

Breathe it in!

Asthma, Culture, and Language in Hispanic Families



Nuestra Salud

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Association*

NM Chronic Disease Prevention Council

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**New Mexico Community
Health Worker Association**

Nuestra Salud



Nuestra Salud

The mission of *Nuestra Salud* is to reduce health disparities affecting Hispanic communities in New Mexico and the nation through research, training, and outreach.

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- New Mexico Department of Health Asthma Control Program
- San Juan College/ Engaging Latino Communities for Education (ENLACE)
- Clovis Public Library



Objectives

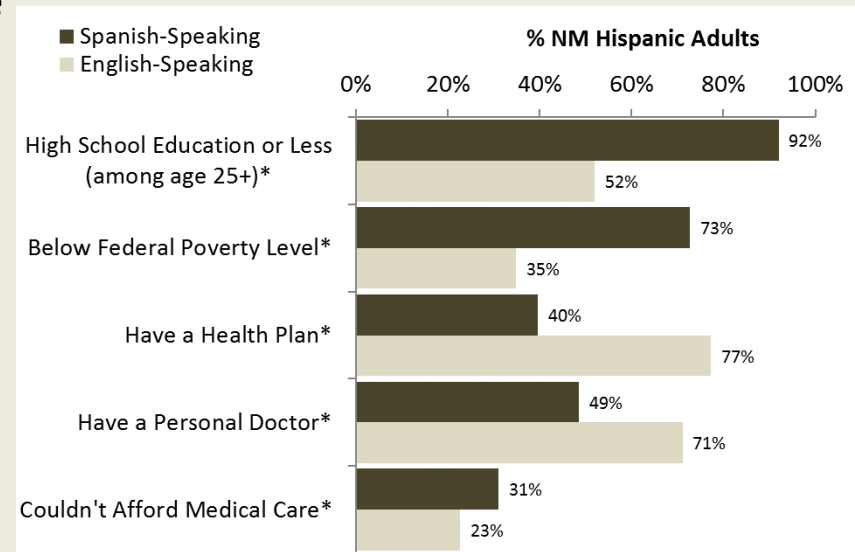
1. Increase understanding of Hispanic family culture related to asthma and children
2. Increase awareness of *photovoice* model and relevance to community empowerment
3. Increase understanding of how the photovoice approach was effective for addressing this topic in this culture
4. Identify key elements of this project that may apply to other topics and communities

Background

HISPANIC FAMILIES AND ASTHMA IN NEW MEXICO

Background: New Mexico Hispanic Population

- New Mexico's Hispanic and Spanish-speaking population is **large**
 - Nearly one million people (48% of the state population) are Hispanic
 - About 29% of the state's total population say they speak Spanish at least half of the time at home, more than half a million people (543,100)
 - About 150,000 say they speak English "less than very well"
- New Mexico's Hispanic population is **diverse**
 - Two-thirds are of Mexican heritage
 - Others are Puerto Rican, Cuban, from multiple countries of Central or South America
- They face **barriers to healthcare**
 - In comparison to English-speaking Hispanics, Spanish-speakers are more likely to experience poverty; less likely to have access to healthcare.



Asthma

- Asthma is a complex chronic medical condition
 - Airway inflammation and constriction make it hard to breathe; symptoms include wheezing, coughing, chest tightness, shortness of breath
 - Can be mild, moderate or severe, even causing death
 - “Triggers” like dust, mold, pet dander can make symptoms worse
 - Effective “control” may include taking quick-relief and/or preventive medication, and reducing exposure to triggers; a “control plan” should be developed together with a healthcare provider
- Culture and language can further add to the challenges of identification and control

Asthma among Hispanic New Mexicans

- About 4% of Spanish-speaking and 10% of English-speaking Hispanic adults have been diagnosed with asthma by a doctor
- About one in four (25%) high school-aged Hispanic youth has *ever* been told they have asthma
 - one in ten (11%) high school-aged Hispanic youth *currently* has asthma

