A Look at Asthma Through A Qualitative Lens

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Objectives
- Acquire a working knowledge of one qualitative research method
- State the components of hermeneutic phenomenology
- Talk about how to use a qualitative research study on asthma
- Hear from families about using the ED for asthma care
- Mention my mentors and colleagues
- Add qualitative research studies to your reading list

Philosophical Underpinnings

Phenomenology
- Roots in psychology and philosophy
- The lived experience of the participants
- Colazzi’s method which is Descriptive Phenomenology (bracketing)
- Van Manen’s method which is Hermeneutic Phenomenology (interpretation)

Qualitative Research

Qualitative Research Methods

Philosophical Underpinnings

- Martin Heidegger (1889-1976), proposed interpretation as part of phenomenological inquiry
- Truth exists in the context of someone to conceive it
- Researcher is in the life-world of the participant

Merleau-Ponty (1908-1961): "It is a philosophy intent upon being an exact science but it is also an account of space, time and the world ‘as lived’.”
- "A genuine conversation gives me access to thoughts I did not know myself capable of..."
The Experience of Puerto Rican Families Who Bring Their Children To The Emergency Department For Asthma Care

Why Study Asthma?

Asthma Statistics
- Asthma is the most common childhood chronic illness
- 6.3 million children in the United States have asthma
- Asthma accounted for 728,000 visits to the Emergency Department in 2000
  (American Academy of Allergy, 2003)

The Cost of Asthma
- 11.5 billion dollars in direct cost
- 12.8 million missed school days (work days)
- Cost of prescription drugs for asthma is estimated at 5 billion dollars a year
- Indirect costs at an estimated additional 4.6 billion dollars a year
  (American Lung Association, 2005)

Asthma Statistics
Asthma in Connecticut
- 15% of the adults in Hartford were reported as having asthma
- 50% of the Hispanic households reported a member of the household with asthma
- Asthma incidence: 44% of homes in poverty versus 25% for higher income households
  (Healthy Hartford Ct)

Asthma Statistics
Hartford was rated the tenth worst city for asthma in the country by the Asthma and Allergy Foundation of America in 2004
  (Asthma and Allergy Foundation of America)
Evolution of the Study

The Aim of the Study

To describe the lived experience of Puerto Rican families when they brought their child to the emergency department for asthma care

Review of the Literature

- Black and Hispanic children use the Emergency Department for asthma care more than other ethnic groups in the United States; however the greatest use is by Puerto Rican children
  
  Boudreaux, 2003; Katten, 1997; Ortega, Gergen, Falleti, Bauscher, Belanger & Leaderer, 2002

Review of the Literature

- The volume, patterns and populations of all children who use the ED for asthma care have been extensively studied.

  Bamenti, 2001; Boudreaux, 2003; Christakis, 2001; Ford, 2001; Homa, 2000; Katten, 1997; Lara, 2003; Ledogar, 2001; Young, 1996

Review of the Literature

- Lara (2003), 96% use ED for worsening symptoms of asthma
- Ford (2001), ? Higher users of the ED had lower internal locus of control
- Christiansen (1996), lack of insurance coverage
- McConnochie (1999), more severe disease
- Morales (2002), lower SES

Review of the Literature

- Boudreaux, (2003), increased ED use despite no difference in severity
- Christakis, (2001), decreased continuity of care, SES
- Liu, (2001), ethnic background=severity
- Lieu, (2002), parent perception of asthma status
- Ledogar, (2000), environment not a factor
Review of the Literature

- Ortega, (2002, 2003), examined severity of illness and found it did not impact use of the ED for asthma care for Puerto Rican Children
- Gonzales, (2004), physiologic differences

Review of the Literature

To date, however, there are no known studies that have explored the emergency department experience for asthma care inductively from the perspective of Puerto Rican families.

Cultural Influence

Cultural influences have been shown to impact health-seeking behavior. Walsh and colleagues used the term “unpacking cultural factors” to describe the process of looking beyond a simple ethnic/race designation to depict a population.

Inquiring about beliefs, attitudes and influences of the individual’s environment provides more insight than a simple broad ethnic designation.

(Walsh, Katz, & Sechrest, 2002)

- Puerto Ricans are 8.6% of the population on the United States mainland
- The Northeast is the area where most Puerto Rican families have settled
- Travel from the island to the mainland and living in two different cultures creates a duality in identity

Cultural Influence

Puerto Ricans are 8.6% of the population on the United States mainland. The Northeast is the area where most Puerto Rican families have settled. Travel from the island to the mainland and living in two different cultures creates a duality in identity.
Spirituality and Herbal Medicine

- Christianity is dominant in Puerto Rican culture
- Does prayer help families cope with illness?
- Does prayer interfere with care?
- Are home remedies used for asthma care?

Parenting A Child with Asthma

- Mothers are primary caregivers
- Chronic illness is: "commander of the family" (Pryor, 2004)
- Fear of asthma felt by parents
- Concern and worry are always present

Pre-Reflective Paradigm

The Study

**Method**

Hermeneutic Phenomenology is a human science approach to research, grounded in philosophy and psychology.

