Final Report: *"**Bad Lungs": Capturing the 'lived experience' of childhood asthma among Mexican immigrant families in California's San Joaquin Valley***

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Executive Summary: Nearly one out of five Mexican American children residing in the San Joaquin Valley in 2007 had an asthma attack at some point in their life; a rate much higher than would be expected based on national and international statistics. Compared to other ethnic groups and Latino sub-groups, Mexican-American children reportedly have the lowest rates of pediatric asthma.[1,2,3,4,5] Ethnographic research conducted in the San Joaquin Valley identified some underlying problems and suggests otherwise. This interdisciplinary exploratory study combined anthropological and public health methods to examine asthma disparities, social suffering and environmental policy in the San Joaquin Valley; an area known for its agricultural produce, large Mexican migrant farmworker population, extreme poverty, and poor air quality.

The San Joaquin Valley is comprised of eight counties; seven of which are rural. By combining in-depth qualitative interviewing with photovoice methods, we hope to explicate how asthma disparities are affecting both US and Mexican born children of Mexican decent, as well as address Valet et al's assertion that "the rural experience with asthma in the United States is insufficiently studied".[6] The project both challenges the current pediatric asthma disparities paradigm as described by Gold et al.[7] and contributes to Canino et al's [3] conceptual framework of pediatric asthma disparities.

Many Valley residents believe that their concerns about the relationship between pediatric asthma and environmental stress are being ignored. A great deal of the asthma education and research is currently being targeted to urban communities, ethnic minorities and Latino subgroups other than Mexican Americans. Ethnographic interviews and Photovoice methods were used to explore the "lived experiences" of members in four marginalized rural Mexican migrant communities in the San Joaquin Valley; none of whom received formal asthma education. Photovoice is an innovative public health tool that, when combined with ethnographic interviewing, provides an opportunity for youth to view themselves as the research 'experts'. Through photographs and interviews, participants expressed their concerns about exposure to pesticides and other noxious pollutants that they believe contribute to childhood asthma. Results of the project, including a short documentary, were presented at academic and policy meetings on both sides of the border. It is our hope to provide a sustainable community-based research methodology which will guide local members in the development and transmission of their collective voices to policy makers.

By conducting ethnographic research at the local level and analyzing data provided by the California Health Information Survey, we were able to bring into question both the current asthma disparities paradigm and the applicability of the hygiene hypothesis[8] to this population. In spending time talking with community members and asking for their input, we learned about their deep-seeded concerns and hope to honor our commitment to translate them to those in political power. This project emerged from the results a prior study: Childhood Asthma, Air Quality and Social Suffering Among Mexican Americans in California's San Joaquin Valley: "Nobody Talks to Us Here". [9]

Introduction and Background: Mexican immigration, the "hygiene hypothesis" and childhood asthma in the San Joaquin Valley

Children of farmworkers who are exposed to agrichemicals and other toxic pollutants on a regular basis are a vulnerable and understudied population. Located in central California, the 200 mile-long San Joaquin Valley is one of the most economically depressed regions in the United States, with poverty rates comparable to those found in Appalachia.[10] Close to 20% of Mexican-origin children have been diagnosed with asthma in the San Joaquin Valley, which houses the majority of America's farmworkers. In certain rural counties, the percentage is even higher.

Current research and planning on childhood asthma focus on the needs of urban communities.[11,12,13] (Weiss 2007 854S. The highly controversial ''hygiene hypothesis'' suggests that growing up in a farming environment may confer a protective factor against the development of asthma,[8,14,15,16,17,18,19,20,21,22] and that children residing in urban communities are at greater risk for developing asthma.[23] Rural children, however, tend to have more unmet medical needs and are at greater risk of delayed care.[24]Additionally, there is evidence to demonstrate that "rural US populations with a large proportion of minority or low-income residents seem, to the contrary, to have an exceptionally high prevalence of asthma".[6 p1221]

The 'precautionary principal': Time for a new paradigm?

