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

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Session Title:
Pediatric Chronic Conditions
Slot:
C 06: Sunday, 29 October 2017: 10:45 AM-11:30 AM
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11:05 AM

Keywords:
long-term care, parent caregivers and qualitative

References:


Abstract Summary:
This is a qualitative study designed to describe 15 (40% Hispanic, 27% Black and 33% White) parents’ perceptions of what was needed to maintain their health and functioning in the first difficult year after their infant’s diagnosis of special health care needs in three racial/ethnic groups.

Learning Activity:

<table>
<thead>
<tr>
<th>LEARNING OBJECTIVES</th>
<th>EXPANDED CONTENT OUTLINE</th>
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<tr>
<td>The learner will be able to describe parent 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 (ISHCN).</td>
<td>Parents described three main themes: 1) Taking care of yourself; 2) Finding a routine; and 3) Not knowing what to expect. Taking care of themselves involved accepting the diagnosis, learning more about the infant’s condition, becoming organized and accepting help. Taking care of themselves after the diagnosis of their ISHSN was not a priority.</td>
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<td>The learner will be able to describe differences parent perceptions in three racial/ethnic groups on 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 (ISHCN).</td>
<td>Results showed more Black and White than Hispanic parents described learning about the diagnosis and being prepared to care for their ISHCN as important for building self-confidence in organizing the care for their ISHCN. More Hispanic and Black parents wanted to provide care for their ISHCN by themselves. In this study, 8 (53%) of the parents (4 Hispanic, 2 Black, 2 White) were discharged home without home nursing services. More Black and White than Hispanic parents discovered many additional needed services after the first difficult year. The Spanish-speaking only parents had difficulty finding and accessing the resources.</td>
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Abstract Text:

Background

Advances in medical technology have increased the survival rates for high risk, compromised infants, but not without a high prevalence of associated life-long morbidity. Consequences of these advances are a group of infants and children who require continuous care that enables them to survive and thrive. Many require complex extended therapeutic care and procedures after discharge including tracheostomy tubes, gastrostomy tube feedings, urinary catheters, injections, painful treatments or other special health care needs at home. This early period after the diagnosis is very stressful, physically and psychologically for parents, requiring them to learn to care for their infant with special health care needs (ISHCN), other children, and meet employment and other household demands. Previous research has documented many challenges faced by parents providing care for older children with special health care needs (CISHCN) and the long-term consequences on parent health and functioning. Few studies examine parents’
perceptions of what was needed for them to remain healthy and functioning in the challenging first year after the diagnosis and hospital discharge of their ISHCN.

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 ISHCN in three racial/ethnic groups.

Design and Methods

This qualitative study used a semi-structured interview guide asking what parents of ISHCN 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?” A purposeful sample of 15 parents (14 mothers, 1 father) with medically complex technology-dependent children were recruited from a previous study (2011-2013) on child and family health outcomes. Parents average age was 43 years; 40% Hispanic, 27% Black, and 33% White; 64% had partners; and 36% were not employed. Interviews were audio recorded, transcribed verbatim, and analyzed using conventional content analysis. Data were managed using the software package ATLAS/ti.

Results

Parents described three main themes: Taking care of yourself; Finding a routine; and Not knowing what to expect. Taking care of themselves involved accepting the diagnosis, learning more about the infant’s condition, becoming organized and accepting help. Taking care of themselves after the diagnosis of their ISHSN was not a priority. More Hispanic than Black or White parents recognized the lack of self-care affected their own physical health. Finding a routine involved finding available resources, competent caregivers, maintaining continuity of care, and finding social networks. More Black and White parents than Hispanic parents discovered additional needed services after the first year. Spanish-speaking parents had difficulty finding and accessing resources. Not knowing what to expect included care requirements/coordination needs, difficulty with the eligibility process, family problems, and initial support ending. More Hispanic and Black parents reported delays in services due to not knowing different eligibility requirements for each service or agency. Understanding what parents perceive as needed to help them remain healthy and functional over the difficult first year after diagnosis is essential. The study adds to nursing knowledge by including parents in three racial/ethnic groups and focusing on parents of ISHCN in the first year after the diagnosis.

Practice Implication

Nurses need to offer guidance and support on what the parents perceive as needed to help them remain healthy and functional over the difficult first year after the diagnosis of an ISHCN. This includes encouraging self-care routines to promote parent health and prevent parent illness. Parents need to be encouraged to find out how the new therapeutic care routines can be incorporated within their family daily life. Discharge education and training sessions should include other family members willing to help the parents at home. Prior to discharge, parents should be introduced to support groups available outside the hospital for continued support. An updated list of local services with correct contact information given to the parents would be very helpful.