Less asthma among Spanish-speaking Hispanics? PROBABLY NOT

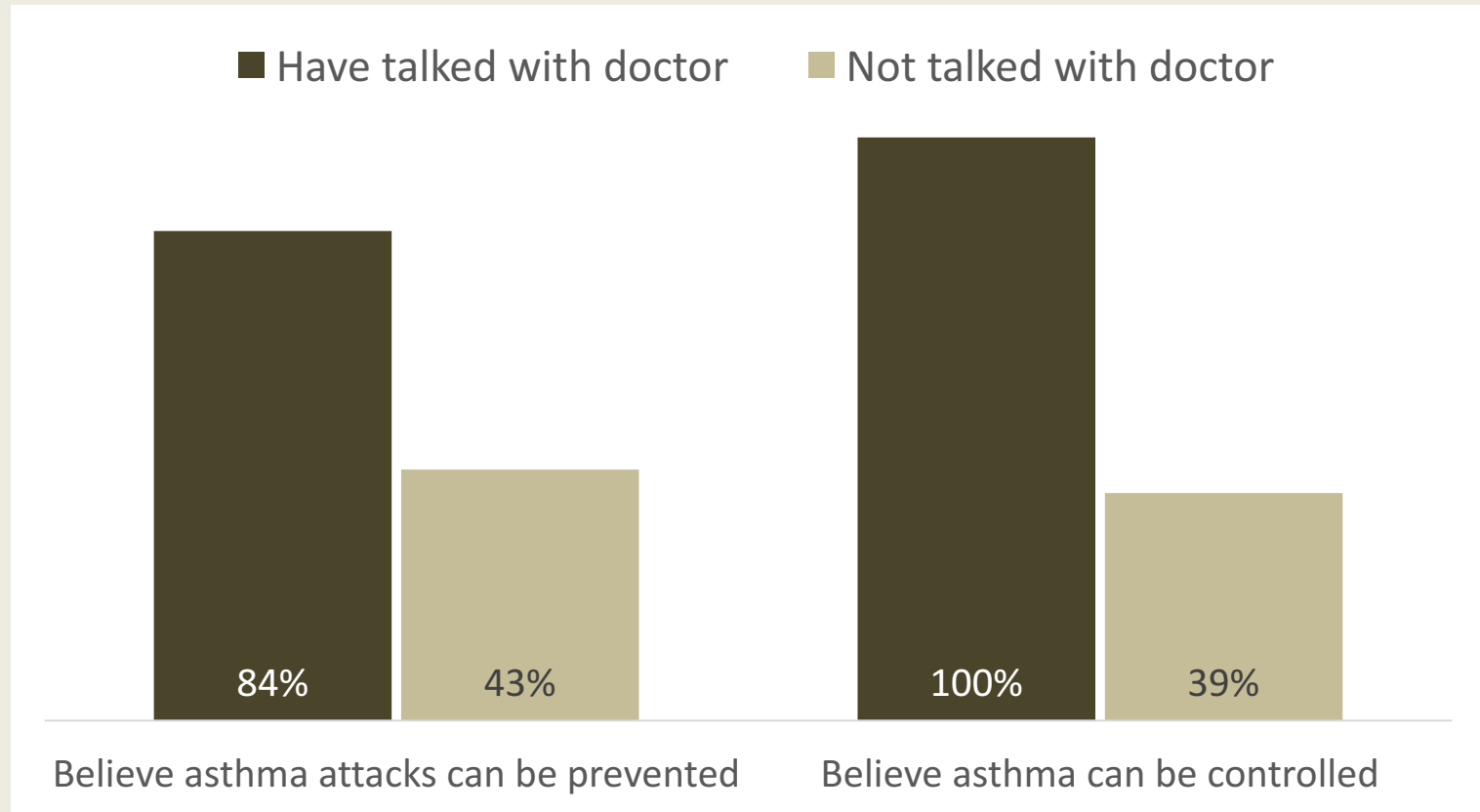
- Asthma prevalence is
 - similar to the general population for English-speaking Hispanics
 - lower for Spanish-speaking Hispanics
- Asthma may be under-reported among Spanish-speaking people due to lack of access to healthcare providers for routine care, or failure to communicate effectively about the condition

Improving understanding of asthma care among Spanish-speaking families

- *Nuestra Salud* conducted focus groups with Spanish-speaking parents of children with asthma in 2015-2016
 - 57 total participants
 - 6 groups at 3 sites across the state
 - Most (91%) said their children were taking asthma medications