Access to clean and healthy air should be a basic human right, and respiratory health is essential to the functioning of the entire body. Many countries have adopted the 'precautionary principle' under which paraquat has been banned in the European Union since 2007.[25] Duderstadt states that: "under this principle, communities with populations living in areas with exposures to chemical pollutants suspected to cause harm can argue for temporary suspension of use or elimination of production of chemical substances until absolute proof that the chemical is not associated with adverse health effects." [26] Paraquat has long been considered a harmful substance. Nevertheless, through the combination of ethnographic inquiry and photovoice, we discovered that paraquat is commonly being stored near the houses of and being applied by agricultural workers in the San Joaquin Valley without prior notification to community members.

Air quality and the San Joaquin Valley

Air quality is not uniformly distributed throughout the San Joaquin Valley. Counties with large pockets of Mexican immigrants tend to have worse air quality than others. Contributing factors may include the presence of highway traffic; dairies; toxic waste dumps and 'recycling centers'; burning of agriculture waste, and exposure to agrichemicals. The World Health Organization lists air pollution as *one of the strongest risk factors for developing asthma* (emphasis added). It was recommended that "primary prevention be addressed to reduce the level of exposure to common risk factors, particularly… air pollution".[27] In an epidemiological study on outdoor air pollution and uncontrolled asthma, Meng et al observed that ozone and particulate matter are associated with frequent asthma symptoms and hospital visits for children in the San Joaquin Valley.[28]

Environmental health inequalities and disparities

Marginalized populations tend to be exposed to environmentally hazardous facilities and are subjected to environmental health disparities.[24,29] Because of their small size, children absorb environmental toxicants into their lungs at a much higher rate than do adults.[30] Carter-Pokras et al. note that "physiologic and behavioral factors that place all children at risk from environmental exposures are compounded for Latino children by social, economic, cultural and political factors. As a result, Latino children are at greater risk of morbidity and premature death from such conditions as asthma…"[31]

The economic burden of poor air quality and childhood asthma

Bahadori et al cite that the increasing economic burden associated with asthma is ranked as one of the highest among chronic diseases.[32] Hall et al estimate that 141,370 asthma attacks could be prevented by meeting the federal standards of air quality in the San Joaquin Valley. They predict that ''the cost of air pollution…translates into a total of nearly $6 billion [per year] in savings if federal ozone and PM2.5 standards were met''.[33]

Childhood asthma, social suffering and poor air quality in the Central Valley: A Mexican-American paradox or just bad air?

This research addresses and challenges the current asthma disparities paradigm, which suggests that "for reasons yet unknown, the prevalence rates are generally reported to be lower among Mexican Americans".[34] Lara and colleagues' analysis reveals marked differences between the highest rate of lifetime asthma prevalence and recent asthma attacks among Puerto Rican children (26 percent and 12 percent, respectively) and the lowest rates among Mexican American children (10 percent and 4 percent, respectively); reflecting a disproportionate burden among Puerto Rican children. First-generation Mexican American children were reported to have lower prevalence, incidence, hospitalization, and attack rates than other ethnic groups, including those within Latino subpopulations. According to Lara's study, being born outside the United States to foreign-born parents was associated with greatly reduced odds of receiving an asthma diagnosis.[4] In the Valley, 90 percent of Mexican American children were born within the United States; which might contribute to the high prevalence rates[35]. Why U.S.-born Mexican American children have higher rates of asthma than those emigrating from Mexico is not clearly understood but is being explored**.**[33] Social factors, including lack of resources, language barriers, long working hours, and fear of deportation, may lead to less utilization of clinic services by parents of Mexican-born children and thus account, at least in part, for lower rates of diagnosis in this population. Other factors, such as not having a listed telephone number or not accepting or understanding their child's diagnosis of asthma, may be contributing factors to underreporting in telephone surveys, as well.

Another study notes that Mexican American children have one-quarter the asthma mortality rate of Puerto Rican children and the lowest asthma mortality rates of *all* ethnic groups included in the study (9.2 per million).[3] This finding seems enigmatic given that Mexican Americans have higher rates of poverty than Puerto Ricans and less access to health care (ibid.). As reflected in the national analysis, Mexican children were more

likely than any other ethnic group to be uninsured, have parents with less than a high school education, and to have no usual source of health care.[4] Why large discrepancies exist between the Puerto Rican and Mexican American asthma rates is not understood. However, if based on the statistics generated by large data bases, programs directed at the Mexican American population are less likely to be funded – and in fact be cut -- since these national databases overlook specific local populations and obfuscate the urgency of addressing health issues of local populations that have thus far been ignored.

