

# Found in translation: women connecting with women living with HIV

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## Abstract

Female medical students were assigned to translate fact sheets posted in English on a Website as part of a summer research experience. The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. It reaches more than 1 million users with Spanish fact-sheets visited more than 300,000 times in 2018. Thirty fact-sheets were selected from 100. The process included: assignments to individual students, group discussions, peer review, multiple draft discussions by email, choosing final versions by consensus and final review by an expert (mentor). Group sessions served to clarify issues and definitions based on science and cultural norms. Choosing the best and most accurate words, translating new scientific terms, selecting the proper, non-discriminatory and inclusive terms were a priority. A duality of benefits encompassed the experience: translating and adapting to the Spanish language and culture providing needed resources to women living with HIV, and learning while becoming increasingly sensitive towards an illness and a community. The following descriptions summarized the overall experience: “eye opening”, “personal empowerment process”, “sense of responsibility”, “provided medical information”, “active learning process”, “becoming aware of women’s experiences”, “reality check”, “HIV is not an obstacle”. Immersing in the issues of women living with HIV by providing access to reliable materials on a diversity of topics to a larger Spanish-speaking audience raised personal awareness and increased female medical student’s commitment to learn and work with this specific population. Adapting the articles was an opportunity to empower women and contribute to the sense of community that The Well Project created.

## Introduction

- Women and girls represent more than half of all those living with HIV worldwide or approximately 18 million.
- HIV is the number one global killer among women of reproductive age (15-44 years).
- Adolescents(15-19 years) account for over 60% of new HIV infections.
- In Puerto Rico, 25% of those diagnosed with HIV are female.
- While a treatable disease, an HIV diagnosis could mean a life-threatening challenge for women.
- Women are more vulnerable for HIV acquisition and progression of disease due to:
  - structural and societal barriers,
  - inequalities in accessing healthcare and health information,
  - gender-based violence and trauma,
  - isolation, stigma and discrimination, and
  - lack of female-controlled prevention methods.
- These factors also hinder achieving Autonomy and Empowerment.
- The Internet presents a powerful way to reach women and girls wherever they are.
- Translating and adapting educational materials provided by *The Well Project* into updated, culturally conscious articles improves women's health literacy, facilitates advocacy for women living with HIV, and builds a supportive community.

## Specific Aims

- Medical students are exposed to HIV infection at different times during their years of education. Social determinants, virology, immunology and pharmacology are covered during the first 2 years. Clinical aspects are covered during clinical rotations. Summer research is a good opportunity for first year medical students to be exposed to clinical and behavior research and cover more in depth the issues of the epidemic and how diverse populations are affected.
- The goals of this summer exposure to HIV in women were:
  - To translate from English to Spanish diverse educational materials available on a website with experience and commitment towers ending the epidemic and empowering women (outcome)
  - To make available the translated materials to women whose primary language is Spanish by posting them on the Well Project website (outcome)
  - To raise awareness among the medical students about the issues of women living with HIV in the world (process and outcome)
  - To accelerate and strengthen the learning process about HIV and the issues that were being translated (process)
- Students participated in clinic activities that included caring for pregnant and non-pregnant women living with HIV (CEMI). One question was whether the students would learn from the issues of HIV by having to search by themselves and discuss the best ways to translate and how the messages would be received.