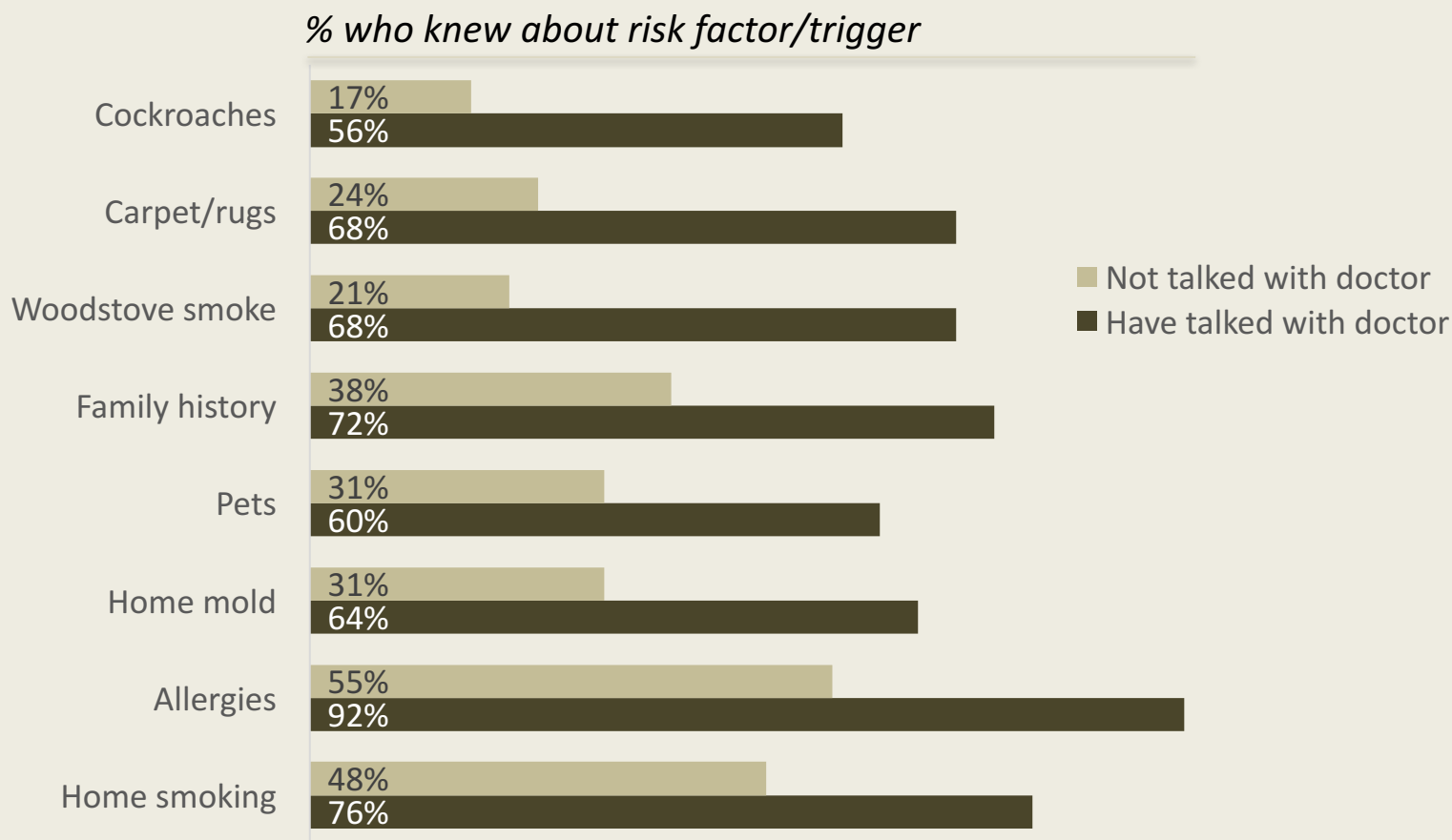


Talking with a Doctor About Causes of Asthma: Stronger Beliefs About Effectiveness of Asthma Prevention and Control



Source: Spanish-speaking parents: perspectives on asthma care for children. *Nuestra Salud*, 2017. Overall (both groups combined) 59% overall believe asthma attacks can be prevented; 66% overall believe that asthma can be controlled. Differences by group were statistically significant.