Children living in the San Joaquin Valley report some of the highest rates of childhood asthma in California.[34] An estimated 3.85 million children in the US have current doctor-diagnosed asthma, with an overall prevalence rate of 6.7%.[36] Twenty percent, or 95,000 US-born Mexican-American children in the San Joaquin Valley aged 2 to 17, were reported as having been diagnosed with asthma—more than double the national lifetime prevalence of 7.8% cited by Rodriguez et al for Mexican American children.[34,35] In one county in the San Joaquin Valley, the lifetime prevalence of diagnosed asthma reached 37% for US born Mexican American children between ages 2 and 17. Compared to recent data from the International Study on Allergy and Asthma in Children (ISAAC), this mounts to what might possibly be one of the highest prevalence rates in the world.[37] We suspect that for a variety of reasons, including undocumented immigration status, many more children are being undiagnosed, uncounted and untreated.

Asthma and Poverty

An epidemiological study conducted among school children in Chicago showed that income was "significantly and inversely" associated with asthma diagnosis; as were some of its salient consequences, such as missing school, visiting the emergency room, being hospitalized, taking medication, and having wheezing severe enough to interfere with speech or sleep.[38] Asthma patients admitted to hospitals with acute symptoms tend to be economically disadvantaged[39] and poor children in the US have been found to be at higher risk for severe activity limitation, and relative underuse of ambulatory health care[40]. Despite the urgent need to increase funding to address issues associated with childhood asthma for underserved populations, the two major programs providing asthma education outreach to the Spanish-speaking community in the San Joaquin Valley recently lost their funding. [41]If advocacy for this problem is going to evolve, it is going to have to do so directly from within the community.

Latino children are the largest racial/ethnic minority group in the United States. The Pew Hispanic Center estimated an unauthorized migrant population of up 12 million persons as of March 2006; the highest proportion of which are believed to reside in California.[42] The Central Valley, known for its agricultural produce, extreme poverty, and poor air quality[43]**,** is a magnet for the Mexican immigrant farmworker population and their families. Close to eighty percent of children of immigrant parents in the San Joaquin Valley lived in households with incomes below 200% of the federal poverty level; double the percentage of children of US-born parents.[44] Of these, many children are food insecure, going without enough food to eat. In Kern County, one of the selected study areas, over half of the Mexican-origin households with incomes below 200% of the federal poverty level reported experiencing food insecurity.[34]

Activities

The co-PIs from COLEF conducted more than 30 semi-structured, in-depth interviews in the language and venue of the interviewee in four key communities: Plainview, Planada, Arvin and Lamont. A site visit was made to Fairmead; which is located in close proximity to the highly trafficked Highway 99. Community members omplain about the noxious odor from a nearby garbage dump; of which we took photographs. Approximately 21 families and 10 professionals participated in at least one interview. Multiple interviews were conducted with key informants. Families were compensated once with a $25 gift certificate. Professionals were not compensated.

A short documentary film directed by independent filmmaker, Owen Palmquist, followed over a period of four months and included numerous families and professionals attending the asthma education camp. Each participant was required to sign a consent form and photo release form provided by the filmmaker. Filming was conducted in Planada and Yosemite Ridge asthma camp and with professionals in other sites, including Fresno, San Francisco, Merced County, Kern County and Yosemite Film participants were not compensated unless they participated in a semi-structured interview.

Seven families participated in Photovoice projects that were conducted in Plainview and Kern County.

In consultation with statisticians at the California Health Interview Survey (CHIS), we were advised of the difficulty of analyzing data associated with the small sizes of the communities we are studying. We therefore decided to concentrate our efforts on in-depth ethnographic interviewing, filming and Photovoice. We were able to retrieve salient statistical data on the county level through the CHIS data bank, which helped us identify the key communities in which we conducted our ethnographic data collection.

