Coccidioidomycosis in Children

Erin Gaab, Ph.D.
Focusing on youth...

Children with Coccidioidomycosis: Preliminary Findings & Reflections

Erin Gaab, Ph.D. (Health Psychologist)
Understanding Children with Cocci

- What is coccidioidomycosis?
- What is HSRI doing about cocci?
- How do families cope with chronic illness?

- What is qualitative research?
- How do families cope with cocci?
- What can we do now?
What is coccidioidomycosis?

- Caused by inhaling a fungus that lives in soil
- Manifests differently in different people
- There may be a seasonal pattern for developing the disease.
- Affects several types of mammals
- Can affect anyone, especially people of certain ethnicities and health statuses
Life cycles of Valley Fever

The fungus that causes valley fever (Coccidioides immitis) grows one way in the ground and another way in an infected person or animal.

1. Valley fever fungus grows in dry, sandy soils in parts of the Southwest.

   - The fungus grows in hair-like structures called Mycelia that are microscopic chains of live and dead cells. As they grow, the dead cells break loose and become wings on the live cells.

2. Living fungal spores take flight.

   - Wind and other disruptions release the spores into the air. The spores' wings allow them to travel long distances.

3. Once airborne, the spores can be easily inhaled.

   - In the lungs, the spores change form once more. They become balls called spherules. They are filled with baby spherules that are released and reproduce in the same fashion. The growing fungus can fill the lungs, causing infection, pneumonia and other problems.

Groups at higher risk of severe infection from valley fever:
- Pregnant women
- African-Americans, Filipinos
- HIV, Hodgkin’s disease and Lymphoma patients
- Diabetics and people with organ transplants
- People undergoing adrenal corticosteroid therapy

Common symptoms of valley fever:
- Fever
- Cough
- Chest pain
- Fatigue
- Shortness of breath
- Chills
- Muscle and joint pain
- Night sweats
- Lack of appetite and weight loss

http://tjgardendotcom1.files.wordpress.com/2012/12/life-cycle-of-valley-fever.jpg
Fungus-ball cavities in lung
A giant cell in a granuloma containing typical intact spherule of *C. immitis*
150,000 INFECTIONS OF VALLEY FEVER OCCUR IN THE SOUTHWESTERN U.S. EACH YEAR

VALLEY FEVER CENTER FOR EXCELLENCE AT THE UNIVERSITY OF ARIZONA

http://www.scaryair.org
Happiness is rolling in the sand without a fear in the world.

Bingo's Big Adventure
(Bingo the cat is my best friend)

http://2.bp.blogspot.com/-g4w0M1RTfM/U2yOoJDR8-I/AAAAAAAAoeI/YDtuvWd10aE/s1600/Lucky%2Brolling.jpg
Figure 1: Timeline of Valley Fever events

1940
1950
1960
1970
1980
1990
2000
2010

1938
Dr. Ernest Dickson presented his coccidioidomycosis research to the Society of American Bacteriologists.

1948
Coccidioidomycosis outbreak reported to the public in the “Toledo Blade.”

1955
The bumps (lesions caused by Valley Fever) are reported in Southern California and spreading near military camps.

1969
Immunity considered by the US as a potential biological weapon.

1970
Pharmaceutical company discovers Nikkomycin Z.

1977
A freak windstorm in the San Joaquin Valley is suspected of creating an outbreak of Valley Fever in north of the usual endemic area.

1979
A Sea Otter is the first free-ranging marine mammal reported infected in San Luis Obispo, CA.

1982
Sponsor provides $300,000 for Valley Fever vaccine testing.

1990
Fluconazole (pill) causing less side effects is released to the public.

2000
Pharmaceutical company developing Nikkomycin Z fails.

2005
University of Arizona acquires the program for developing Nikkomycin Z with NIH and FDA funding.

1990
AIDS patients and “people with darker complexions” such as Filipinos and Hispanics identified as at-risk groups.
Recent Attention from the Media

- “Just One Breath” series
- Interest of Congressman McCarthy

Why does HSRI care?

- This is our region, community and responsibility
- HSRI seeks to “establish new and strengthen existing interdisciplinary research partnerships across all levels of the university and with community partners.”
  
