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Parent Need and Impact on Family for Parents whose Children have Special Healthcare Needs

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Statement of the Problem: Parenting a child with special healthcare needs adds to the everyday parenting challenges as parents become caregivers. When providing care for a child with special healthcare needs often the increasing needs of parents are overlooked. Unmet parental needs may lead to stress, anxiety, and depression.

Purpose: To examine the relationship among a child's special healthcare need, parent need, and family impact; and to identify attributes that mitigate parent risk and maladaptive behaviors.

Subjects: A convenience sample of 33 parents/guardians of children enrolled in a mid-Atlantic coordinated health service plan has been identified, invited and signed consents. Each parent/guardian had at least one child with special healthcare needs. HSCSN is a Washington, DC Medicaid health plan exclusively for children and young adults with special healthcare needs.

Methodology: This research is a mixed quantitative and qualitative descriptive methodology that combines measures of parents' needs and impact on the family with open-ended interview questions probing personal experiences of parenting a child with special healthcare needs. Parent Needs were measured using the Parent Need Scale (PNS) and impact on the family was measured using the Impact on Family Scale (IFS). The interview was a, rehearsed, semi-structured set of questions conducted via telephone in privacy lasting 20-30 minutes, transcribed and prepared for analyses. The reason for combining both quantitative and qualitative data is to gain a better understanding of how a child's special healthcare need effects the family system and parental need; as well as to gain a better understanding of the attributes mitigate parent risk and maladaptive behaviors.

Results: Findings from the qualitative interviews suggest that this sample of parents and guardians demonstrate personal strength and have environmental support. Themes identified were hope, determination, self-reliance, optimism, acceptance, connection and involvement. Scores from the scales represent parents and guardians reported level of need and illness impact on the family. Mean scores on the Parent Needs Scale for both "Parenting in General" and "Parenting a Child with Special Healthcare Needs" represent how parents report problems at this time. On average these parents and guardians indicated a low level of need at the time of the interview ($m=1.1, 0.8$). Mean scores on the Impact on Family Scale may represent a level of illness that is not acute. On average these parents and guardians agreed with statements indicating their child's special healthcare need did have a "Total Impact", "General Impact" and "Financial Impact" on the family ($m = 2.6, 2.5, 2.6$); however on average they disagreed with statements indicating there was a "Disruption of Social Relations" ($m=2.3$). The mean score for "Coping" showed that these parents and guardians agreed with statements indicating they are positively coping with the impact their child's special healthcare need has had on the family ($m=1.7$). There is a statistically significant correlation among factors in both scales. The PNS may be a better tool to understand parents' needs. Participation in support groups offered through HSCSN appears to have had a positive effect on the parents reported level of need and illness impact on the family. "Participation in Support Groups" uniquely accounts for 19% of variance in the dependent variable "Parenting a Child with Special Healthcare Needs" ($\beta = -.546, t = -2.643, p = .016$).

Implications: Nurses foster individual strength and assist parents and guardians in the navigation and negotiation of support services. Measuring parents' needs allows nurses to offer appropriate interventions to support parents and guardians as they care for their child. Future implications may suggest how education, policy, practice and research be used to better fit the needs of parents and guardians of children with special healthcare needs.