Study Methods

Participatory photography empowers people.
Nick Danziger; PhotoVoice.org

The study employed traditional ethnographic and community-based research methods to explore the intersection between anthropology and public health in relation to childhood asthma disparities, social suffering and environmental health policy. Specifically, the research question explores the "lived experiences" of marginalized rural Mexican-origin families living in communities dealing with a combination of poor air quality and childhood asthma; which we designated as 'hotspots'. Each of the chosen communities is situated in a county rated as one of the Top 10 Most Ozone Polluted Counties in the Nation in 2007 by the American Lung Association. The project aims to bridge the gap between community members and policy makers by using methods designed to diagnose specific problems and give expression to family members to have their voices heard.

In-depth ethnographic interviews and the construction of grounded theory

Ethnographic interviewing has value for investigating complex and sensitive social issues, allowing the researcher to describe phenomena in great detail in "the original language of the research participants".[45] In-depth, ethnographic interviewing and observation allows time to build trust and 'presence' in the community, and to develop a base from which to collect culturally relevant data. Having already built that trust over a number of years, we decided to concentrate on highest risk communities and to include those spokespersons who have not been included in previous studies.

In-depth, semi-structured interviews were conducted in four designated 'hotspot' communities between April 2009 and June 2010. These were supplemented by interviews with medical professionals and community advocates in Plainview, Planada, Arvin and Lamont. A site visit and photography expedition was made to Fairmead; a community subjected to the diesel fumes of the highly traveled Highway 99 and the noxious odor from a nearby garbage dump. Semi-structured interviews adapted from Kleinman's explanatory models of chronic illness[46], were conducted in Spanish or English and included a policy question along the lines of: "If you could make one statement to a policy maker about how your community's situation could be improved, what would it be?" By providing cameras to selected study participants, we hoped to further capture their lived experiences in a manner that would not be possible if the researchers were present. The results were astounding.

A local, bi-lingual project co-ordinator who was familiar with each of the communities, as well as with community leaders and professionals throughout the San Joaquin Valley, made initial introductions for both the Photovoice project and in-depth interviews. Interviews were also conducted at the Yosemite Ridge asthma camp and were filmed by the independent filmmakers.

Study Sample

A purposive-snowball sample was constructed to include families and key participants in the selected communities and representatives of the San Joaquin Valley. Photovoice projects traditionally include fewer than 20 participants (cite) and participation is based on interest. Participants were recruited through flyers and word of mouth.

Inclusion Criteria

- ***Photovoice***
  - Self-described as Mexican-American or of Mexican-origin *and*
  - Member of selected medically underserved farming community *and*
  - Child between 6-18 years of age with diagnosed asthma or resident of county with greater than 20% asthma prevalence *and/or*
  - Parent of child with diagnosed asthma or at-risk for asthma

- ***In-depth ethnographic interviews***
  - All of the above *or*
  - Key community member; local level or higher elected official or staff; farmworker supervisors (mayordomos); farm owners or representatives; agribusiness representatives; NGO representatives; clinicians.

Entrée was established through prior contacts and by hiring local bi-lingual staff members. Interviews and observations were conducted in public and private settings including but not limited to: homes, agri-fields, grocery stores and corner markets, churches, clinics, schools, elected official's offices, parks, and an educational asthma camp. Photovoice training took place in a public setting or private home.

Photovoice

Photovoice is an interactive process that allows marginalized communities to express their points of view to target audiences through the combination of photography and grassroots social action. As a participatory action research strategy it has been used globally and combines well with grounded theory.[47] It has been used as an effective, ethical tool with youth and vulnerable populations as a means to enable them to express their concerns to policymakers.[48,49,50,51,52] The primary goals of Photovoice include "enabling people (1) to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about personal and community issues through large and small group discussion of their photographs, and (3) to reach policy makers".[53] The project engaged children aged 8-17 and their parents in two farmworker settings with particularly high prevalence rates of asthma, low socioeconomic status and poor air quality. The communities were chosen, in part, to participate in the Photovoice project based on the interest of the community and entrée through a team of local, bi-lingual project co-ordinators. Seven parent-child dyads were guided specifically to photograph and document their indoor and outdoor environments and to record assets and challenges to their daily lives.