## Methods

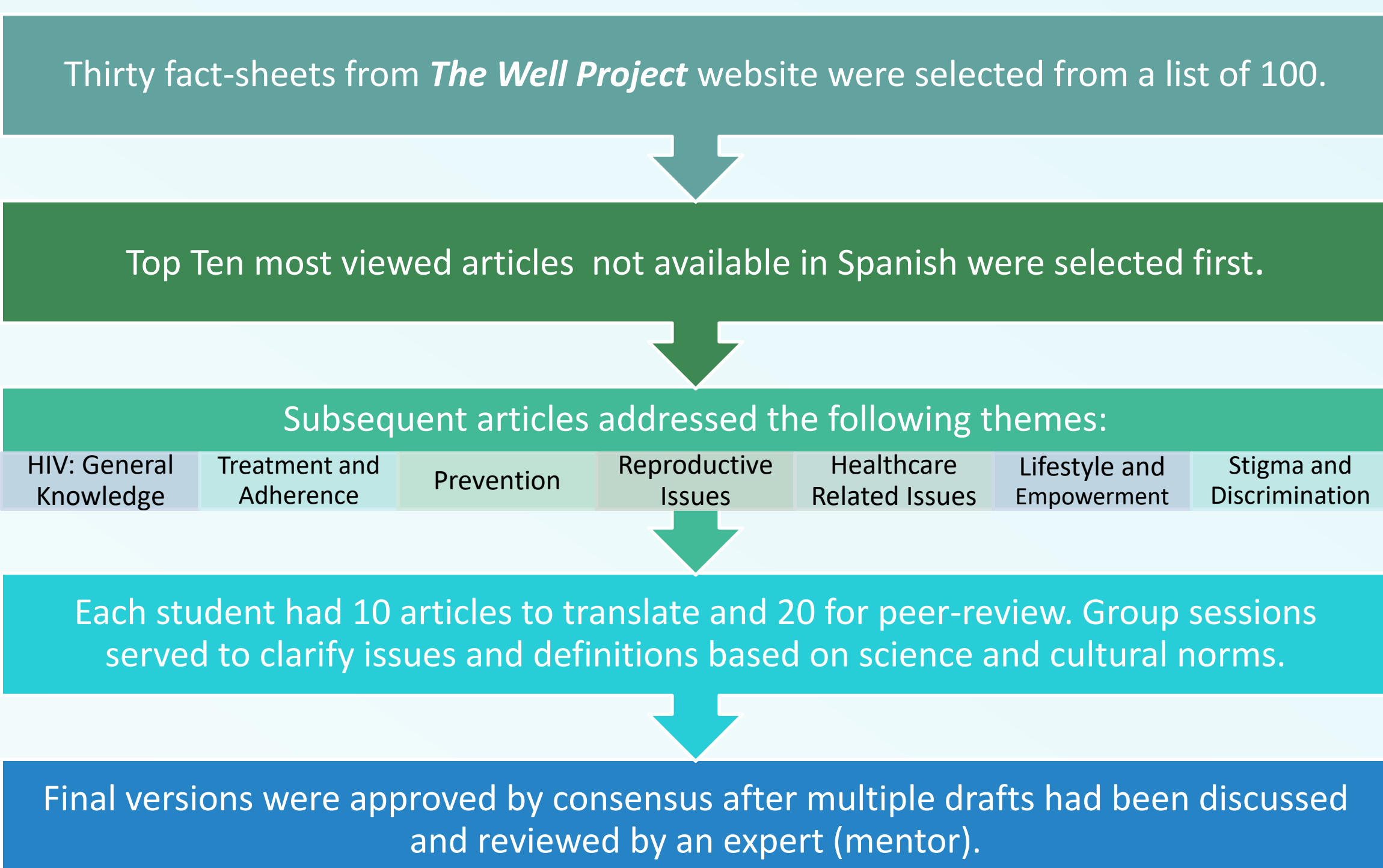


Figure 1: The process of selection, translation, adaptation and revisión of the articles.

- Among the issues confronted were:
- How to best choose words that could be used in all Latin America?
  - How to translate new scientific terms?
  - How to select the proper, non-discriminatory and inclusive terms to refer to women living with HIV, providers, partners and community?.

## The Well Project



- The Well Project is a non-for profit organization founded in 2002 whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls.
- Its approach makes it a leader in the fight against HIV by revolutionizing the availability and accessibility of meaningful and relevant information designed specifically for women and girls living with HIV.
- It has served as the main online resource for women living with HIV both in the US and the world, thus improving their health and quality of life.
- Through its online platform it provides up to date and trustworthy information about HIV, as well as help create and strengthen community support for women living with HIV and promote activism.
- The web page is visited by more than 1 Million viewers annually.
- The Well Project’s fact sheet were visited more than 300,000 times in 2018 and as of January 2019, they have had dramatic increases in visits from Spanish-speaking countries:
  - Mexico 109% (31,000 in 2017 to 65,000 in 2018),
  - Spain 62% (18,000 to 28,000),
  - Argentina 136% (10,000 to 23,000),
  - Colombia 167% (9,000 to 23,000),
  - Peru 192% (7,000 to 22,000),
  - Chile 188% (7,000 to 19,000), and
  - Puerto Rico 98% increase (from about 1000 to 2000 visitors).

## Results

A duality of benefits encompassed the experience:

- translating and adapting to the Spanish language and culture providing needed resources to women living with HIV
- learning while becoming increasingly sensitive towards an illness and a community.

