



TOGETHER

CASE STUDY:

The Lily Project: Building a woman-focused community health response in Nicaragua

The loss of Anielka Medina's mother, Azucena, to cervical cancer inspired Anielka's quest to bring cervical cancer prevention to rural areas of Nicaragua, combating not only the disease itself but underlying cultural issues of disempowerment and stigma that hinder efforts to safeguard women's health.

In 2015, clinical bioanalyst Anielka, healthcare executive Susan Cotton, and community development expert Jonathan Butcher co-founded **The Lily Project** in memory of Azucena, a single parent whose Spanish name translates to "lily." In only five years, the Lily Project's mobile clinics have provided cervical cancer screening to over 20,000 women in rural areas of Nicaragua, along with critical education on women's health.

Cervical Cancer and Women's Health in Nicaragua

Unlike women in many parts of the world, a disheartening proportion of Nicaragua's women lack access to effective tools for the prevention and treatment of cervical cancer. These include vaccines against human papillomavirus (HPV) – the sexually

transmitted virus that causes most types of cervical cancer – which provides lifetime protection to young women if immunized before they are exposed to the virus. Low-cost, highly accurate health technologies can identify precancerous cervical lesions, and the use of cryotherapy or thermal ablation can remove those lesions before they threaten a woman's life.

The Lily Project's mobile clinics bring critical women's healthcare with a patient-centered approach to rural Nicaraguan women, who otherwise would have little to no access to these services. Lily Project clinics have screened over 20,000 women for cervical cancer and provided sexual health education for 9,000 adolescent girls. The success of the Lily Project can be summarized in four key principles:

- Listen to women.
- Empower women.
- Confidentiality is essential.
- Partner with national and local authorities.

This lack of access leads to fatal consequences in the small country of 6.2 million people. **Cervical cancer kills more Nicaraguan women than any other cancer.** In 2018, 677 Nicaraguan women were diagnosed with cervical cancer, and 409 women lost their lives to the disease.¹ Cervical cancer can represent an existential threat to a family unit in Nicaragua, where nearly 50% of rural households are headed by single mothers like Azucena.



Anielka Medina speaks to women in Rancho Grande, Nicaragua. Photo by Jonathan Butcher.

Insufficient women's healthcare in Nicaragua is compounded by cultural factors including machismo that normalizes sexual violence and stigma that falsely correlates cervical cancer to promiscuity. Inadequate education regarding women's health can leave women without clear understanding of even basic processes like menstruation. Together these factors contribute to an environment where women lack the knowledge or agency necessary to seek effective care for themselves. And even in cases where they do seek care, Nicaraguan women can often feel judged or ignored by overburdened health providers hard-pressed to provide even the most basic services.

Bringing women's health services to communities

The Lily Project navigates these challenges by taking women's healthcare and health education to Nicaraguan communities directly in the form of mobile

clinics. Prioritizing where best to focus Lily Project resources can be a challenge given that insufficient women's healthcare is an issue across almost the entire country. The Project analyzes available data and partners with Nicaragua's Ministerio de Salud (MINSa) to identify communities to which to send one of two currently active mobile clinics.

Essential to launching Lily Project activities in new communities is engagement and collaboration with community leaders, the first step toward building relationships with the women Lily Project seeks to serve. "Trust is key, especially since this will be the first experience with a women's health provider for many women in these communities," says Anielka. Coordination between Lily Project staff and community leaders ensures that the community context is well-understood and that Lily Project activities receive critical buy-in in advance.

The Lily Project's mobile clinics can be set up in minutes to provide confidential spaces for women to be screened, and don't require electricity, often a limitation in rural areas. Once operational, the clinics act as the base of operations providing holistic women's health services, including screening and treatment of cervical cancer, education in sexual and reproductive health, and counseling. As many as 100 women per community project can be screened for cervical cancer over the course of a week.

Each Lily Project clinic is under the direction of an experienced Lily team leader and staffed by two nursing graduates from the University of Nicaragua who are trained to deliver quality screening for and treatment of cervical cancer while garnering valuable on-the-job experience. The Project also employs women recruited from communities themselves to strengthen rapport with patients.

Stigma around cervical cancer discourages screening, provoking fear in women that their results may be shared with others in the community. At each event, The Lily

Project team presents information and education regarding culture and sexual health to the women attending, discussing factors such as stigma and ways to overcome and remove such harmful associations.