Photovoice and community-based participatory research

As a community-based participatory research strategy developed by Caroline C. Wang and Mary Anne Burris, Photovoice offers marginalized communities members the opportunity to document the strengths and concerns of their community in an effort to make them known to policy makers. [52] According to Wang and colleagues, "Photovoice entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for social action and change in their own communities." It gives voice to members of any age group, allowing them to identify and describe their community's unique problems and assets related to a particular topic. Photovoice has been used as an effective, ethical tool with Latina immigrant youth[54] and vulnerable populations as a means to enable them to reflect on and document their communities' assets and concerns and critically discuss their photographic images with policymakers and the public.[55,56,57] In line with the concept of community-based participatory research, the photovoice methodology includes the involvement of young people in all aspects of the research. [58,59]

Photovoice has yet to be fully employed by medical anthropologists and is especially appropriate for exploring the social suffering and consequences for immigrant families and communities coping with abnormally high rates of childhood asthma and exposure to agrochemicals and other pollutants. There is as yet, no published photovoice data that include farmworker families or children with asthma. Photovoice projects are traditionally conducted in partnership with local non-profit organizations. Anthropologists are trained to work directly with communities while conducting field work. Due to the sensitive nature of immigration status, undocumented workers may be reticent to participate in a research project or request services provided by non-govermental organizations. Rather than relying on organizations to establish contact with participants, we used a snowball referral technique and asked participants to refer us to other families of children with asthma. While we encountered many challenges in locating and retaining participants, we encountered no refusals to participate.

Participating children and their parents took photographs of places and/or things that support or are barriers to active living and healthy breathing. Community members were recruited with the hopes of breaking through the 'silence barrier'. The number of training sessions typically ranges from 2-20. Strack suggests that the best participation occurs with long-term involvement in the community[47]; this was designed to be a long-term, ethnographically-informed project. However, the number of training sessions is decided by the participants and only two training sessions were held in each community.

Limitations and challenges encountered include: parents' work schedules; children getting sick; loss or damage to cameras; families moving, and distance and travel of the investigators to the researcher sites. These issues were addressed by establishing flexible research times; purchasing and replacing inexpensive disposable cameras; hiring local bi-lingual project co-ordinators. The principal investigators from Mexico visited each site and conducted all ethnographic interviews in the communities as well as the asthma camp. Adult participants had the option of participating in either photovoice, open-ended interviews or both.

Although fewer than five meetings were held, five photo assignments were proposed and discussed with participants, dependent on their age, interest and ability to comprehend the assignment:

1. What is it like to be a farmworker/child of farmworker living in your community?
2. What are some issues associated with air quality in your community? (Probe pesticides, dairies, cars, indoor smoke/pollution…)
3. What are some issues associated with childhood asthma in your community? (Probe access to health care, stigmatization…)
4. What is the relationship between asthma and air quality in your community?
5. What are some solutions to issues brought up in earlier assignments? (e.g., organic farms, indoor play areas…)

Recruitment and training of photovoice participants

Recruitment of participants was conducted through word-of-mouth and distribution of a printed flyer in English and Spanish and in partnership with local community-based organizations. Both youth assent and parental/guardian consent was required. Participants then attended an initial orientation/training and follow-up meetings that were facilitated by the photovoice leader. The two-hour orientation included an

information section on what photovoice is, and the purpose of the project. Training addressed ethics of photography, discussion of consent forms, instructions on taking pictures and the six questions the students answered to assess their photographs. Cameras were then supplied to those participants who provided the orientation/training facilitator their Participant and Photograph Permission Form, with its required signatures. The participants were given a time period of two weeks in which to take photos of the aspects of their environment that are seen to contribute to the occurrence of asthma or its prevention. Once the two weeks had passed, the cameras were collected and pictures developed by project staff. The facilitator will then met once again with the participants to allow them to choose three photographs and answer the six questions about each of the three chosen photographs. The questions include:

1. What do you see here?
2. What is really happening?
3. How does this relate to our lives?
4. Why does this problem or strength exist?
5. What can we do about it?
6. What are your feelings toward this photograph?

