Latina Mother’s Stories: Narratives of Parenting Experiences of Children with Cystic Fibrosis (CF), Health Beliefs, and Health Care Experiences

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Outline

- Researcher “reflexivity”
- Brief overview of CF
- Background
- Sample
- Methods
- Analysis-maternal voices
- Implications

**all names are fictitious to protect individual’s identity.**
MY STORY
Background and Significance

Cystic Fibrosis (CF)

- Caucasian 1:2,500 - 3,000
- Hispanic 1:4,000 - 10,000
  - Higher risk for increased morbidity and mortality not explained by genetics

- Overall, 10 million carriers of CF in the U.S.
Background and Significance
Background and Significance

- CF: life shortening, multi-system, chronic condition
- Average life expectancy – early 4th decade
- Average health care cost up to $50,000/yr. (O’Sullivan, et al., 2011)
- Hispanic population - minority in U.S. and in the CF community

2010 U.S. census: 43% growth of Hispanic population
Four times the growth of the general population
CF in the United States

- Increase in overall CF survival
- Increase in risk factors r/t CF health outcomes
- Increase in Latina population in the U.S.
- Anticipate increase in Latinas with CF from NBS*

Compelling case to explore and deepen understanding of Latina maternal perspectives of parenting a child with CF

*NBS= newborn screening
Research Question and Aims

What is it like to parent a child with cystic fibrosis (CF) from the lens of Latina mothers?

- AIM 1: Explore and describe Latina maternal perspectives of parenting a child with CF
- AIM 2: Explore and describe health beliefs related to their child’s CF
- AIM 3: Explore and describe health care experiences with CF care
Many studies exist on experiences of parenting a child with CF. 

**GAP: Absence of CF studies specific to the Hispanic population**

An under represented group
Design/Method: Narrative Inquiry

- Involves the interdisciplinary study of activities consisting of creating and analyzing stories of life experiences.
  
  (Schwandt, 2007)

- Narrative is one way individuals construct and give meaning to their lives.
  
  (Mishler, 1986)
Human Subjects/Ethics

- IRB reviewed
- Informed consent: Spanish/English
- Voluntary participation emphasized
- Spanish interpreter
Setting and Recruitment

- **Setting**: accredited Cystic Fibrosis Foundation CF center, southwest U.S. in a tertiary children’s hospital

- **Recruitment**
  - Majority recruited through face to face invitation at routine outpatient CF appointments
### Inclusion Criteria

**Mothers**
- Biologic
- Self identified Hispanic
- English or Spanish speaking

**Child**
- Confirmed CF diagnosis for at least 1 year
- Age 1 yr. to 21 yr.
- May have known CF complications

### Exclusion Criteria

**Mothers**
- Adoptive or non-Hispanic mothers

**Child**
- History of co-diagnosis (autism, ADHD, developmental delay)
- Acute care hospitalizations within 2 weeks of interviews
Sample

- Candidates from the Cystic Fibrosis Foundation Patient Registry

- **Sample:**
  - 10 Latina mothers
    - 5 English speaking; 5 Spanish speaking
      - 3 mothers crossed the border for medical care
  - Total of 19 children with CF; 3 families had a total of 12 children with CF
Maternal Characteristics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N = 10</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal age</td>
<td>32 yr.</td>
<td>24 yr. – 48 yr.</td>
</tr>
<tr>
<td>(median)</td>
<td>(median)</td>
<td></td>
</tr>
<tr>
<td>Education level completed</td>
<td>12th grade</td>
<td>8&lt;sup&gt;th&lt;/sup&gt; grade (1) – 5 yr. of college (1)</td>
</tr>
<tr>
<td>(median)</td>
<td>(median)</td>
<td></td>
</tr>
<tr>
<td>Country of origin</td>
<td>Mexico (6)</td>
<td>El Salvador (2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nicaragua (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spain (1)</td>
</tr>
<tr>
<td>Language spoken at home</td>
<td>Spanish (6)</td>
<td>English (4); Both (1)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married (9)</td>
<td>Single (1)</td>
</tr>
<tr>
<td>Employment status</td>
<td>Employed (2)</td>
<td>1 part time; 1 full time; 3 wanted to work</td>
</tr>
<tr>
<td>Recall of genetic counseling</td>
<td>No recall 4</td>
<td>6 affirmed</td>
</tr>
<tr>
<td>Medical insurance: government funded</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Demographics</td>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Ages</td>
<td>Median age 10 yrs. Range: 4 yrs. to 17 yrs.</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>13 males 6 females</td>
<td></td>
</tr>
<tr>
<td>Confirmed CF diagnosis by sweat test/DNA</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 Newborn screening (subsequent siblings were diagnosed)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 Families = 10 siblings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 Prenatal test (subsequent sibling was diagnosed)</td>
<td></td>
</tr>
<tr>
<td>Severity of CF measured by pulmonary function</td>
<td>Normal 13 (72%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mild 1 (5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moderate 2 (11%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Too young 3</td>
<td></td>
</tr>
</tbody>
</table>
Data Collection