What is UCM’s HSRI doing about coccidiomycosis?
CA Valley Fever Initiative:

- Connect researchers, healthcare providers and community members in California’s Central Valley to tackle Valley Fever issues.
- Initiate and support research projects which focus on the prevention, detection, diagnosis and treatment of coccidioidomycosis (Valley Fever).
- Disseminate research findings and educational efforts into the community.
HSRI’s Meetings to Date

- December, 2013 – Children’s Hospital Central California’s call for action on Valley Fever research at UCM
- June 29, 2013— Valley Fever Researcher Meeting at UCSF Fresno (35 researchers from SJV)
- November 9, 2013—Valley Fever Community Conference at UCSF Fresno (70 researchers, advocates, and organizations from CA and AZ)
- February 19, 2014— UCM Board of Trustees Meeting for community support
- March 12 – now— UCM Valley Fever Seminar series
- April 5, 2014— ASU’s 58th Annual Cocci Study Group
November 9, 2013 Meeting Panel Discussion

Some of the Advocates & Representatives...

Sharon Filip & David Filip,
Founders of ValleyFeverSurvivor.com
Authors of "Valley Fever Epidemic"

Vince Fong,
District Director for Congressman Kevin McCarthy

Jessica Einstein,
Valley Fever Americas Foundation

Terry Majewski,
American Cultural Resources Association President

C. Bryan Little,
Director, Labor Affairs, California Farm Bureau Federation
HSRI’s Goals:

- Organizational
- Biomedical
- Public Health
- Treatment
- Advocacy

http://eecs.campuscms.ucmerced.edu/sites/eecs.ucmerced.edu/files/images/eecscampuspano1600.jpg
Goal: Organize for Action

- Maintain network of Valley Fever researchers.
- Develop and maintain website.
- Coordinate development opportunities (including mobile BSL 3 lab and spore count monitor to enhance our research).
- Organize and publicize speaker series.
- Coordinate grant opportunities.

https://www.youtube.com/watch?v=wahHlqXWmEo
Goal: Biomedical Research

- Support research of the host response and risk and organism diversity (genomics and virulence) to identify risk factors for disseminated disease.

  https://www.youtube.com/watch?v=wahHlqXWmEo

- Identify patterns of airborne exposure to the airborne (UC Berkeley), soil (CSU Bakersfield) and PCR (UCSF) studies.

- Make links with veterinary researchers.

- Write an article to illuminate Valley Fever in a biomedical journal.
Fresno research leads to speedier Valley fever test

BY BARBARA ANDERSON
The Fresno Bee  March 22, 2014

Doctors in the San Joaquin Valley have a new, fast way to help diagnose Valley fever using a test developed in a Fresno hospital laboratory.

The new DNA test for the fungal disease — a first in the state — can provide results in five hours instead of the two-plus weeks it now takes for a blood or culture test.

The sooner patients with Valley fever can be diagnosed and receive treatment, the better, doctors say. The disease can spread from the lungs, causing meningitis and other problems — and can be fatal. There is no cure, but drugs can prevent the infection from growing.

Until now, a doctor who suspects a patient has Valley fever would order a blood test. If the test is negative, the doctor would order another blood test. If the first test was positive, the doctor would order a culture test. If that test is negative, the doctor would order a third test.

http://www.fresnobee.com/2014/03/22/3837700/fresno-research-leads-to-speedier.html
Goal: Treatment

- Establish a collaborative relationship with the study team at the NIH and CDC clinical trial to enhance the study design.
- Develop network of providers.
- Develop tissue bank.
- Write and overview of the state of Valley Fever to date and an article with PH directors about their recommendations.
- Survey healthcare providers to understand current treatment protocols being followed.
- Collaborate with UCSF to analyze the Burden of Disease caused by Valley Fever.
Goal: Public Health

- Examine what happened in Lyme, Connecticut for public health campaign ideas.
- Survey healthcare providers to understand current treatment protocols being followed.
- Collaborate with UCSF to analyze the Burden of Disease caused by Valley Fever.
- Survey targeted occupational and at-risk groups (prisoners, HIV/AIDS, farm workers, etc.) and age groups (children, etc.) to characterize the illness for patients.
- Write and overview of the state of Valley Fever to date and an article with PH directors about their recommendations.
What do people in the SJV want to know?

- What is it?
- How is it contracted?
- How prevalent is it?
- How can it be avoided?
- How and where is it treated?
Recommendations:

**General population**
1.) Stay indoors when there are high winds / dust storms.
2.) When traveling through areas where the disease is prevalent, keep windows of the vehicle rolled up.
3.) Avoid / limit any activity that involve coming into close contact with disturbed dust/soil.
4.) Avoid / limit travel to areas where the disease is prevalent.
5.) Keep your immune system healthy.