Participants discussed their findings and possible solutions in small groups and reported back to the whole group. The facilitator then collected the chosen photographs and the written narratives and printed them in poster size, developing one poster for each participant that included all three images and their corresponding narratives. The next step in the project will be to involve the project participants in the presentation of the posters back to community members, organizations and policymakers in the form of a community event.

The children focused on taking photographs of the environment as much as possible. Images involving people were taken from afar and do not include clearly identifiable facial images. No pictures involving community people were taken at close range. To avoid other safety problems, children were advised to take pictures while with others, during the day, and in areas in which the child feels safe.

Photovoice makes it possible to learn from the social actors' experience, their perception of how the environment may impact their health; which may differ from the researchers' perspective. This information may be used in conjunction with scientific data to help determine environmental and policy interventions for the affected participating communities.

A professional photographer from El Colegio de la Frontera Norte consulted on the project and assisted with the final presentation. All recorded material is in the process of being transcribed and translated and analyzed using Atlas.ti to construct the grounded theory. The Co-PIs will be responsible for all published material. Audio and video recordings are being transcribed verbatim and a body of raw data created and subjected to grounded theory analysis. The PIs will supervise the analysis of data using the descriptive coding scheme developed by Strauss and Corbin.[60,61]

Internal Review Board Approval and Confidentiality

The project was approved by the Internal Review Boards of El Colegio de la Frontera Norte and California State University, Fresno. Confidentiality was guaranteed for all participants and original recorded and written data kept locked and coded to protect confidentiality. Written consent was required of each adult participant and verbal consent of each child. Participants of the film were required to sign a separate consent form provided by the filmmakers. A professional photographer will delete all identifying information from photographs. Participants with questions were referred to the Committee on Human Research at California State University, Fresno.

Results: Childhood Asthma and Air Quality: An Ethnographic Perspective

> *Executive Order (EO)13045, Protection of Children From Environmental Health and Safety Risks [signed in 1997], directs each federal agency to ensure that its policies, programs, activities, and standards address disproportionate environmental health and safety risks to children.*[62]

> *The air is not clean because of all the pesticides… I have to breathe all this… I feel bad because it makes me sick… (8 year old Photovoice participant, Juan; 2009)*

Migrating can be a difficult and complicated process for healthy families. For families of children with chronic illness, the experience can be devastating. This project explored the "lived experiences" of recent immigrant and established families in the San Joaquin Valley dealing with childhood asthma, including their cultural perceptions of the relationship between asthma and the environment. Children of immigrant families in the San Joaquin Valley are economically disadvantaged and may be underdiagnosed for asthma due to lack of access to care. Little ethnographic research has been conducted on the management of childhood asthma among the population of Mexican migrants and little is known about the rich cultural beliefs and daily activity in the homes of families of children dealing with this illness.[63,64,65] Even less is known about the families' experiences surrounding the development of asthma in their children and the onset and reaction to acute episode of it.

Many parents expressed concern that children are being unduly exposed to pesticides and that their requests to be notified when overhead spraying takes place are being ignored. Through providing cameras to children and their parents, we discovered that children play in the adjacent agricultural fields and eat pesticide laden fruit directly from the fields without washing the fruit. Plainview, a small community consisting of approximately four square blocks is surrounded by agricultural fields and has no playground; thus children are forced to use the surrounding fields as a playground. This was first uncovered through responses to open-ended, in-depth interviews. The information was substantiated through photographs taken for the Photovoice project. At the completion of the Photovoice project, we contracted with independent filmmaker,

Owen Palmquist, to produce a short documentary. The film recorded children in Plainview playing the agricultural fields and the streets, as well as children in Planada attending asthma camp, visiting Yosemite National Park, and playing in their home town. Interviews for the film were conducted with parents in both communities and in asthma camp; as well as with professionals.

The general perception among professionals is that poor air quality due to particulate matter and pesticide exposure is a contributing factor to childhood asthma in the San Joaquin Valley. This corroborates with the current literature on the relationship between particulate matter and asthma. It is also a concern of clinicians that asthma is being underdiagnosed and undertreated.

