Fors Marsh Group

October 17, 2014
Cultural Values

• **Respeto (Respect):** Demonstrating respect towards authority figures.

• **Familismo (Family):** interdependent networks within and across immediate and extended family.

• **Confianza (Trust):** Creating a warm and friendly approach.

• **Personalismo (Personal Connections):** Building a personal connection and taking emphasis away from institutions.
Beliefs

• *Fatalismo* (Fatalism): All events are predetermined and therefore inevitable.

Impact

Cancer is a certain death sentence.

Why sign up for health insurance? Something will eventually kill me anyway?
Language Practices-Preferences

Monolinguals

More Spanish than English

Bilinguals

More English than Spanish

Monolinguals
Acculturation

Process in which members of one cultural group adopt the beliefs and behaviors of another group.
Data to Build Personas

- Quantitative & Qualitative
Data to Build Personas

- Quantitative & Qualitative Data to Build Personas

Data to Build Personas

- Quantitative & Qualitative Data to Build Personas
Data to Build Personas

- Quantitative & Qualitative Data to Build Personas
Data to Build Personas

• Quantitative & Qualitative

Florida Trend

Breast Cancer: A Cultural Divide
Outreach efforts aim to tackle taboos among some ethnic groups.

Art Levy | 10/1/2007

Jeanne P. Bertlik has spent much of her career touting the benefits of monthly breast self-exams, annual mammograms and early treatment. Some women, however, aren’t
Data to Build Personas

• Quantitative & Qualitative
  – Nielsen
  – Web analytics
  – Interviews with stakeholders and users
ANTONIO & CLAUDIA

Co-Browsers
Nosotros estamos averiguando lo que necesitamos saber.
(We are finding out what we need to know.)

Claudia has a family history of breast cancer—her grandmother and mother were diagnosed years ago, and her sister was diagnosed when she turned 30. They heard that there is a family connection, and Antonio and Claudia are worried.

Both of them speak and read English well. Claudia earned an associate’s degree and is the manager at a clothing store. Antonio completed a bachelor’s degree and works in accounting.

Antonio and Claudia access the Internet through a desktop computer at home. They are not very skilled, and they only use it together—one never goes on the Internet without the other. Claudia will often sit on Antonio’s lap while they look for cooking recipes. Because Claudia has more experience with the Internet than Antonio, she is usually the one who uses the mouse when they browse. Antonio usually points out items on the screen as they are browsing. When they are navigating a site, they discuss and then decide together where they will click before actually doing so. They have a shared account on Facebook—they “like” and share information, but usually just photos.

Like many women in their community, Claudia takes the lead in finding health information for her family. When she finds good medical information, she prints it. She sticks to a few sites that she likes and trusts, including some Spanish-language ones.
Confirmación datos
Checking Facts
Busco información breve.
(I'm looking for a few quick pieces of information.)

After Javier’s childhood friend died from cancer, he was inspired to become a health educator. Javier works part time at a restaurant as a server while he attends college part time, studying biology. His goal is to become a cancer health educator in the Latino community, His family is afraid of openly talking about cancer. Javier lives with two classmates in an apartment not very far from his parents, and he plays in a futbol pickup league. His parents are of Mexican ancestry and they only speak Spanish, but Javier is bilingual and is more proficient in English than Spanish. He often is the information-seeker for his family—his parents rely on him to help them find information on the Internet.

Javier has access to the Internet through his iPhone, and he uses it to check class schedules, email and text friends and family, and to access social media. On social media, he looks up exercise routines (on YouTube), “likes” health topics (on Facebook), such as exercise, and he communicates with family in México.

He doesn’t go out of his way to look up medical information because he relies on his schoolbooks. He uses the Internet to look up cancer-related information when something in the books is unclear or when something is particularly interesting. He uses Google, visits many sites, and does not stay on any of them too long. He has not had good experiences with Spanish versions of sites and thinks that they are often poorly written. So he prefers to use English websites and then toggle to the Spanish language translation of the site when needed. He gets annoyed when he can’t simply toggle from an English page to an equivalent page in Spanish. He does not expect the Spanish version of the page to be identical, but he does expect it to be very similar conceptually.
RENATA (13)

Servicio de Información sobre el Cáncer
(Cancer Information Service (CIS) Spanish Call Center)
Brindando apoyo y recursos
(I offer support and resources.)

As a representative of the NCI, Renata answers calls and emails from patients and family members who seek information about cancer in Spanish and/or English, depending on the family. Her goal is to understand and prioritize the needs of callers, find simple to understand cancer information, and sending them information. She keeps a list of frequently asked questions and answers at her desk. Using NCI’s English and Spanish sites, the CIS has a wide range of information across the cancer continuum.

Most inquiries from patients come via email. Family members (especially spouses and parents) and friends of patients often call the CIS Spanish Call Center to request information, such as how to obtain financial assistance. Renata has found that Spanish-speaking callers typically need more emotional support, while English-speaking callers are typically more cut-and-dry and procedural. Sometimes students and researchers contact the center for information too, seeking information about the psychosocial effects of cancer and emotional wellness.

About 50% of those requesting information would like it printed, but due to the high costs of printing, Renata first tries to provide online materials. She often recommends .gov resources in Spanish, and when Spanish versions are not available, she provides detailed explanations of materials. Addressing the needs of callers who do not have access to the Internet is also a priority.

Renata also monitors social media and responds to requests for information on Facebook. The requests are often in Spanish, and she spends a lot of time translating content that does not exist in Spanish.
Contact Information

Silvia Inéz Salazar, MPA, Health IT
National Cancer Institute
Office: (240) 276-6631
salazarsi@mail.nih.gov

Jennifer Romano Bergstrom, Ph.D.
Fors Marsh Group
Office: (571) 858-3795 Mobile: (202) 538-0728
jbergstrom@forsmarshgroup.com