



Vivir a todo pulmón

(Live life to it's fullest)

Robin Lewy, MA
Rural Women's Health Project
North Central Florida

- Pensar
- Detectar
- Tratar



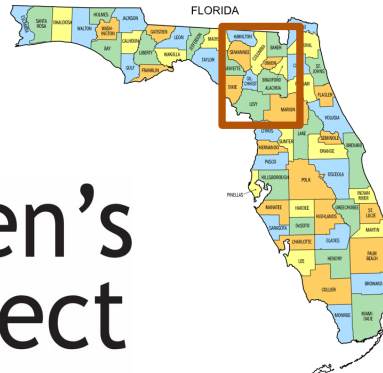


Rural Women's Health Project

www.rwhp.org *El Proyecto de Salud en Pro de la Mujer Rural*

The RWHP works in rural North Central Florida; all counties are medical shortage areas, highly agricultural, and some of the poorest counties in the State.

For 32 years we have served Latina/o communities, most immigrants from the Latin American diaspora. We serve Spanish and some indigenous Mayan speakers.



Territory Served:
6 Counties

Team:
4 full-time
3 part-time



Community-based Team:
7 Promotores de Salud
15 Comunicadores



Referral System:
1 Multi-lingual system
980 text system recipients



RWHP Serves (2023*):
459 Referral
1782 Text system
5300 Direct outreach



*to date

Community demographic shifts over the past 32 years.

Currently our population consists of:

- Mexicans
- Guatemalans
- Venezuelans
- Columbians
- Puerto Ricans
- (Haitians)

Forms of employment:

- Agriculture
- Construction
- Service



Background on our work on Tuberculosis

In 2005, the RWHP began to work with the Southeastern National Tuberculosis Center.

The work was steeped in the findings of outreach the RWHP carried out in Kentucky and North Central Florida.

Methodology consisted of Community Exchange Sessions (CNS) and *Promotor de Salud* facilitated 306 20-question surveys.

The findings articulated steps to raising Tuberculosis awareness the Latino Community.



TB 101 Consejo Novela



Calendar

Poster

TB Treatment Consejo Novela



RWHP developed 4 materials for the ¡Vivir! Initiative (2006-9)



Rural Women's Health Project
www.rwHP.org

Major Findings from the Needs Assessment in 2005-2006



Of 306 surveyed:

- 33% had never heard of tuberculosis
- 73% had received BCG vaccine
- 97% did not know the mode of TB transmisión
- 84% had never Heard of “latent or inactive” TB
- 27% knew that an xray or skin test was necessary to confirm TB
- 49% believe that TB is a problem in their community
- 74% would go to a doctor if they suspected TB
- 34% listed socio-economic barriers to seeking healthcare



TB survey findings:

- 100% TB is curable
- 30% treatment lasts 6 months or longer
- 90% say TB affects the lungs
- 45% say the hospital is where to get TB test
- 61% say TB testing is a skin test on the arm
- 90% understand the term “latent tuberculosis”
- 69% have had a TB test
- 60% said that “latent” tuberculosis requires medical treatment
- 45% believe Latinos are least likely to contract TB

Health-barrier survey findings:

- 44% have barriers to accessing health care
- 40% have never (or it had been more than 3 years since), a medical exam
- 73% suffer (or have a close family member) who suffers from a chronic health condition
- 98% have no health insurance
- 86% don't speak English

Findings
from a 2023
mini-survey
on TB to
Promotores
de Salud and
survey of
health access
challenges



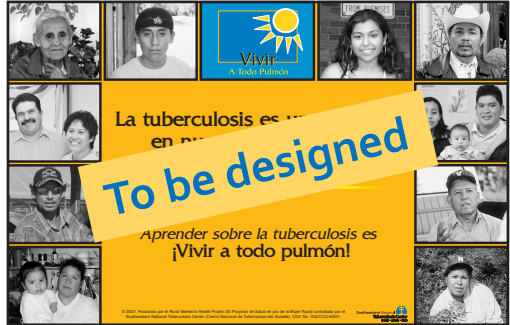
New Material

Aprender sobre la tuberculosis es



Vivir
A Todo Pulmón

Pensar. Detectar. Tratar.