- Interviews: 7 in the home setting / 1-2 hours each
  - Semi-structured interview schedule; probes to gain information related to the study aims
  - Spanish interpreter used with 5 mothers
  - Digitally audio taped
  - Transcribed with Dragon Naturally Speaking™ software
- Interviews until saturation reached
Sensitizing Frameworks

- Critical Social Theory (Campbell & Bunting, 1991)
- Feminist Theory
- Analysis informed by Dr. Sara Ruddick’s Maternal Thinking framework (1995)
Mothering

Scientist: “writing up her experiment, a critic working over a test, or a historian assessing documents,” . . . She asks certain questions — those relevant to her aims . . . she accepts certain criteria for truth, adequacy, and relevance of proposed answers; and she cares about the findings she makes and can act on.”

(Ruddick, 1995)
### Ruddick’s Framework (1995)

<table>
<thead>
<tr>
<th>Demands of Maternal Work</th>
<th>Elements of Mother’s Work to Meet Demands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preservation</td>
<td>Preservative love</td>
</tr>
<tr>
<td>Growth</td>
<td>Nurturance</td>
</tr>
<tr>
<td>Social acceptability</td>
<td>Training</td>
</tr>
</tbody>
</table>
THEMES and Subthemes

- Mothering*
- Growing and growth
- Mother Talk
- Connected

- Life Disrupted:
  - Guarded optimism
  - It's just hard

- Being Here
  - Gendered parental differences
  - More mother talk
  - Education
  - Communication won’t happen without interpreters

*Structural analysis applied; thematic analysis applied to majority of stories
Analysis

Structural Analysis

- Riessman (2008)
- Labov’s structural elements of a story

<table>
<thead>
<tr>
<th>Structural elements</th>
<th>A   = abstract</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>O   = orientation</td>
</tr>
<tr>
<td></td>
<td>CA  = complicating action</td>
</tr>
<tr>
<td></td>
<td>EV  = evaluation</td>
</tr>
<tr>
<td></td>
<td>R   = resolution</td>
</tr>
<tr>
<td></td>
<td>C   = coda</td>
</tr>
</tbody>
</table>

Miller
Children’s & Women’s Hospital
Long Beach
MemorialCare Health System
Mothering: Structural Analysis

SIMILARITIES

- Characteristic stories having a beginning, middle and end.
- 3 Stories: Infants were born fine; went home with mothers; multiple trips to the doctor, treated for URIs. Mothers were worried. Returned for medical treatment numerous times, in one instance infant was taken to Tijuana.
- Drew in the listener by relating events temporally. A range of details depicted what happened. Turning points in their story described specific details.

- Represent the preservative love described as protective in Ruddick’s maternal thinking framework.
- Role transition and subjective ways mothers know were called out as central to this theme.

Structural analysis revealed differences that may have been overlooked with thematic analysis.
“So then, one night I just had him getting smaller and skinnier and I didn’t see him, like good, like when he was born. So yeah we just decided around 11 in the night we took him to where he was born. . . So that’s when everything started . . . because when we got there he was bad, really bad, really bad looking.”

She continued to talk about what the health team said:

“. . . you know . . . we need to do some other tests, like the sweat test, and we’ll see what comes out and that’s the first that I heard about cystic fibrosis. . . and then it came out positive and then that’s when everything started...”