Analysis

Analysis of semi-structured interviews is being conducted using the coding system as described in grounded theory by Strauss and Corbin (cite). Open coding is used to identify, name, categorize, and describe phenomena found in the text. Emergent cultural domains and themes informed by ethnographic and Photovoice data include:

- *Environmental justice and air quality*:
    - pesticide exposure at home, school and play
    - preventive measures: keep children indoors; change work clothes
    - perceived etiology: geology of valley; agrichemicals; diesel fuel; dairies; agricultural burning
    - lack of knowledge of specific pesticides and chemical substances; names of landowners
- *Policy requests*
    - inform community when spraying is to take place
    - establish safe play environment for children
    - provide nebulizers so that parents do not have to rely on urgent care
    - regulate burning of trash and location of dairy farms

- *Access and barriers to care*
    - cost; distance to clinic; clinic hours; cultural sensitivity and language; fear of deportation; availability of culturally appropriate low-literacy educational material; affordable medications; transportation; inability to request time off from work
- *Goals, opportunities and expectations*
    - *Educational goals and opportunities for children*

Tulare and Merced Counties: Plainview and Planada

> *I would like it if they did not put…a lot of pesticides next to my school…so I won't get sick (8 year old, Juan; Photovoice participant 2009).*

Disposable cameras were distributed to a total of seven parents and children with asthma in Plainview for the Photovoice project. The participants were given specific instructions to photograph and comment on their living environment in relationship to childhood asthma. Results of the combined Photovoice project and in-depth interviews revealed that community members are 1) aware and concerned that exposure to pesticides can have a negative effect on respiratory health; 2) unfamiliar with the names of the pesticides being used (but photographed the storage of pesticides, with the name of the pesticide and the manufacturer on the bags); 3) familiar with precautionary measures needed to protect themselves and their children from pesticide exposure, but not always able to afford the recommended protective clothing; and 4) not familiar with the names of the land owners; nor have they ever had an opportunity to discuss their concerns with them. Housing conditions, for most part, could be considered fair to poor. This community's greatest concern is that children are being exposed to pesticides during the day while in school or playing outside in the fields or the street. Children are also aware of and concerned that pesticide exposure is related to asthma. Their request to policy makers is that they be informed of the pesticide spraying schedule.

Five children from Planada attended the Yosemite Ridge asthma camp in Wawona, California. In-depth interviews and filming with families and professionals for the documentary were conducted before, during and after camp. Additional film interviews were conducted with staff and attendees of the camp. All individuals and/or their guardians were required to sign permission forms prior to being filmed or interviewed. Eleven children under the age of 18 and 25 adults, including professionals, were interviewed for the documentary.

We found a wide disparity between levels of health care which may be related to immigration status and length of time spent in the United States. For example, one long-term, English speaking resident who works in a nearby clinic as a medical assistant had her three year old son demonstrate how he uses a $50 nebulizer which was provided by

Medi-Cal. Even though she is concerned about overhead spraying of pesticides, regular nebulizer treatments helps keep her son's symptoms under control. However, for a low-income, newer Spanish-speaking resident without access to health care coverage, controlling her child's asthma is proving to be more difficult. She was told by an emergency room physician to bring her child to the emergency room for care when she is ill; thus resulting in more costly treatment, as well as less effective medical treatment.

Kern County: Arvin, Lamont and Bakersfield

Kern County has some of the worst air quality in the nation and houses many migrant workers from the poorer regions of Mexico. Half of the Mexican-origin children living below 200% of the poverty line reported food insecurity –e.g. going to bed hungry—on the 2007 California Health Interview Survey[34]. The Photovoice project was introduced to family members in Kern County by way of a local non-profit organization. To-date one completed assignment has been returned, with results complementing and contributing to those from Plainview. By photographing cows near their home and the remains of agricultural burning, this family has expanded our visual knowledge of the sources of concern for those exposed to such environmental irritants. In response to the question about what the mother would like to communicate to policy makers, the mother said that she would like the cows to be moved away from her living environment.