HIV: General Knowledge	
Article Title in English	Article Title in Spanish
Aging and HIV	La vejez y el VIH
AIDS-Defining Conditions	Condiciones que definen el SIDA
HIV Testing	La prueba de VIH

Treatment and Adherence	
Article Title in English	Article Title in Spanish
Adherence	Adherencia
Care and Treatment for Children Living with HIV	Cuidado y Tratamiento para niños viviendo con VIH
Complementary Therapies	Terapias complementarias
Considerations Before Starting HIV Treatment	Consideraciones antes de comenzar el tratamiento contra el VIH
Finding a Cure for HIV	Encontrando una cura para el VIH
Getting HIV Drugs in the US	Como conseguir medicamentos para el VIH en Estados Unidos

Prevention	
Article Title in English	Article Title in Spanish
Cleaning Equipment for Injecting Drugs	Limpieza de los equipos para uso de drogas inyectables
Sexually Transmitted Infections or Diseases (STIs or STDs)	Infecciones o enfermedades transmitidas sexualmente (ITS o ETSS)
Substance Abuse and Addiction	Abuso de sustancias y adicciones

Reproductive Issues	
Article Title in English	Article Title in Spanish
Birth Control and HIV	Control de Natalidad y VIH
Getting Pregnant and HIV	Quedar embarazada y el VIH

Healthcare Related Issues	
Article Title in English	Article Title in Spanish
Anemia and Women	Anemia en las Mujeres
Bone Health	Salud ósea
Cancers	Cáncer
Caring for Your Gut: Dealing with Diarrhea, Nausea and Other Stomach Problems	Cuidando tu intestino: lidiando con diarrea, náuseas y otros problemas estomacales
Caring for Your Heart	Cuidando tu corazón
Caring for Your Liver	Cuidando tu hígado
Diarrhea	Diarrea
HIV and the Brain	VIH y el cerebro
HIV and Your Mouth	VIH y tu boca
Human Papillomavirus (HPV)	Virus del Papiloma Humano

Lifestyles and Empowerment	
Article Title in English	Article Title in Spanish
Considering Going Back to Work	Considerando regresar al trabajo
Depression, Women, and HIV	Depresión, la mujer y el VIH
Getting Your Sexy On!!	¡Ser sexy, ponerse sexy!
Housing Options for People Living with HIV in the US	Opciones de vivienda para personas que viven con VIH en Estados Unidos

Stigma and Discrimination	
Article Title in English	Article Title in Spanish
Factors Affecting HIV Among US Women of Different Race/Ethnicities	Factores de riesgo para el VIH en mujeres de diferentes razas y etnias en Estados Unidos
HIV Criminalization and Women	Criminalización del VIH y las mujeres

Figure 2: The final list of translated and adapted articles categorized by themes.

## Personal Perspectives

The overall experience can be summarized by some of the things we realized along the process:



“This project learning topics go from virology to self-esteem. It was an unique educational experience. It was important to enhance our sensitivity to the hardships women living with HIV endure throughout their lifetime, inside and outside the doctor’s office.”

“As young women it was an eye opener to realize how different our life experiences have been and although we were not able to completely empathize, the lessons learned will determine how we will handle ourselves if we are ever confronted with similar situations”



“The amount of information about HIV that has been made available during recent years still does not compensate for the misinformation people have about the disease. I believe that pages like this, that provide accurate information, that expose testimonies and detail real experiences about women living with HIV can have a great impact in diminishing the gap in knowledge. The more a patient knows about its disease, the more power they have over it. Something I have learned through this experience is that being able to have control of your lifestyle and to approach a normal life as much as possible should be a priority in every doctor and patient agenda, specially when dealing with a chronic illness such as HIV.”



“This project instilled a greater sense of responsibility in the process of translation. Not only were we providing medical information about HIV but attempting to adapt it to the different realities of these women.”

“The information could not only be scientifically correct but had to be sensitive to the women’s needs and approachable for them to actively use it.”

“Adapting these articles presented as an opportunity to empower women and contribute to the sense of community that The Well Project has created.”

Figure 3: Perspectives of the Second year Medical Students participating in the Project.

## Conclusions

- Immersing in the issues of women living with HIV by providing access to reliable materials on a diversity of topics to a larger Spanish-speaking audience raised personal awareness and increased female medical student’s commitment to learn and work with this specific population.
- The experience of individual work with translation of documents with novel or confusing information was in a way similar to the experience of a person with a new diagnosis.
- Adapting the articles was an opportunity to empower women and contribute to the sense of community that *The Well Project* created.
- As women who used this platform in the process of article adaptation and who greatly expanded their knowledge on HIV and its impact on many facets of women’s lives, we recognize the importance of having an online resource that is accessible, approachable, and led by women from different disciplines, some of which also live with HIV.

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