To be designed

La tuberculosis es...
en...

*Aprender sobre la tuberculosis es
¡Vivir a todo pulmón!*

Outreach Plan

Total Impact Goal: **2580** unique recipients



- 480 Latinos will receive one-on-one education from a *Promotor de Salud*
- 200 workers/church-goers will see poster messages
- 1500 will receive two messages each via our text service
- 400 will receive 2 messages each from *Comunicadores*
- 50 posters distributed to church and work sites
- 2 regional radio ads will run for one month each



Vivir a todo Pulmón: A Needs Assessment to Reduce Tuberculosis Transmission and Increase Compliance with Recommended Tuberculosis Treatment in Foreign-born Spanish-speaking Communities.

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1. Background

In the United States, racial and socio-economic disparities are associated with TB. In 2004, a CDC report stated that the U.S. Hispanic population is up to 7.5 times more prone to be infected with TB when compared to Whites (Lord and Calabria, 2005). Notably, in 2000, 46% of all TB cases in the United States, were among immigrants (Zuroweste, 2002). Of these immigrants, 25% are Mexicans, the largest subgroup of occurrences of TB cases among the foreign-born (Tickner, 2004). More importantly, it is noted that also in 2000, migrant farm workers in the U.S. were assumed to be six times more likely to develop TB when compared to the overall U.S. population of employed adults (Zuroweste, 2002). Additionally, in 2000, Central Americans comprised almost 5% of all the foreign-born cases (Wells, 1999).



2. Objectives

This assessment focused on the Spanish-speaking immigrants living in the Southeastern United States; their perceptions, cultural beliefs and knowledge of TB. The findings will serve as the foundation for the development and implementation of a Comprehensive Education Plan. This plan will support clinicians' efforts to test, treat and diminish the incidence of TB in the Spanish-speaking immigrant community, as well as increasing community awareness of the existence of TB in the United States.



3. Methods

Project Partners: SNTC (Southeastern National Tuberculosis Center), RWHP (Rural Women's Health Project) Advisory Board, MCN (Migrant Clinicians Network) and four lead site partners. The input from the project partners was critical for both approaches (review of the community education session plan and the survey development).

Six key locations, three each in Kentucky and Florida, were selected for the assessment. A two-pronged approach to information gathering was utilized through:

1. Community Education Sessions (community members and lay health workers).
2. The administration and analysis of the 30-question survey (mostly open-ended).

Community Education Sessions (CES)

Six sites were selected for Community Education Sessions in the communities of Lexington and Paris, Kentucky and Bradenton, Pierson and Belle Glade, Florida. There was an average of 12 participants at each session.



Surveys

1. Survey questions were developed in Spanish.
2. Surveys were pre-tested with site partners and altered as necessary.
3. Surveys were implemented by lay-health workers (trained for this project by the RWHP).
4. Surveys, when completed by each lay-health worker, were signed, dated and returned to the RWHP.
5. Surveys, as received, were recorded and dated for input.
6. Data was then dated, coded and input by an MD/MPH into Excel and SPSS.

August, 2006.

4. Goals

The goals of the assessment included the identification of:

- * Community knowledge of TB
- * Cultural beliefs related to TB
- * Key aspects of TB relevant to the community (self-identified risk, prevalence, fear, U.S. Immigration and Customs Enforcement, etc.)
- * Issues that effect community health information delivery and medical attention (socio/economic and internal barriers, accessing of services, cost, communication with clinician, etc.)
- * Factors that must be in place to initiate or sustain change (issues of stigma, perception of medical care, testing and treatment protocol, etc.)