Talking with a Doctor about Causes of Asthma: Greater Knowledge of Asthma Risk Factors or Triggers



BUT fewer than half (44%) had ever talked with a doctor about causes of asthma

- **Women were more likely** to have talked with a doctor about causes of asthma than men (46% vs. 36%)
- **People with some form of insurance were more likely** than those without insurance or self-pay to have talked with a doctor (57% vs. 30%)
- **Those who had been living in the U.S. for 10+ years and those born in the U.S. were more likely** to have talked with a doctor than those who had been in the U.S. for fewer than 10 years (55% vs. 31%)



Surprisingly, there was no association between having talked to a doctor about causes of asthma and income level or education

Intervention

“PHOTOVOICE” FOR COMMUNITY EMPOWERMENT

Photovoice

An established approach in public health^{1,2}

- Participatory projects where people can “identify, represent and enhance their community through photographic technique” Method is closely aligned with principles of community-based participatory research (CBPR)
- Used internationally, among diverse age groups, to address multiple topics (e.g., infectious disease, reproductive health, chronic disease, political violence, and discrimination)

1. Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/9158980>

2. Cataloni, C, Minkler, M. (2010). Photovoice: a review of literature in health and public health, *Health Education & Behavior*, 37 (3), 424-451

Photovoice Model

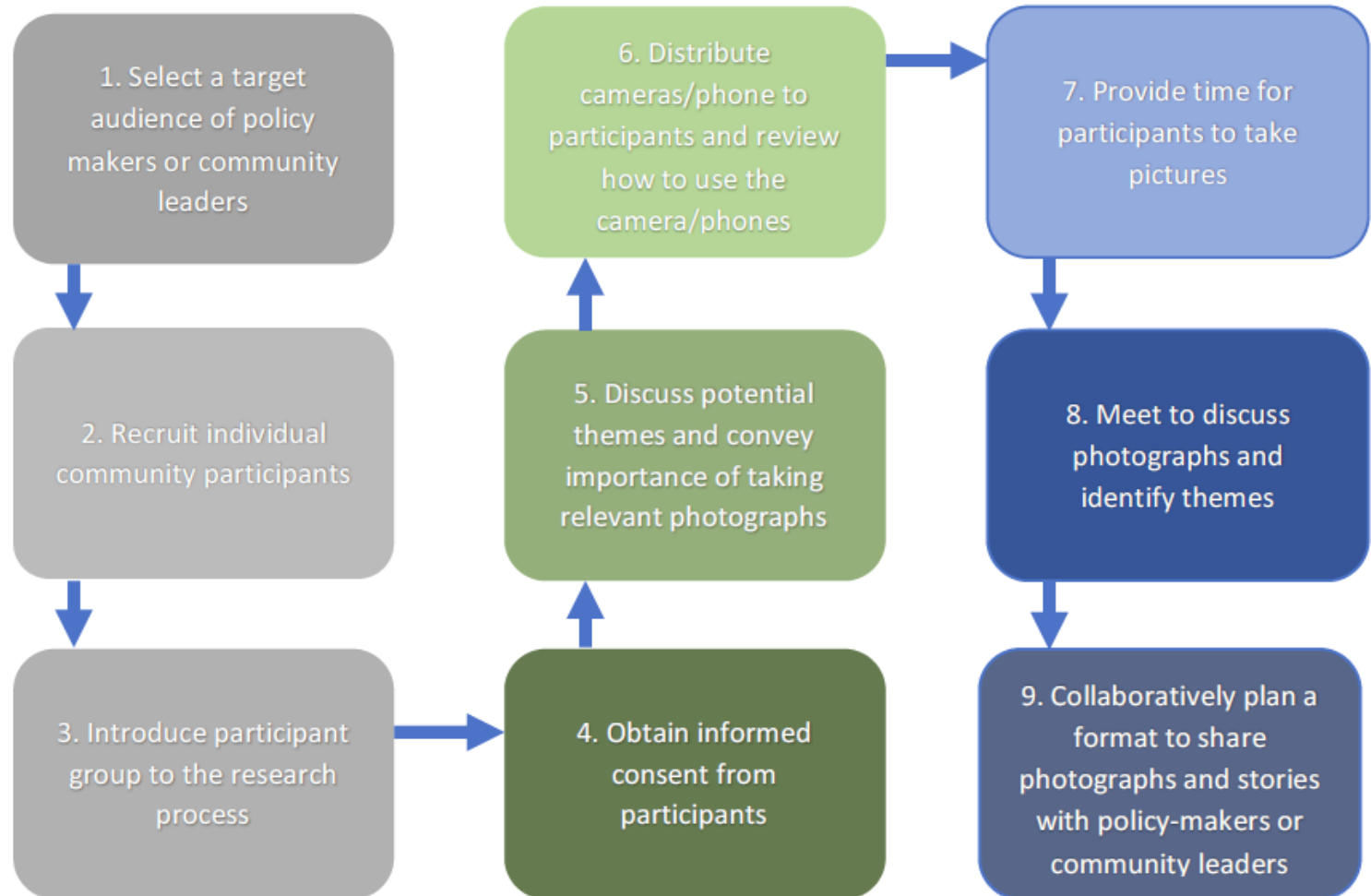


Figure A: The Nine Steps of the Photovoice Method

Photovoice Goals

Intervention to support Spanish-speaking families and their children with asthma

- Identify and document strengths and concerns within the community
- Promote dialogue among families and providers
- Educate the public and policy makers about the challenges of asthma control in Hispanic families

