Maternal Coordination of Care for Low-Income Children at Risk for Developmental Delay

Eileen K. Fry-Bowers, PhD, JD, RN, CPNP
Associate Professor
University of San Diego, Hahn School of Nursing and Health Science
Betty and Bob Beyster Institute for Nursing Research, Advanced Practice, and Simulation

BACKGROUND
Children with special health care needs (CSHCN) have or are at risk for a chronic physical, developmental, behavioral or emotional condition and also require health and related services of a type or amount beyond that required by children generally. 
- 15% of children < 18 years of age (11.2 million children) in the U.S. have a special health care need, 
- 23% of households with children in the U.S. have at least one CSHCN, and 
- About 1 in 6 children have one or more developmental disabilities or delays.
By definition, these children need and use the majority of pediatric health care services and are more vulnerable to poor outcomes when unable to access those services.

Early identification, referral and receipt of coordinated intervention services improves outcomes for CSHCN across developmental domains.

However, for Latino CSHCN in the U.S., all of the following contribute to poor coordination of care:
- poor access to primary care, 
- low economic status, 
- language/cultural barriers 
- distrust of / decreased levels of comfort with providers 
- low levels of health literacy

SPECIFIC AIMS
This qualitative study seeks to understand the perceptions of and expectations for care coordination among low-income Latina mothers of young children who have or are at risk for developmental disability.

METHODS
Design: Qualitative design using Grounded Theory methods and subjective and constructed knowledge as data.

Setting: High Risk Infant Clinic at a regional children's hospital, southern California, U.S.

Inclusion Criteria: 
- English-speaking Latina mother of child, 0 – 3 years, at risk for/ diagnosed with developmental delay; 
- Low-income, as defined by receipt of public assistance (e.g., Medicaid) or self-reported income of < 200% FPL

Data Collection: 
- Semi-structured interview 
- Socio-demographic survey

Data Analysis: 
- Constant comparative analysis

PRELIMINARY RESULTS
Demographic Profile, n = 12

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Range</th>
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<tbody>
<tr>
<td>Maternal age</td>
<td>27.25 yrs</td>
<td>19 – 39 yrs</td>
</tr>
<tr>
<td>No. of children in home</td>
<td>2.33</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Adults in home</td>
<td>2.5</td>
<td>1 – 6</td>
</tr>
<tr>
<td>Children in home</td>
<td>2.5</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Health literacy: Single Item Literacy Screener (SILS)²</td>
<td>4.5</td>
<td>3 – 5</td>
</tr>
<tr>
<td>Acculturation: Short Acculturation Scale for Hispanics (SACH)²</td>
<td>3.38</td>
<td>2.2 – 4.2</td>
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</tbody>
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EMERGING THEMES
On providing day-to-day care for their child with special health care needs:

From Fearful Vigilance to Daily Routine

“Ana,” age 25: “It was like...a little scary...I would be constantly checking on him”

“Bianca,” age : “It was scary...but then it would, after a while it got, I got used to it”

“Emilia,” age 28: “At first it was traumatizing me... it was just heartbreaking to see him like that, you know...Sometimes you wish you could be in their position instead.”

On “coordinating care” for their child with special needs:

Maternal Responsibility

“Claudia,” age 31: “When you have a healthy child you take on responsibilities that that takes, so what's the difference with a child that's born with health issues...it should be the same...but it's definitely hard...to have someone guiding you, I could see a benefit”... “It can be frustrating...you know, I'm dealing with this and now I have to take care of that...I have the phone here and I have a baby here...it's frustrating when you know what has to be done... to find out how to do it...”

“Delores”, age 25 [has sister with special needs]: “I feel like as a mom you want your son to get the best care anyway...so even if I didn’t have [the experience with my sister] I would push...it would bother me if he didn’t get the care he needed.”

IMPLICATIONS FOR PRACTICE
Many low-income Latina mothers of CSHCN report challenges in coordinating care and services for their child, which leads to significant family dissatisfaction with care and delays in services resulting in less than optimal health outcomes.

An improved understanding of maternal experiences with care coordination will facilitate and enhance nursing care of this population, and potentially improve quality of care and reduce health disparities.

CONCLUSIONS
Greater awareness of Latina mother’s perceptions of care coordination, within the context of pediatric developmental disabilities, can lead to more exacting research, and the design of more effective nursing care strategies for use with this population.

ACKNOWLEDGEMENTS
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References: Please see handout.