**Workers**
6.) Clean any skin injuries that were exposed to any soil or dust thoroughly.
7.) Wear a **mask** if working in an environment with disturbed soil/dust.
8.) Wet soil before digging.
Prevention

- No large scale interventions implemented
- CDC recommends an N95 mask respirator
- Planting grass and paving roads may prevent coccidioidomycosis infection
- Valley Fever Vaccine Project

www.uvm.edu
Detection

- Confirmed Valley Fever case = a case with one or more of six listed clinical presentations that is confirmed by laboratory finding of coccidioidal IgM or IgG, or by skin test conversion.
- Spore detection in soil and air
Policy level...

- Lack of coordination in CA...
- Recent event in Bakersfield
- ...Overall, it is difficult to get national attention

http://www.npr.org/blogs/health/2013/05/13/181880987/cases-of-mysterious-valley-fever-rise-in-american-southwest
Goal: Advocacy

- Target the media, schools and health boards to push for greater awareness of this illness.
- Organize our current and future data and make it available to the public.
- Prepare a fact sheet for the public.
- Develop a personal stories article.
- Develop a network of community members to support Valley Fever research
UCM: Current Research Projects

- Reviews of what we know/awareness raising:
  - Fungal infection on people’s health
  - Impact of Valley Fever on people’s quality of life
  - Burden on society

- Current efforts:
  - Where and how do people currently get diagnosed?
  - What is the impact on patients and families?
  - Can we make it easier to identify using biomarkers?
  - What strategies have people adopted to prevent getting infected?

http://www.cdc.gov/features/valleyfever/
HSRI Research Assistants: Valley Fever Awareness Efforts

- Facebook page: “Valley Fever Advocate”
- Twitter messages
- YouTube clip
- Merced Flea market poll
- News Article archiving
- Radio programs awareness announcements
- Memes
Recent Publicity for UCM’s Valley Fever Work

Newspaper articles:
- Public pushes for new thinking in valley fever research…
- UC Merced researchers to study kids, Valley fever...
  http://www.mercedsunstar.com/2014/03/31/3578263/uc-merced-researcher-taking-closer.html?sp=/99/100/ &ihp=1#storylink=cpy

Television clips:
- KVIE, Sacramento clip…
  https://www.youtube.com/watch?v=wahHIqXWmEo
- Mother Jones clip…
  http://www.motherjones.com/environment/2013/08/mystery-illness-valley-fever
Public pushes for new thinking in valley fever research

Advocates of valley fever research have complained that the disease does not affect enough people to garner attention and funding, local doctors often misdiagnosed it, most data about the disease dates back decades, and the public has little knowledge of the disease and its impact. But they hope to raise awareness with key focus points agreed upon at this public event.

FRESNO — Dr. Erin Gaab, a researcher with the UC Merced Health Sciences Research Institute, was unaware of valley fever until about a year ago when doctors from Central California Children's Hospital visited her and spoke of how the disease has affected their young patients.

León's and Gaab's unfamiliarity with a disease that has found a home in the Valley's and conditions underlines the reason researchers...

About This Series
This project results from a new venture – the Reporting On Health Collaborative – which involves the Bakersfield Californian, the Merced Sun-Star, Radio Bilingüe in Fresno, The Record in Stockton, Valley Public Radio in Fresno and Bakersfield, Vida en el Valle in Fresno, the Voice of OC in Santa Ana and Reporting on Health.org. The collaborative is an initiative of The California Endowment Health Journalism Fellowships at the University of Southern California's Annenberg School for Communication and Journalism.

RELATED STORIES THIS WEEK
Public pushes for new thinking in valley fever research
Advocates of valley fever research have complained that the disease does not affect enough people to garner attention and funding, local doctors often misdiagnosed it, most data about the disease dates back decades, and the public has little knowledge of the disease and its impact.

Valley Fever Research Day Aims To Connect With Community
Community members are invited to attend Valley Fever Research Day Saturday at the UCSF Fresno Center for Medical Education and Research. The event is an opportunity for researchers to connect with community members who have...
“Cocci Kids” Project… Starting with Pediatric Illness Research
How do children and families cope with illness?

- **Acute Illness**
  - Most infectious diseases are not chronic.
  - In → Quick Fix → Out

- **Chronic Illness**
  - Multiple hospitalizations, disabilities, and adjustments
  - Whole families affected (and sometimes more than one member is ill)
  - Healthcare, educational, and other systems challenged
What is Chronic Disease?

- Chronic diseases are noncommunicable illnesses that are prolonged in duration, do not resolve spontaneously, and are rarely cured completely.

- Examples of chronic diseases include heart disease, cancer, stroke, diabetes, and arthritis. — CDC
What is quality of life?

- physical functioning
- psychological status
- social functioning
- disease or treatment-related symptamatology
- interference with activities of daily living
Why study quality of life?