“You know what, now we know how to treat him.”
<table>
<thead>
<tr>
<th>Narrative clause</th>
<th>Structural Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 So one night I just had him getting smaller and skinnier</td>
<td>CA</td>
</tr>
<tr>
<td>2 and I didn’t see him, like good…</td>
<td>EV</td>
</tr>
<tr>
<td>3 ...we just decided around 11 in the night</td>
<td>CA</td>
</tr>
<tr>
<td>4 we took him to where he was born in hospital</td>
<td>CA</td>
</tr>
<tr>
<td>5 So they recommend straight to the local children’s hospital</td>
<td>RE</td>
</tr>
<tr>
<td>6 When we got there</td>
<td>O</td>
</tr>
<tr>
<td>7 he was really bad looking</td>
<td>EV</td>
</tr>
<tr>
<td>8 really bad…</td>
<td>EV</td>
</tr>
<tr>
<td>9 ...and then it [sweat test] came out positive...</td>
<td>EV</td>
</tr>
<tr>
<td>10 and that’s when everything started</td>
<td>RE</td>
</tr>
<tr>
<td>11 You know what, now we know how to treat him</td>
<td>RE</td>
</tr>
<tr>
<td>12 He’ll be getting gaining his weight back</td>
<td>RE</td>
</tr>
<tr>
<td>13 he’s just, we’ll know how to treat him</td>
<td>RE</td>
</tr>
<tr>
<td>14 and and so that’s when everything changing for him</td>
<td>CO</td>
</tr>
</tbody>
</table>
1. “I was very happy that I was going to have a little girl and I finally had my little girl and this is what happened…” (M4)

2. “You know what, now we know how to treat him.” (M9)

3. “The doctors don’t have the medications necessary and everything was very expensive. So my mom and I decided for me to come the U.S. to work.” (M11)
Thematic Analysis

Coffey & Atkinson (1996)

Level 1: General categories for coding themes

Level 2: More complex details lead to subthemes

Level 3: Prepare data for interpretation
Theme 2: Growing and Growth

- Fostering growth and nurturance in children is a second distinct element in Ruddick’s framework.

- Growth extends to all aspects of the child’s being. Nurturance is more relevant to the judgment mothers continually exercise to promote holistic growth or support decisions and actions.

- Mothers’ descriptions of care changed as their children’s development progressed.
“He was the first one [child], we did not know how to do treatments…when he was a baby it was easier for me…I mean ‘cuz I would just grab him in my arms and do the pounding [treatments]…I try to have the same rules for the 3 of them [2 well sibs]…I mean I don’t want him to grow up and think and me, no, I can get away with everything; ….and he questions me, why do my bother and sister get to play and I have to go upstairs and put my treatments [treatment vest]?” Mother of son 9 yr.
Theme 3: Mother Talk

- Mothers expressed narratives that represented the training element of Ruddick’s framework. This element prepares the child for social acceptability.
- Mothers repeatedly described talking to their children as a training-teaching approach.
- Maternal strategies changed to meet the challenge of training demanded of the respective developmental stage to help their children make sense out of their life experience with CF.
“So it’s a little challenging for me and for him, that’s why I talk to him every day, … you know, and then talk to him every day. I mean he’s growing up, growing up…and have him know why he has to, why it’s important for him to take care of himself…”

mother, son 9 years
Mothers’ responses were child centered, related to what most parents might take for granted every day, that their child will wake up and proceed with their typical day’s activities.

Majority of mother’s expressed a deep gratitude for their child

“Women not only define themselves in the context of human relationships but also judge themselves in their ability to care.

Women develop and relate to the world through connectedness, relationships, and communication.” (Gilligan, 1993)
Theme 4: Connected

“The thing that helps me the most getting through every day is getting up and seeing my daughters becoming more independent . . . . and that’s what I usually look forward to every day. . . I feel very connected to my daughter and everything my daughter experiences. I, in some way, experience it myself as well. When my daughter is sick, I feel sick or when my daughter is sad, I feel sad.”

(mother of 17 year old daughter)
“She sometimes expresses to me that her life expectancy is about 30 [years] and so she kind of has a worry about that, but I tell her that there’s other cases where individuals have lived up to 40 even 60 or longer. I explain to her that science is advancing and maybe in the future there’s going to be better options.”

(mother of 14 yr. old daughter)

Majority of mothers spoke of just how hard the care is to do each and every day, regardless of their child’s age.
Theme 6: Being Here

• Subthemes
  ▪ Gendered Parent Differences
  ▪ Education
  ▪ More Mother Talk
  ▪ Communication won’t happen without interpreters
Theme 6: Being Here — Summary

- Marital conflict was described with gendered spousal denial of CF

3 mothers shared difficulty their spouses had with coping and resisting to discuss their sons' CF with extended family members.
Theme 6: Being Here — Summary

- Marital conflict was described with gendered spousal denial of CF

- Mismatch of how extended family members perceived the care of CF as a result of incongruent cultural values and beliefs suggesting …

“…Oh that medication’s not gonna work in 10 years because the body getting used to it…."