Women in rural Nicaraguan communities are accustomed to seeing their information written down on paper, so the Lily Project's collection of confidential data via a secure electronic platform reinforces a feeling of trust and security with the women being served. That emphasis on confidentiality extends throughout the Lily Project process, ensuring each woman can receive and discuss their results with her preferred source, either a community leader or Lily Project staff. This data is securely compiled and aggregated, building an evidence base that guides future Project activities.



Lily Project staffer Adilia Navarro providing results to a woman in San Dionisio, Nicaragua / Photo by Jonathan Butcher

As required by the Ministry of Health, The Lily Project performs cervical cancer screening either through Pap smears (for women ages 16-28 or above age 51) or visual inspection with acetic acid (VIA) (for women ages 28-50). When precancerous lesions are identified, same-day cryotherapy treatment is available but often declined due to the woman's comfort level. With the Project's patient-centered approach, this experience is not considered a success until the appropriate treatment is received. This is another area where trust between the Project and the woman is key: maintaining

a relationship with the woman and building confidence in safety and confidentiality can greatly increase the odds for follow-up treatment appointments. Women who need more advanced treatment are referred to hospitals in urban areas and guided through the process by Lily Project staff.

The Lily Project's goals extend beyond reducing the burden of cervical cancer in these communities to empowering women and girls to understand and advocate for their health needs. Separate from its cervical cancer programs, the Lily Project implements educational activities for girls ages 10-17 to combat Nicaragua's high rate of teen pregnancy and encourage healthy sexual behaviors. As young women better understand their own health, they are more likely to delay their first pregnancy and set themselves on a path defined by their own choices. Further, sexual health education can improve the chances that these young women will go through life prepared to engage health systems for preventive care such as cervical cancer screening.

Driving results

The Lily Project's community-oriented approach to holistic women's health is having an impact. By the end of 2019, the Project had screened almost 20,000 Nicaraguan women for cervical cancer, and rolled out educational programs reaching over 9,000 adolescent girls. These results come at a reasonable price, less than US\$20 per woman. Dedicated and inspired staff power the Lily Project's operations, but these driving principles underpin the Project's success in bolstering women's health in Nicaragua:

- **Listen to women.** In a region where women have lacked agency to expect and access quality healthcare, building trust with women is important. The Lily Project's patient-centered system ensures that women feel valued in the process, building relationships that encourage women to access cervical cancer screening and follow up for results and where necessary, treatment.

- **Empower women.** Providing sexual health education to young women in these communities can break cycles of poor health later in life, increasing uptake of family planning strategies and preventive health services, including cervical cancer prevention, screening, and treatment.
- **Confidentiality is essential.** Stigma represents a massive barrier between women and critical health services. Confidential provision of results allows women to feel comfortable being screened.
- **Partner with national and local authorities.** The Lily Project's strong working relationship with MINSA allows them to work within the public health system and to develop quality programs. Replicable results at the community level support national health efforts, allowing the Lily Project to reinvest the government's trust into future activities and ensuring that communities will be more willing to host future mobile clinic visits.

The future

Each mobile clinic – consisting of staff, a truck, and equipment – has the capacity to screen 3,300 women each year. With plans to quadruple capacity from two active mobile clinics to eight, the Project holds the potential to screen nearly 30,000 Nicaraguan women and girls annually by 2024. At that point, more than 100,000 will have been screened with an estimated 8,400 treated. However, Lily Project co-founder Susan Cotton knows that truly turning the tide against cervical cancer in Nicaragua will require more than just scaling up current Project activities. Currently, the HPV vaccine and screening for the HPV virus are mostly unavailable to Nicaraguan women “Our clinics are designed to readily adapt to new technologies. We are ready and would love to play a role in getting more effective prevention tools to the women that need them.”

In a short five years, the Lily Project has taken the fight for women's health to the community front in Nicaragua, building a bond of trust with mothers and daughters alike that empowers and prolongs lives – and families. “Losing a mother is hard, especially when she is lost to something that is preventable,” says Anielka. “I know my mother would be proud to see we are creating healthier futures for women and their families in Nicaragua”.



Yanoris Tórrez presenting to a group of women in El Tuma, Nicaragua / Photo by Adrienne Cotton.

To learn more about the Lily Project's work in Nicaragua, visit www.thelilyproject.org

This case study was authored by Tom Harmon of TogetHER for Health. Special thanks to Anielka Medina and Susan Cotton of the Lily Project.

¹ <https://gco.iarc.fr/today/data/factsheets/populations/558-nicaragua-fact-sheets.pdf>