Implementing Photovoice

- **Who?** Spanish-speaking adults with children who have asthma, recruited through parent programs, ESOL classes, and word of mouth.
 - Participants received a stipend for completing the program, and signed photo/video releases so that their experience could be shared through media.
- **Where/When?** Rural Farmington and Clovis New Mexico during 2018-19.
- **How?** Facilitation was in Spanish by bilingual/bicultural facilitators. Each group met twice for 6-7 hours, and again for a final presentation.
 - Training 1: Background training to select up to 5 photos for making a phototext (including with smartphones)
 - Training 2: Discussed selected photos with the group, made final selections
 - Final presentation of phototexts



Measures and Methods

- **Content analysis:** photovoice content and discussion themes were documented and categorized by staff or by participants.
- **Data from individuals:** existing tools were translated to Spanish
 - *Participant characteristics survey* of demographic and other information
 - *Individual empowerment survey* 25-question personal empowerment survey¹ to assess individual confidence in addressing personal and community challenges (post-program)
 - *Partnership survey* 25-question collaboration inventory² to assess community member and organizational factors for achieving broad goals (post-program)

1. Rogers, E. S., Chamberlin J., Ellison M. L., Crean T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. (1997). Psychiatric Services, 48(8), 1042–1047. <https://doi.org/10.1176/ps.48.8.1042>.

2. Wilder Collaboration Factors Inventory <https://www.wilder.org/wilder-research/resources-and-tools>

SHOWeD Method¹ for Discussion

- Used to facilitate group discussion of each photograph
- Generated themes for summarization of content and discussion

S what do you See here?
¿Qué es lo que ve aquí?

H what is really Happening here?
¿Qué es lo que realmente esta pasando aquí?

O how does this relate to Our lives?
¿Cómo se relaciona esto en nuestras vidas?

W Why does this problem, condition, or strength exist?
¿Porque existe este problema, condición o resistencia?

D What can you Do to educate others about the problem, condition or strength?
¿Qué puede hacer para educar a otros sobre este problema, condición o resistencia?

Figure B: The SHOWeD Method Questions

Participants

- **20 total participants (19 completed the project)**
 - Most were not born in the U.S. but had been living in the U.S. for more than 10 years (2 were born in the U.S.)
 - Ages 18-55
 - 90% female
- **Ethnicity**
 - 16 identified as Mexican-American or Mexican/Chicano(a)
 - 3 identified as Hispanic New Mexican
- **Language**
 - 17 said they speak Spanish “always” (85%)
 - 90% said they think in Spanish “often” or “always”
 - 85% watched Spanish TV “often” or “always”
 - 60% listened to Spanish language radio “often” or “always”

Their Children

- All participants had children with asthma
 - 27 children with asthma, among 36 total children
 - Ages infant to age 18
 - About one-third of the children were ages 5-7 years
- Most (85%) said their children were taking asthma medications. Among those
 - 89% used an inhaler
 - 42% used a nebulizer
 - 16% used pills



Experience with healthcare

- Half (55%) had no medical insurance
- 70% said a doctor had ever talked with them about causes of asthma
- Most knew about common causes of asthma
 - But more than 25% did *not* know that pets, family history, smoke from a woodstove or fireplace, and cockroaches can be risk factors or triggers