- Provides basis for interventions
- Can help pinpoint which problems are likely to emerge for patients with diseases
- Assesses the impact of treatments
- Is used to compare therapies
- Can inform decision-makers about care

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<td>Home environment</td>
<td>23</td>
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<td>Health and social care: Accessibility and quality</td>
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<td>Transport</td>
<td>25</td>
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WHOQOL-BREF
Emotional Responses to Chronic Illness

- **Denial**: a defense mechanism by which people avoid implications of illness
- **Anxiety**: patients become overwhelmed by potential changes in their lives and/or the prospect of death
- **Depression**: debilitating reaction to chronic illness

http://www.minddisorders.com/Del-Fi/Denial.html
Coping strategies and chronic illness

- Social support/direct problem-solving
- Distancing
- Positive focus
- Cognitive escape / avoidance
- Behavioral escape / avoidance

http://www.makeuseof.com/tech-fun/he-finally-did-it/
"Dirt don’t hurt?"
What is Qualitative Research?

“I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand?”

— James P. Spradley

“It is better to know the patient who has the disease than it is to know the disease which the patient has.”

— Hippocrates (ca. 460 – 377 BCE)

Health Psychology: an exciting and relatively new field devoted to understanding psychological influences on how people stay healthy, why people become ill and how they respond when they do get ill.

How do health psychology and qualitative methods relate?

Health Psychology:
- Biopsychosocial model
- Systems Theory
- Health Belief / Behavior models
- Multidisciplinary, trans-approach

Qualitative Research:
- T.A., I.P.A
- G.T., D.A.
- Used within mixed-methods research
- New, exciting territories in Psych
- Good for sensitive populations
- Often used together

New, exciting territories in Psych
- Good for sensitive populations
- Often used together
Qualitative Research

= (1.) Techniques and/or (2.) paradigm

…”Small q” methods

“Big Q” methodology

• of analyzing “words as data”
  • Recognizes context
  • Generates “rich” descriptions
  • Inductive, subjective, reflective, accommodative method

Why use qualitative methods?

- Quantitative methods can’t answer many “Why?” or How?” questions.
- Qualitative methods can describe people’s motives, opinions, and feelings.
- Experience is subjective – filtered through the perceptions and world views of the people undergoing it, so it’s important to understand those perceptions and world views.
Qualitative Research Paradigm

- Non-positivist
- Assumes that there is more than one reality
- Words are not reducible to numbers
- Interest in meanings
- Inductive, theory-generating
- Researchers bring subjective views

What makes a qualitative researcher good?

- An interest in meaning
- A critical approach
- An ability to listen and critically reflect simultaneously
- A reflexive stance
- Friendly interpersonal skills

Qualitative focus

- Qualitative research focuses on...
  1. Patterns,
  2. Interactions, &
  3. Stories
- And collects data thru...
  1. Words
  2. Symbols
  3. Interactions

Entering the Unknown:
Pediatric Coccidioidomycosis

- Little has been written about children with coccidioidomycosis (Chu, Feudtner, Heydon, Walsh, & Zaoutis, 2006; Connelly & Zerella, 2000; Fisher et al., 2010; McCarty et al., 2013).
- The data about age distribution of valley fever patients is conflicting and may be influenced by the age distribution of the inmates at Avenal State Prison, where rates are high (Smith, 1940; Mac Lean, 2011).
- The presenting symptoms of children and adults with valley fever may differ (J. Galgiani, Coull, Kauffman, & Thorner, 2004).
- Newborns are also at risk of developing coccidioidomycosis (Bercovitch et al., 2011).
- A substantial proportion of the Infectious Diseases practice at Children’s Hospital Central California (CHCC) is comprised of VF patients (McCarty et al., 2013). Anecdotally, doctors report that in many cases, disseminated pediatric coccidioidomycosis patients experience fatigue and other symptoms that limit them from some activities (Geertsma, Ross, Krogstad, personal communication, April 30, 2013).
To our knowledge, only one study has looked beyond strictly physical symptoms, disease incidence and biological underpinnings of the coccidioidomyces fungus. Snyder et al (2005) examined cognitive dysfunction as a less frequent first symptom of coccidioidomycosis that may be diagnosed as dementia.