“…Do the natural way, its gonna kill them sooner if you keep giving them this medicine…"
Theme 6: Being Here — Summary

- Marital conflict was described with gendered spousal denial of CF
- Mismatch of how extended family members perceived the care of CF as a result of incongruent cultural values and beliefs suggesting...no need for medications, “their body will get used to it”
- Education was highly valued by the mothers.

“When I had to ask the nurse in regards to contact the physician, I feel when they see a Latina person, and more with me because of my accent, and it’s a really heavy accent, they think you aren’t educated.”
Theme 6: Being Here — Summary

- Marital conflict was described with gendered spousal denial of CF.
- Mismatch of how extended family members perceived the care of CF as a result of incongruent cultural values and beliefs suggesting no need for medications, “their body will get used to it.”
- Education was highly valued by the mothers.
- Interpreter use for medical encounters decreased as the child’s age increased, not offering interpreters.
“In the beginning a lot of doctors would ask if I needed one [interpreter]. However, now not everyone will ask or offer…They sometime will have Isabel [14 year old daughter] kind of as a translator…That’s still very difficult because there’s still terms she doesn’t even understand…and maybe can’t even explain it to me…I have questions and I have Isabel kind of ask questions…and hopefully she will understand…she will tell me she doesn’t understand what they just told her.”
Theme 6: Being Here — Summary

- Marital conflict with gendered denial of CF
- Mismatch of how extended family members perceived the care of CF as a result of incongruent cultural values and beliefs suggesting . . . no need for medications, “their body will get used to it”
- Education was highly valued
- Interpreter use for medical encounters decreased as the child’s age increased, not offering interpreters
- The Hispanic community is underrepresented in the greater CF community; Mothers expressed a desire to increase awareness of Hispanic representation to avoid stereotyping CF as only Caucasian
Theme 6: Being Here-Summary

“…the whole assuming our kids didn’t have it [CF] because of their ethnicity and being told we were being denied diagnosis from our health care plan [when obtaining authorization for out of network consult [to CF center]]…”

“…for my kids, too, they don’t really see other kids that look like them that are featured in [CF] advertisements…I think if people would stop saying it’s a Caucasian disease…”

“…The kid’s pediatrician…after she found out that my kids were diagnosed… she said, “they have had asthma or bronchitis but I never thought to test them.”

mother of multiple children with CF
BEING HERE

These moments required mothers to exercise their maternal ways of knowing to have the presence of maternal thinking to:

✓ Be supportive of spouses in denial,
✓ Be a diplomat with extended family tensions,
✓ To (un)consciously be mindful of power relations within the patriarchal health care system.
✓ Treated as equals to Euro-American dominant counterparts.
Qualitative Trustworthiness

- Field notes
- Audit trail
- Member checks
- Peer debriefs
- Reflexivity
Affirmed current literature:

- Mothers’ parenting experiences were consistent with those of Euro-Americans with a child with CF.
- Health beliefs were aligned with prescribed CF treatments.
- Majority of mothers did not express experiences of disrespect or discrimination. Yet described experiences of being treated different.
- Language was cited as a barrier.
- Majority of mothers were grateful for their child’s medical care.
We are more alike than different
Limitations

- Hispanic mothers were not homogenous and may not be representative of the multiple cultures across Hispanic ethnicities.

- Findings cannot be generalized yet give insight into the personal spaces of Hispanic mothers’ experiences.
Nursing Implications: Education and Clinical

- Provide education to mothers to navigate through their spaces toward empowerment.
- Represent silent Latina mothers’ voices in the CF community.
- Work to unify public and private spheres to empower mothers to be active agents in their child’s care.
- Educate nurses about the discipline of mothering and maternal thinking: Valuing and recognizing the work of maternal thinking, listening to their voices, validate their skills, support their growth and caring across sociocultural contexts.
Nursing Implications: Future Research

- Study **mothering** from **cultural and generational** perspectives to highlight the valuing, respect, and credibility of maternal thinking and work.

- Explore **chronic illness** and **posttraumatic stress symptoms** in relation to **gender differences and diagnosis**.
GRACIAS

THANK YOU

BIYAN

SHUKRIA