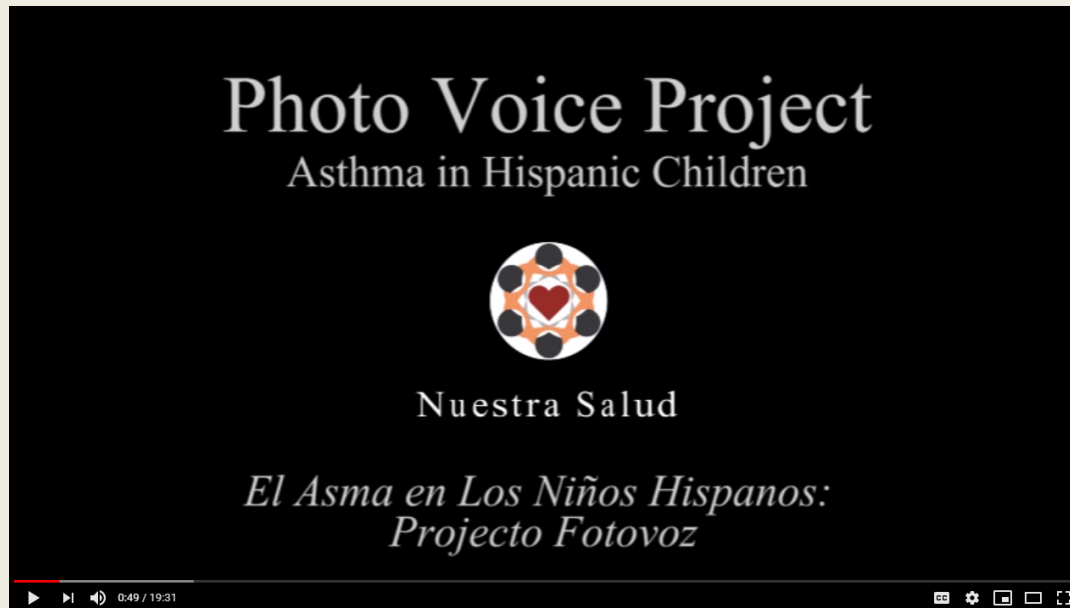


Spanish-speaking Parents of Children with Asthma

***PHOTOVOICE* RESULTS**

Process Results

- 66 phototexts were completed (photo with explanatory narratives)
- Final meetings and presentations of projects took place at the Clovis Public Library (May 2019) and in Farmington at the San Juan College Enlace Family Center (June 2019)
- Each participant received 4 copies of the photobook and an electronic copy on CD to share with families and healthcare providers
- 80 photobooks (print and digital copies on CDs) were distributed in the communities



within YouTube search “Asthma in Hispanic children”

<https://www.youtube.com/watch?v=4z6OvUihafk>

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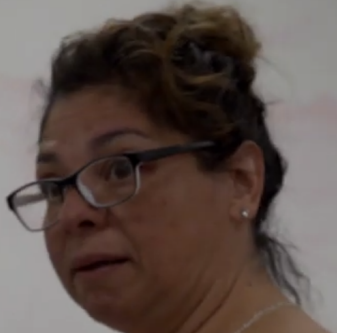
Photo Voice Project

Asthma in Hispanic Children



Nuestra Salud

*El Asma en Los Niños Hispanos:
Proyecto Fotovoz*



My youngest daughter has respiratory issues and a lung problem because of the environment. She's had lung problems since she was tiny – months old. But she wasn't diagnosed with asthma until approximately three years ago.



Lucia
Clovis

These are the notes in my medical record – in my children's medical history. It's there in the record. He was five years old and they were giving him medicine for coughing, coughing, coughing. But he's got asthma.



First of all, informing us, educating us about this illness and its causes, and also giving us the authority or the power to ask questions to the appropriate people... who can bring about change in our community.



Because, as I said last time, you are the ones who know, who are the experts about your lives and about what works and what hasn't worked. We have learned a lot from you.

Photovoice Content

Among the 66 phototexts completed

- Setting: half (52%) were indoors, 39% outdoors, and 3 were inside/outside, and 1 “other”
- 8 concepts that emerged, sorted by rank:
 1. Home adjustments, changes, exposures (n=13)
 - 2/3/4. Hazardous sources, Airborne/respiratory exposures, Pets (n=9)
 5. Nature (n=8)
 6. Physical activity (n=6)
 7. Lifestyle adjustments/limitations (n=5)
 8. Communication (n=1)

Photovoice Topics

The 66 phototexts completed were categorized into three topics

- Objects (47%, n=31)
 - pets, stuffed animals, leaky pipes, train emissions
- Actions (45%, N=30)
 - avoiding using the fireplace, walking to school, cleaning air ducts, medication adherence
- Events (8%, n=5)
 - cotton season, moving to Clovis, being diagnosed with asthma

Results from Individual Measures

- Participants completed 2 surveys at the conclusion of the Photovoice project:
 - Empowerment survey
 - Partnership survey