5. Findings

Demographics

306 people surveyed
 51% were married
 59% female, 41% male
 83% from Mexico and 10% from Central America
 67% do not speak English
 78% have no health insurance
 53% have been in the US for less than 6 years
 26% work in agriculture



Survey Highlights

33% had never heard of TB
 73% received the BCG vaccine
 97% did not know the mode of TB transmission
 84% had never heard of latent or inactive TB
 27% knew that a PPD, x-ray or other exam was necessary to confirm TB
 74% would go to a doctor if they suspected they had TB
 49% believe that TB is a problem in their community
 26% listed economic barriers for not seeking medical services
 34% articulated socio-linguistic barriers to seeking services (fear, deportation, lack of legal documentation, limited language skills, lack of knowledge of resources)



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Zuroweste M.D., Edward. (2002) Manual for the Management of Binational Tuberculosis Patients. (Available from Migrant Clinicians Network 225 Carter Hall Lane Millwood, VA 22646, (340) 837-2100)

Community Education Session Highlights

Of those participants who had heard of TB, most believe that:

1. There is only one type of TB (Pulmonary).
2. Once vaccinated via BCG, they are protected and can't become infected with TB.
3. When treated for latent TB, "the disease was removed from their lungs" and "it makes it so you can't get TB again."
4. TB germs are in the saliva.
5. One can get TB from the BCG vaccination.



Additional Comments about Medical Services

1. One needs to provide their own translator to assure translation service.
2. Undocumented participants fear that health records are shared with immigration authorities.
3. The community doesn't know how to access medical services.
4. There is a lack of clarity in the doctor's explanation of diagnosis and treatment.
5. Most choose not to disclose home remedy use for fear of being chastised or belittled by medical personnel.

6. Conclusions

Spanish-Speaking immigrants are at an elevated risk for contracting TB. The findings show that inaccurate information about TB is a primary obstacle. The communities' access to and confidence in medical services continues to be an area requiring additional improvement in order to diminish treatment non-compliance and the further transmission of the disease. Additionally, stigma and issues of fear related to TB, which are broadened by the difficulties of immigration, require a vigorous campaign to normalize the perceptions of the illness and to re-introduce TB into mainstream discussion, supporting clinical education.



7. Recommendations

- To implement the Comprehensive Education Plan.
1. Patient education material to support clinician education
 2. Community Awareness Campaign to diminish stigma and increase community knowledge
 3. Training of lay-health educators to bridge the community to services
 4. Message partnering to increase community investment in TB
 5. Clinician education on Latin American treatment protocols and cultural information

Acknowledgements

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Appreciation is extended to: Michael Lauzardo, MD and Karen Simpson, MPH, Southeastern National Tuberculosis Center, Gainesville, FL; Bluegrass Farmworker Health Center, Lexington, KY; Lexington Public Library, KY; *Radio Vida*, KY; Glades Health Initiative, Belle Glade, West Palm Beach County, FL; Project *Claridad*, Crescent City and Belle Glade, FL; and Fabiola del Castillo, MA-Anthropology.

"Spanish-speaking immigrants are at an elevated risk for contracting TB... findings show that inaccurate information about TB is the primary obstacle."

Vivir a Todo Pulmon: Increasing Tuberculosis Awareness and Treatment Adherence in Spanish-speaking Communities

By Francine Picardo, BA, Director of Education, Rural Women's Health Project; Robin Lewy, MA, Director of Development, Rural Women's Health Project; Myrtha Barbara E. Forgiel, MD, MPH, Research Coordinator and Medical Consultant, Rural Women's Health Project.

The incidence of tuberculosis among foreign-born in the U.S. has been on the rise since 1993.¹ Although the disease had previously been under control, there has been a documented increase of TB in immigrant populations. It is also noted that in 2000, migrant farm workers in the U.S. were assumed to be six times more likely to develop tuberculosis when compared to the overall U.S. population of employed adults.² More significantly, since 2003 there have been more cases of TB reported among Hispanics than any other racial/ethnic population.³

In the United States, racial and socioeconomic disparities are associated with tuberculosis, and it has been a difficult issue to address with the immigrant communities. Further complicating the challenges is the target community's need for services and information is the reality of tuberculosis-related stigma among both the Hispanic population in the U.S. and their service providers. As stated in an article by M. Hadley and D. Maher,

"The benefits of getting well are unlikely to outweigh the costs of social and family rejection and the loss of employment and accommodation at the early stages of the disease." (Hadley and Maher, 2000).