There are no quality of life or well-being studies of coccidioidomycosis patients (Barnato, Sanders, & Owens, 2001).
Mixed Methods RESEARCH PROPOSAL: Pediatric Coccidioidomycosis Patients — Perceptions, Quality of Life and Psychosocial factors

**Investigators:** Dr. Erin Gaab, Dr. Fouzia Naeem
**Collaborators:** Dr. Jan Wallander, Dr. Jitske Tiemensma, RAs

1. What **psychosocial issues** are faced by coccidioidomycosis patients and their families?
2. How is the **quality of life** of coccidioidomycosis patients affected?
3. How do coccidioidomycosis patients **perceive** their **illness**?
How do families cope with cocci?

http://blogs.ucmerced.edu/eringaab/
Children with Valley Fever: Inclusion Criteria

- Age 8 or more years at enrollment (or primary caregiver of child with coccidioidomycosis of age 3 or older)
- Diagnosis of coccidioidomycosis (or primary caregiver of child with coccidioidomycosis)
- Developmental level sufficient for completion of interviews (for primary caregivers), KIDSCREEN-27, CIPQ, KidsCope and drawing tasks.
Project Plan

- Primary Caregiver Semi-structured Interviews
- Child Structured Interviews
- Primary Caregiver Structured Questionnaires
Questionnaires (for Primary Caregivers of cocci patients)

- Child’s overall health
- Child’s current and past condition (adapted from National Health Interview Survey)
- Experiences with diagnosis, treatment, and healthcare
- Family demographics

http://www.huffingtonpost.com/2013/05/06/valley-fever_n_3221257.html
Detection: Variable 1st Signs

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<tr>
<th>8. Main Symptom</th>
<th>9. Child's health at first symptom</th>
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<tr>
<td>Rash</td>
<td>Good</td>
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<tr>
<td>Chest Pain &amp; Mucus</td>
<td>Poor</td>
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<tr>
<td>Fever</td>
<td>Good</td>
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<tr>
<td>Shortness of breath (couldn't breathe)</td>
<td>Poor</td>
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<tr>
<td>“De la nariz”</td>
<td>Poor</td>
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<td>Fever</td>
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<td>“Lungs”</td>
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<tr>
<td>Fever</td>
<td>Poor</td>
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<tr>
<td>Stomach Pain</td>
<td>Fair</td>
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Preliminary Qualitative Results

Emergent Concerns:
- Misdiagnoses before diagnosis
- Much more unknown than known
- Concern about child’s long-term health
- Valley fever comes from pollution
Parents Responding with More Questions than Answers

- Is there a cure for Valley Fever?
- Will my child be on medications for the rest of their life?
- Why is the medication merely keeping their health stable?
- Can the medication be changed to improve my child’s health?
- How will Valley Fever affect the development of my child?
- Will Valley Fever affect my child’s ability to have children?
- Will Valley Fever affect children my child may have in the future?
- Would it best for my child to move to another state where the endemic is not severe?
- Are there any side effects to the Valley Fever my child is taking? And if so, what are they?
- After receiving treatment, is it possible that my child is still experiencing symptoms of Valley Fever? What can I do about it?
- What symptoms should I be looking out for and call my doctor about when I see them?
Child Drawing Task:

We’re interested in how you think the valley fever, the medicine and the other things the doctor has made you do affect your body…
Child Drawing Task:

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Child Drawing Task:

We’re interested in how you think the valley fever, the medicine and the other things the doctor has made you do affect your body…

1. A drawing of how your body there you looked like before you got Valley Fever.

Description: Not sick

2. A drawing of your body at this time, during treatment for Valley Fever.

Description: Sick - because I was skinny. I threw up. I had the cough and... that’s it. I had a runny nose.
Child Drawing Task:

We’re interested in how you think the valley fever, the medicine and the other things the doctor has made you do affect your body…
Child
Drawing
Task:

We’re interested in how you think the valley fever, the medicine and the other things the doctor has made you do affect your body…
So… Where to from here?

- Continue connecting researchers, patients and advocates
- Continue listening and responding to this great need in our community
Questions for you…

- What kind of prevention activities do you think we should promote?
- What policies should we advocate for?
- Would you like to help us? If so, how?

http://www.cdc.gov/fungal/images/phil-12196_lores.jpg
Thank you…

- Sierra Health Foundation
- Kaiser Foundation
- Professor Paul Brown
- Dr. Fouzia Naeem, Dr. Jim McCarty (Children’s Hospital Central California)
- Professor Michael Peterson
- Sarah Milhoff
- RAs: Crystal Bui, Fiona Bui, Michelle Burrowes, Allan Cha, Iliana Fierros, Celeste Guerra, Tiffany Hsue, Gracy Mantoan, Karina Rodríguez, Mirian Velasquez-Martínez, Mai
- Trevor Hirst
- Dr. Derry Ridgway
- Professor David Ojcius
- Larry Johnson
- Professor Katrina Hoyer
- Professor Carol Sipan
- Professor Ricardo Cisneros
References:


Any Questions?

Thank you for your attention.
- Erin Gaab: egaab@ucmerced.edu