Empowerment

- Individuals did not feel personally empowered, but did feel empowered in a group
 - **0% agreed** *I can pretty much determine what will happen in my life*
 - **But 100% agreed**
 - *People have more power if they join together as a group* (63% strongly agreed)
 - *People working together can have an effect on their community* (63% strongly agreed)
 - *Working with others in my community can help to change things for the better* (80% strongly agreed)

Partnership and Collaboration

Responses were characterized as the most common given within each the two communities separately

- **Both communities strongly agreed** about group cohesion
 - Group members were trusted, respected, supported participation by all, listened to those who are shy
 - Had a clear sense of roles, common goals, similar ideas
- **Both agreed, but less strongly** about
 - Agencies in the community working together, the general community thinking the group can succeed, having a unique purpose, having enough “people power”
- **Both groups disagreed that they had adequate funds to do what they want to accomplish**

Spanish-speaking Parents of Children with Asthma

PHOTO NARRATIVES & DISCUSSION

Group Discussion



- Participants were very engaged in each other's photo stories, working together to identify solutions to potential problems
- Recurring themes that emerged from discussion included:
 - **Empowerment:** educating themselves, advocating for children (including to others)
 - **Living normal lives:** including taking medication to support this
 - **Finding solutions:** taking action to reduce triggers and risks
 - **Cleaning:** needing to keep environments free of dust and dander, but cleaning products can also be a problem

Caminando a la Escuela (Long walk to school)

CAMINANDO A LA ESCUELA

“Todos los días tenemos que caminar a la escuela 1.5 millas de ida y 1.5 millas de regreso a casa. Para ser exactos lo hacemos en los diferentes climas cuando esta haciendo mucho calor y cuando esta extremadamente frio, cuando llueve y nieva. Mi hija siempre me pregunta si nos podemos sentar un rato para descansar porque siempre se cansa y empieza a tener problemas para respirar luego que se recupera un poco ella se comporta muy valiente y nunca se da por vencida y seguimos nuestro camino.”

“Every day we have to walk to school 1.5 miles one way and 1.5 miles back home. To be exact we do it in the different climates when it is very hot and when it is extremely cold, when it rains and snows. My daughter always asks me if we can sit down for a rest because she always gets tired and starts to have trouble breathing but after she recovers a little, she behaves very brave and never gives up and we continue on our way.”



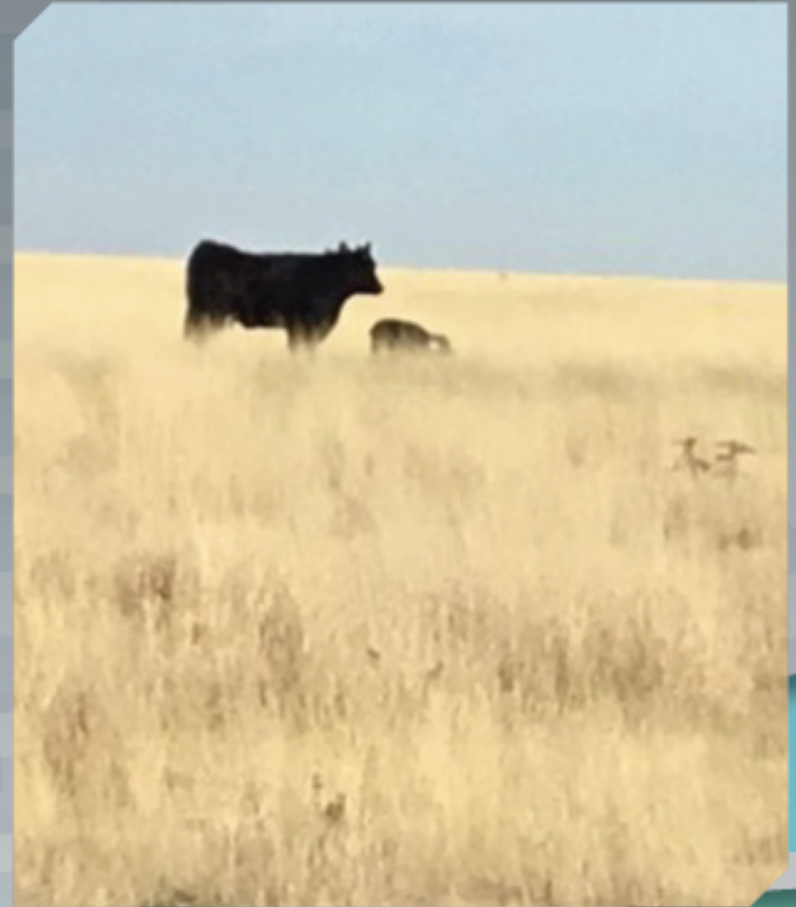
Topic: Action – Long distance walk to school in all climates.