Research Method

"Even minor phenomenological research projects require that we not simply raise a question and possibly soon drop it again, but rather that we ‘live’ this question, that we ‘become’ this question." - Jean Marxen, 1990
Gaining Access

- Internship with the Asthma Center at Connecticut Children’s Medical Center
- Hermeneutic discussion with co-workers

The Emergency Department

- Observation in Emergency Department waiting area
- Shadowing a nurse in Emergency Department

The Neighborhood

- Driving in the neighborhood

Sample

- Persons of Puerto Rican descent comprise approximately 40% of the population of Hartford, Connecticut
- Purposeful sample of families who attended the clinic at the Asthma Center

Sample

- Self Identified as Puerto Rican on the Easy Breathing© survey
- Parent or caregiver (at least 18 years old) of a child 6 months-18 years old with asthma
- Child must have had at least one ED visit in the past year

Procedure

- IRB approval from UCONN and CCMC
- Interviews conducted over a 6 month period
- Families invited to participate during clinic visit
- No-show rate for clinic: 40-60%
Procedure

- Show rate first few weeks of the project was 0%.
- This show rate translates to a "mostly dead" project

Procedure

- Research assistant participated in 8/10 interviews and translated for Spanish speaking participants
- Interviews taped and transcribed
- Participants contacted to discuss interview transcripts
- Field notes
- Hermeneutic discussion

Language spoken at home | Child's Age | Visits to the ED past year | ED Location | PCP
--- | --- | --- | --- | ---
English and Spanish | 2 | 4 | COMC | Y
English and Spanish | 2.5 | 1 | COMC | N
Spanish | 6 | 1 | COMC | Y
English | 11 | 3 | COMC & SF | Y
Spanish | 14 | 1 | SF | Y
Spanish | 8 | 1 | COMC | N
English | 9 | 1 | COMC | Y
English and Spanish | 18| >30 | COMC | Y
Spanish | 5 | 1 | SF | N
English | 2 | 1 | COMC | N

Data Analysis

- Turning to a phenomenon which seriously interests the researcher and commits them to the world
- Investigating experience as we live it rather than as we conceptualize it
- Reflecting on the essential themes which characterize the phenomenon
- Describing the phenomenon through the art of writing and rewriting
- Maintaining a strong and oriented pedagogical relation to the phenomenon
- Balancing the research context by considering parts and whole

The Phenomenologic Text

Loss of Manuel
Elizabeth Baez
2006
Last night another was born. Monsona Quintana’s child was one of those purple babies so common in our mountains... She was ready to do anything to save her little [baby]... She took off her new petticoats to make some good diapers, kept her eyes on the cradle and prayed to Santa Rita, patron of country children... Monsona Quintana pulled up the sleeves of hope to save her child from death... day after day a new herb was used... hour after hour; the agonized shadows grew under the mother’s eyes... His mama walks him with fearful stride, with passionate rage... the medicine woman has no art to calm that cry....

Monsona Quintana’s Purple Child
(El Niño Morado De Monsona Quintana)
Emilio S Belaval

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<th>Research Theme</th>
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<td>Folklore of Asthma</td>
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<td>She kept her eyes on the cradle</td>
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<td>And prayed to Santa Rita</td>
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<td>She was ready to do anything to save her little baby</td>
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<td>Monsona Quintana pulled up the sleeves of hope to save her child from death</td>
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<td>Day after day a new herb was used, the medicine woman has no art to calm that cry</td>
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Folklore of Asthma

- "Down from my grandparents, down from my father, my brother, myself, my two daughters, my sister and my cousin"
- "Grandmother, father, mother, me, sisters, yea the whole family, aunts yup my grandmother died from that"
- "Yeah there is a lot of asthma in my family"
- Asthma permeated their lives

In Awe of Asthma

- "Asthma Kills!"
- "And you know, I get concerned as my mother died from asthma"
- "I just get very afraid of asthma"

In Awe of Asthma

- "It is scary because you feel out of control"
- "Scary because I feel like OK there is nothing else I can do. You are scared because you know asthma can kill"
Praying to God  
Si Dios quiere

- "I rock with her and will start praying and she'll relax and fall asleep"  
- "I pray like there is not tomorrow at night, Oh God help me"  
- "I just pray because I am scared"

The Decision  
Time to Go

- "I felt uncomfortable because he would start wheezing at home and I just rushed him in"  
- "One time he completely stopped breathing"  
- "If I can control it in my house, fine. If I can't I bring them to the ED"  
- "Lots of services here"

The Decision  
Time to Go

"I gave her the machine and she kept coughing"

The ED Environment  
Care and Cussing

- The ED staff know me... "cause I cuss everyone out"  
- "The hospital workers are very good for the children"  
- "The last time I went to the ED it was packed, I mean packed. There were kids crying"  
- "Noise, yeah lots of noise"

Culture and the  
Medicine Woman

- "The only thing that I use and it seems to help me because I'm asthmatic, is ginger root tea and we have been doing it since I can remember. You just buy the root, crush it and smash it and put it to boil. We took like a spoon or two"

Intellectual growth should commence at birth and cease only at death.

Albert Einstein (1879-1955)
Future Research

- Additional interviews which include male caregivers
- Refine the instrument based on the findings from this study
- Pilot the instrument

"To do Hermeneutic Phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the life world, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal."

van Manen 1990

“A good phenomenological text has the effect of making us suddenly ‘see’ something in a manner that enriches our understanding of everyday life experiences.”

van Manen 1990