On a fieldtrip to Kern County, Dr. Schwartz conducted in-depth interviews with five families in Arvin and Lamont—two popular migrant communities. Four representatives from three NGO's were interviewed during this trip: Race, Poverty and the Environment, Head Start and the United Farmworkers. She also photographed the nearby garbage dump and 'recycling center'; both of which make the air extremely unpleasant to breathe. One of the interviewees in Lamont confirmed our findings from Plainview that children play in the agricultural fields where pesticides have been applied.

Local sources of air pollution, include agrichemicals, noxious waste dumps, bovine pollution, illegal burning of agricultural trash, and that generated by trucks on the heavily traveled highways that weave their way through the Valley. In addition, pollution from Los Angeles and the San Francisco Bay Area gets trapped by the cloud covering of what residents of the San Joaquin Valley have deemed 'a bowl with a lid on top.' Residents of Lamont, Kern County, a heavily contaminated farming community located at even lower altitude that other parts of the valley, describe living in a 'bowl within a bowl'. The living conditions according to one mother are 'unbearable'.

Participants of the Photovoice project captured their concerns on film, including a nearby dairy and the residue created by burning of agricultural waste. They articulated that they would like the burning to be better monitored and the cows to be moved further from their home. The interim director of Race, Poverty and the Environment expressed concern that current child protective environmental policy is not being implemented well; thus putting vulnerable children at risk of environmental illness.

Conclusion and discussion

We explored in great detail the lives of families living in farmworker communities where the rates of childhood asthma are reported to be 25 percent or greater. We challenge the current paradigm of asthma disparities, which suggests that children of Mexican-origin are at low risk for asthma in comparison to other ethnic groups and Latino sub-groups; and we question the applicability of the hygiene hypothesis to children in farming communities who are exposed to agrichemicals and other air borne toxicants on a regular basis. Further, we suggest that existing child protective environmental policies, such as Executive Order (EO)13045, the Protection of Children From Environmental Health and Safety Risks, need to be implemented and better monitored.

In-depth ethnographic interviews conducted during a prior exploratory study in the San Joaquin Valley revealed the nature of social suffering related to high rates of childhood asthma and the context in which it occurs.[9] There was a general feeling among those interviewed that their health needs and the causes of the health problems are being ignored by policy makers. Community members have expressed concern about the lack of communication. Said one mother in an isolated rural community of new immigrants in Tulare County, "Nobody talks to us here; we're too rowdy". The desire to return to Mexico is overshadowed by the need to stay in the United States, "Here, we have Medi-Cal; but our children were healthier in Mexico", said another mother. An immigrant store owner in Merced County displayed the infected arm of his young son and asked the investigator to spend a summer in the field in order to observe the overhead night spraying of pesticides. He described a situation in which the house shook in the middle of the night and he covered the faces of his young children with wet cloths in order to prevent them from inhaling the pesticide residue.

For the current project, we followed up on these results by providing families with cameras, photography lessons and journal material that allowed for the first hand documentation of such poignant lived experiences. We also conducted in-depth ethnographic interviews and observations in selected 'hotspots' of farmworker communities with combined high rates of childhood asthma and poor air quality. Interviews were conducted with family members, community leaders, directors of non-profit organizations. One family was followed in greater detail and featured in a short documentary. The parents, farmworkers who were born in Mexico, never had asthma or breathing problems. At the current time, two of their four children have asthma, and they are uncertain about whether the youngest child—still a baby—will develop it. There concerns and fears reflect those of many of the families we came in contact with on our journey through the San Joaquin Valley.

Presentations and Future Plans

The results of the Photovoice project and in-depth interviews conducted in Plainview were presented at the Annual Meeting of the Society for Medical Anthropology, Yale University in October 2009 and at the monthly meeting of ReformHealthCare.org. An updated Spanish version of the Photovoice project, along

with a ‘premier’ showing of the documentary, was presented at the Colegio de la Frontera Norte in June 2010.[66] (See attachment).

Drs. Schwartz and von Glascoe have applied for funding and are awaiting the results from the National Institutes of Health and hope to apply for future funding from PIMSA to analyze statistical data and continue conducting ethnographic research with policy makers. We are in the process of writing a scholarly paper and expect to publish our findings in a journal of medical anthropology.

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