Las Vacas (The dairies)

LAS VACAS

“Esta zona es muy industrial así que hay muchos químicos y materias en el ambiente que nos enferman de las vías respiratorias. Es muy difícil respirar. Siempre tenemos que ir al médico para mejorarnos porque nos dan mucha congestión en los pulmones. Tal vez hasta somos alérgicos a las vacas y ni siquiera sabemos. Es muy difícil saber pero siempre nos enfermamos. Las plantas secas y las vacas levantando el polvo y la tierra son perfectos para que nos den las alergias y el asma.”

“This area is very industrial so there are many chemicals and materials in the environment that make us sick of the respiratory air ways. It is very difficult to breathe. We always have to go to the doctor to get better because the cows cause us a lot of congestion in the lungs. Maybe we are allergic to cows and do not even know. It is very difficult to know but we always get sick. Dry plants and cows raising dust and dirt are perfect for allergies and asthma.”



Topic: Object – Cows in the area cause allergies and put dirt in the air.

El Ducto (Ducts)



EL DUCTO

“Este es el ducto del calenton de mi casa. Y todo lo que se ve alrededor es del polvo que se levanta y se va a todas partes de la casa por ahi. Es muy importante tener los ductos limpios en todo momento porque ese aire que pasa por ahi, es el que respiramos todos en la familia. Ese por seguro es un motivo muy por el que nuestros hijos sufren de asma.”

“This is the heater duct of my house. And all you see around you is the dust that rises and goes to all parts of the house around there. It is very important to have the ducts clean at all times because that air that passes through there, is what all the family breathes. That for sure is a reason why our children suffer from asthma.”

Topic: Object – Heater ducts inside the house;
Action – Keep ducts clean to keep air clean.

El Cigarro (Cigarette)



EL CIGARRO

“Lo peor que podemos hacer, es fumar cerca de nuestros niños, es malo para sus pulmones y causa muchas enfermedades, puede ser mortal para muchas personas y no tenemos conciencia de daño que ocasionamos al fumar cerca de la gente que no fuma. Aparte se quedan las colillas de cigarro tiradas afectando el medio ambiente. El cigarro es malo para nosotros y contamina el medio ambiente.”

“The worst thing we can do, is to smoke near our children, it is bad for their lungs and causes many diseases, it can be deadly for many people and we are not aware of the damage we cause when smoking near people who do not smoke. Also people throw cigarette butts away affecting the environment. The cigar is bad for us and pollutes the environment.”

Topic: Object – Cigarette butts; Action – smoking around children.

Limitations

In terms of how well this project's findings translate to other Spanish-speaking communities, consider:

- Convenience sample
- Representation was largely rural
- Small numbers of people

Conclusion

WHAT'S NEXT?

Recommendations



Photobooks and phototexts can be used by individuals and organizations to educate healthcare providers, funders, decision-makers and community members in a variety of settings, including:

- **Raise provider awareness** regarding the willingness of Hispanic patients to discuss asthma. Because this population uses healthcare fairly regularly, suggest to providers that each visit is an opportunity to discuss asthma self-care.
- With these partners, identify opportunities to **deliver culturally sensitive educational programs or campaigns** for Spanish-speaking Hispanics to be delivered by a Spanish-speaking individual in order to reduce disparities in the burden of asthma.
 - adherence to medication
 - concerns about side effects
 - using long-term control medications even when symptoms are not present
 - reducing triggers or exposure to them in the home or other environments
- **Strengthen school-based support and policies** for Hispanic children with asthma
- **Support anti-discrimination and equity-focused practices in healthcare settings.**

Conclusions

- This Photovoice project had several benefits
 - **Individuals:** Improved knowledge, skills, and empowered Spanish-speaking parents with information about their children's asthma needs. Developed connections with other community members who have common goals.
 - **Public health entities:** Provided data about the current knowledge among Spanish-speaking parents, and tools for talking about asthma with communities, healthcare providers, schools.
 - **Stakeholders working toward Hispanic community health:** Empowered community members who can advocate for and support children with asthma.
- Given the results, a photovoice model may also be useful for
 - Addressing other health topics
 - Empowering other communities or groups (e.g., adolescents)

Thank you!

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