Similarly, Tao Kwan-Gett, M.D. adds "This stigmatization has obvious consequences for health care providers. In addition to complicating adherence

to diagnostic and therapeutic plans, it makes household contact tracing a sensitive issue. In a close-knit community, where two or three families may live where two or three families may live under one roof, people are as reluctant to share information about their diagnosis of TB as they would be about HIV" (Kwan, 1998).

To address this health issue, the Southeastern National Tuberculosis Center and the Rural Women's Health Project partnered to develop *Vivir a Todo Pulmon*. The project employed a two-pronged approach that combined Community Education Sessions (CES) and lay-health worker facilitated surveys to gather information on the perceptions, cultural beliefs and knowledge of TB in the Hispanic immigrant community. The assessment findings have since served as the foundation for the development and implementation of a comprehensive education plan for Spanish-speaking immigrants living in the southeastern United States. This plan supports clinicians' efforts to screen, treat and diminish the incidence of TB in the Spanish-speaking immigrant community, as well as increasing community awareness of the existence of TB in the United States.

Findings from the 306 open-ended *Vivir a Todo Pulmon* surveys found that Spanish-speaking immigrants are at an elevated risk for contracting TB. The findings show that inaccurate information about TB is the primary obstacle. The communities' access to and confidence in medical services continues to be an area requiring additional improvement in order to diminish treatment non-compliance and further transmission of the disease. Additionally, tuberculosis-related stigma and fear – factors multiplied by the difficulties of immigration – require a vigorous campaign to support clinical education and on tuberculosis and immigrant culture, and to normalize the perceptions of the illness and re-introduce TB into mainstream discussion.

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3. "Trends in Tuberculosis Incidence – United States, 2006." *MMWR Weekly*, 23 March 2007, 56(11): 245-250. <<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5611a2.htm>>

The *Vivir a Todo Pulmon* project has developed a series of tuberculosis education materials that are now available for health centers, state agencies and grassroots organizations serving Spanish-speaking immigrant communities. These clinician education materials and community materials (available in *Winter, 2007*) are the result of two years of community work carried out by the Rural Women's Health Project.

To meet the objectives of the project the RWHP partnered with community-based organizations committed to utilizing trained community liaisons (lay-health workers), each with an established outreach program capable of serving the target population's follow-up needs. The project had six sites in Florida, divided evenly between Kentucky and

Three hundred and six people were surveyed (50% female, 41% male; 83% were from Mexico; 67% spoke no English; 78% were uninsured, and; 26% worked in agriculture). Thirty-three percent of respondents had never heard of TB, yet 49% believed that TB is a problem in their mode of TB transmission. Although 73% mentioned receiving the Bacille Calmette-Guérin (BCG) vaccine, they were not knowledgeable of its purpose, and many believed that since they had been vaccinated, they were no longer susceptible to contracting TB. Eight-four percent had never heard of latent or inactive TB.

When asked about barriers to seeking medical services, 26% listed economic

reasons as their main obstacle, while 34% articulated socio-linguistic barriers (fear, limited language skills, lack of knowledge of resources). When asked about how they would know if they had TB, the respondents replied that a Purified Protein Derivative Standard (PPD), x-ray or other exam was necessary to confirm TB (27%) and that they would go to a doctor if they suspected they had TB (74%).

The outcome of *Vivir a Todo Pulmon* is a multi-year program to develop a comprehensive education plan that will include materials to support clinician education, materials to launch community education campaigns (to diminish stigma and increase community knowledge) and a training DVD to support clinician education. All these materials are developed by the RWHP and eastern National Tuberculosis Center, which offers many of the materials for download from their website at <http://nntc.medicare.afl.gov>. Working together, we can take steps to reduce the incidence of tuberculosis in the Spanish-speaking immigrant communities. For more information, contact the Rural Women's Health Project (RWHP) at (352) 372-1095 or <http://www.rwhp.org>.

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"The outcome of *Vivir a Todo Pulmon* is a multi-year program to develop a comprehensive education plan that will include the development of patient education materials to support clinician education"



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