Children With Special Healthcare Needs: Needs After the First Year of Diagnosis

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Background and Significance

Advances in medical technology

Survival rates for high risk, compromised infants

Special health care needs at home:

- Tracheostomy tubes
- Gastrostomy tube feedings
- Urinary catheters
- Painful treatments
Background and Significance

Early period after the diagnosis

Very stressful, physically and psychologically

Requiring parent caregivers to learn and adapt:

Caring for their infant with special health care needs

Other parenting responsibilities - siblings

Meet employment obligations

Other household demands.
Background and Significance

Many challenges are faced by parents providing care for older children with special health care needs and the long-term consequences on parent health and functioning.

Few studies examine parents’ perceptions of what was needed to remain healthy and functioning in the difficult first year after the diagnosis of an infant with special health care needs and hospital discharge.
Purpose

To describe parents’ perceptions of what was needed to maintain their physical and mental health and functioning in the difficult first year after the diagnosis of their infant with special health care needs in three racial/ethnic groups.
Study Design

Qualitative study used a semi-structured interview guide asking what parents of infants with special health care needs needed to remain healthy and functioning after the diagnosis.

To elicit the parent's story, open-ended questions included:

“Tell me what helped when you first received the diagnosis that your infant had special health care needs.”

Follow up questions and probes addressed: 1) “What helped early after the diagnosis?” 2) “What helped during the first year?” and 3) “What did not help?”
Study Sample

After IRB approval, a purposeful sample of 15 parents with medically complex technology-dependent children from a previous study (2011-2013) on child and family health outcomes with the highest and lowest family health outcomes were recruited.

Of the 15 parents not participating:

- 12 received two telephone messages without responding
- 2 had disconnected telephone numbers
- 2 parents reported their child had passed away
Procedure

The principle investigator (PI) called the English speaking parents and the research assistant (RA) called the Spanish only parents at their last known telephone number and invited to participate. During the scheduled meeting, questions were answered, and consent was obtained. Interviews were audio recorded, transcribed verbatim, and analyzed using conventional content analysis. Data were managed using the software package ATLAS/ti.
Sample
## Characteristics of the Parents

<table>
<thead>
<tr>
<th>Relationship to child</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Mother</td>
<td>12 (80%)</td>
</tr>
<tr>
<td>Adoptive Mother</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Guardian</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Biological Father</td>
<td>1 (6%)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White non-Hispanic</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Black non-Hispanic</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6 (40%)</td>
</tr>
</tbody>
</table>
Characteristics of the Parents

Age
- 29 to 61 years old M (SD) 43.3 (SD 9.5)

Marital status
- Married/Partnered 9 (60%)
- Single/not partnered 6 (40%)
## Characteristics of the Parents

### Employed
- Full time ≥ 40 hours/week: 4 (27%)
- Part time < 39 hours/week: 5 (33%)
- Not employed outside home: 6 (40%)

### Income
- < $30,000: 6 (40%)
- $30,000 - $50,000: 5 (33%)
- > $50,000: 3 (20%)

### Educational status
- < high school: 1 (6%)
- High school graduate: 4 (27%)
- Some college/vocational: 4 (27%)
- College degree: 5 (33%)

M (SD) $30,399
### Characteristics of the Children

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
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<tbody>
<tr>
<td>Males</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Females</td>
<td>11 (73%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age at time of interview</th>
<th>M (SD) 10.3 ( 6.1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 - 6 years old</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>7 - 12 years old</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>13 - 21 years old</td>
<td>5 (33%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Respiratory, feeding, and/or Neurological problems</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Congenital anomaly/rare syndrome</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>3 (20%)</td>
</tr>
</tbody>
</table>
Characteristics of the Children

Condition Severity
- Moderate disability  2 (13%)
- Severe disability  11 (73%)
- Vegetative  2 (13%)

General health status
- Very Good to Excellent  5 (33%)
- Good  5 (33%)
- Poor to fair  5 (33%)
### Characteristics of the Children

#### Age at diagnosis in months

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 month</td>
<td>8</td>
<td>53%</td>
</tr>
<tr>
<td>2 to 5 months</td>
<td>4</td>
<td>27%</td>
</tr>
<tr>
<td>18 to 66 months</td>
<td>3</td>
<td>20%</td>
</tr>
</tbody>
</table>

M (SD) 7.8 (17.7)

#### Medical Technology Devices

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>1 to 3</td>
<td>4</td>
<td>27%</td>
</tr>
<tr>
<td>4 to 7</td>
<td>5</td>
<td>20%</td>
</tr>
<tr>
<td>8 or more</td>
<td>3</td>
<td>20%</td>
</tr>
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</table>

M (SD) 5.3 (3.1)
Results

Parents described three main themes:
Taking care of yourself
Finding a routine
Not knowing what to expect.
Taking Care of Yourself

Taking care of yourself involved:
- Accepting the diagnosis
- Learning more about the infant’s condition
- Becoming organized
- Accepting help
Quotes – Taking Care of Yourself

• P4: You have to take care of yourself. It gets a little hard to be selfish. I have a hard time taking care of me.

