Parents of Children with Down Syndrome and Their Interactions with Pediatric Health Care Providers

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Background

- Parents are often dissatisfied with health care provider interactions at the time of their child’s initial diagnosis with Down Syndrome (DS)
- Literature is lacking in describing parental experiences, beyond the initial diagnosis, with primary pediatric health care providers (PPHCPs), as their child ages.
- Health supervision guidelines for children with DS clearly state the PPHCPs need to counsel parents of children with DS throughout pediatric care.
- Guidelines lack specific information on communication techniques, or parental experiences

Purpose

To gain a deeper understanding of parent’s, who have a child with DS, personal experiences with their child’s PPHCPs.

Method

- Qualitative inquiry, descriptive phenomenological methodology
- 10 parents with a school-aged child with DS between 6 to 11 years of age, self-identified as the child’s primary care taker
- Recorded, semi-structured interviews, transcribed
- NVivo software used to organize and analyze these data
- Colaizzi’s (1978) method used to identify themes that describe the phenomenon.

Sample Characteristics

Characteristics	Count
Child Gender	
Male	6
Female	4
Child Age	
6 – 8 y	8
10 – 11 y	2
Health Care Conditions	
1-2	2
3-6	6
>7	1
Unassigned	1
Race	
Caucasian	6
American Indian	1
Asian	1
Black	1
Not reported	1
Suburban residence	8
Rural residence	2

Characteristics	Count
Parent Gender	
Male	1
Female	9
Parent Age	39 - 50
Married	10
Highest Degree	
Bachelors	7
Masters	1
Doctorate	2
Employment	
Employed	8
Not employed	2
Income	
\$50K-99K	2
\$100K - 199K	2
≥\$200,000	5
Unassigned	1
Private Insurance	10
PPHCP type	physician 8
	unassigned 2

Results

Implications for Research and Practice

- Future studies
- Further training in healthcare education
- QI project in primary care settings

Conclusion

- Insight on communication and interactions
- Parental needs are an important consideration in this setting
- Parents are advocates for their children with Down Syndrome
- PPHCPs interactions with parents on condition-specific health education and anticipatory guidance can direct relationship-based care necessary to optimize outcomes of the child with DS