• P6: Your baby is first and foremost your baby. Forget the diagnosis. All babies need love and attention. All babies need their needs met just like a typical child. That hasn’t changed. You are mom; so quit focusing on the diagnosis.
Quotes – Taking Care of Yourself

- *P 2: It was word of mouth, another parent found it…*

- *P13: In the internet, I researched and found an association with the same syndrome and I connected with them.*
Taking Care of Yourself

Taking care of themselves after the diagnosis of their infant with special health care needs was not a priority.

More Hispanic parents than Black or White parents recognized the lack of self-care affected their own physical health.
Finding a Routine

Finding a routine involved:

Finding available resources
Competent caregivers
Maintaining continuity of care
Finding social networks
Quotes – Finding a Routine

• P5: For me, it’s more planning. Things happen; something gets pushed back between calling and making sure [infant] has appointments, there’s no real breaks. You catch your breath for a second, but then you got to remember to do this and that.
Quotes – Finding a Routine

• **P10**: They told me that they have not been able to get [service] because it very difficult to find it here [locally]. I went to [local hospital] and they told me that there is a long waiting list. So, the more time that goes by, the more she deteriorates. This has me very worried.
Quotes – Finding a Routine

• *P12:* I don’t know if anybody can take care of [infant] the way I want her taken care of.

• *P1:* Family is the best way. [It is a] challenge trying to get everybody on the same page.
Finding a Routine

Spanish-speaking parents had difficulty finding and accessing resources.

More Black and White parents than Hispanic parents discovered additional needed services after the first year.
Not Knowing What to Expect

Not knowing what to expect included:

Care requirements/coordination needs
Difficulty with the eligibility process
Family problems
Initial support ending
Quotes – Not Knowing What to Expect

• P12: I want somebody to tell me what I am going to expect with [infant]. The problem is there was no one to teach me, to show me, okay this is the baby, this is what I have, this is what I need to do, this is the service, and this is where I need to go.
Quotes – Not Knowing What to Expect

• **P13**: I have a nurse for 40 hours a week during the day only because [infant] has the g-tube and the medicines. I can be out only less than 2 hours because the feeding is every three hours.
Quotes – Not Knowing What to Expect

• *P13: It’s important the doctor work with you. They have to do everything with prescription; the supplies, the medicines, wheelchairs, hospital bed. I have respiratory treatment machine, suction machine. If not, you not get it.*
• *P5:* With my mom, whenever [infant] would pull the trach out, she [my mom] would be, like the end of the world is about to happen, so I stick it back in and say she’s alright.
Not Knowing What to Expect

More Hispanic and Black parents wanted to provide care for their infant by themselves.

More Hispanic and Black parents reported delays in services due to not knowing different eligibility requirements for each service or agency.
Limitations

While the study sample included three racial/ethnic groups of parents, Hispanic parents were over represented.

The children were medically complex technology-dependent, most with severe physical and mental disabilities.

The average time since diagnosis was 10.3 years (SD 6.1) range 4-22 years.
Limitations

Memory recall bias minimized:

Frequently identifying the study purpose for details at the time immediately after diagnosis of their infant and during the first year.

Four participating parents read a document of the synthesised data and felt it was an accurate depiction.
Results

The study adds to nursing knowledge by including parents in three racial/ethnic groups and focusing on parents of infants with special health care needs in the first year after the diagnosis.

Such data are necessary to guide practice to promote parent health and prevent parent illness.
Practice Implication

Encouraging self-care routines to promote parent health and prevent parent illness.

Encourage parents to find out how the special health care needs can be incorporated within their family daily life.
Practice Implication

Include other family members willing to help at home during discharge education and training sessions.

Prior to discharge, introduce parents to support groups available outside the hospital for continued support.
Conclusions

More infants are discharged home with increasingly complex extended care treatments or procedures, usually the purview of NICU/PICU nurses, are relegated to parents after discharge home.

Once home, parents must develop a process of adapting daily routines beyond that of caring for a healthy infant.