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Analysis of Care Coordination for Children with Special Health Care Needs: a Parent's Perspective

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Background

Care coordination involves organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve improved outcomes. In recent years there has been a focus to improve care coordination nationally. Compared to the national average, a higher percentage of Vermont children are cared for in an office that meets medical home criteria. However, there is limited research on medical home and care coordination for children with special health care needs (CSHCN) in the state of Vermont.

Objectives

The goal of this study was to assess family perceptions, knowledge, and attitudes about how well care coordination is working for Vermont families with CSHCN.

Methods

A paper and an electronic anonymous survey was developed for Vermont families with CSHCN. The surveys were then distributed by Vermont Family Network and the UVMCC Department of Pediatrics. 30 surveys were initiated by participants.

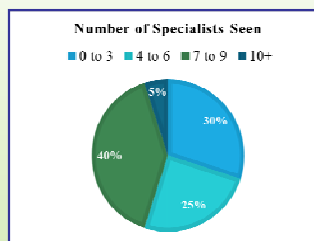
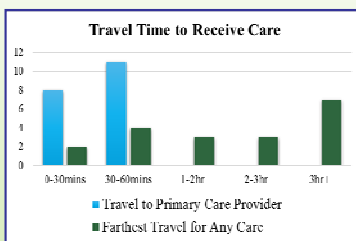
Focus group interviews were also conducted at Vermont Family Network to provide family insight to explain the quantitative data.

Survey Response Rate	Number	Percentage
Eligible to complete survey	20	67%
Ineligible to complete survey	9	30%
Did not complete survey	1	3%

Results

Fast Facts

100% of respondents were parents
95% of respondents were female
79% of respondents were over 40 years of age
69% of respondents were the primary caregivers for 2 or more children
58% of respondents were residents of Chittenden County



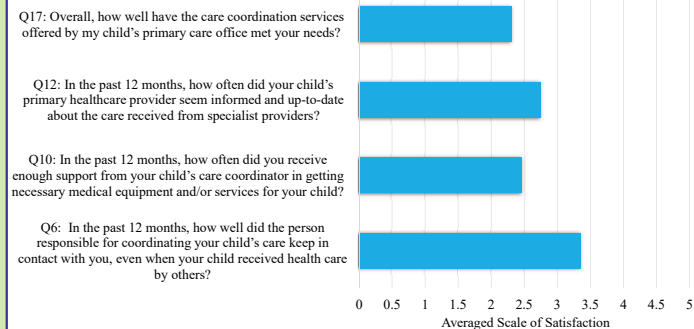
Quotes from Parents Regarding Barriers to Care Coordination

- “We had to educate our coordinator on what should be covered [by insurance]. It took us a good three weeks of constant phone calls to get what we were legally qualified for.”
- “...the communication [is] huge...the care and relationship are so important.”

Quotes from Parents Regarding Successful Care Coordination

- “Care conferences are a huge asset...the parent is a part of the team, not the one having to own all the information.”
- “We are 100% covered by our care coordination, it wasn't like that a few years ago because this has been an evolution.”

Care Coordination Survey Results



Discussion

Overall, the findings indicate that families are not satisfied with the level of care coordination currently provided.

- Composite Satisfaction Score*: 54%
- Barriers to adequate care coordination include but are not limited to: lack of access to care coordination services during transitional periods, lack of communication between health care providers, insurance formalities, and outsourcing of medical services outside of hospital network (i.e. Care in Boston although primary care is provided in Vermont)
- Sample size (n=20) limited the ability to conduct specific statistical analysis to prove significance. Therefore, future directions include recruiting the involvement of more families receiving care coordination services.

*: Composite Satisfaction Score = $\sum(\text{average of questions \#6, 10, 12, 17})$

Recommendations

- Care Conferences
- Individualization of services
- Family Centered Care
- Provision of educational materials for families within the clinic setting
- Provider education on complex health care needs
- Pre/post appointment phone calls

References

1. Farmer, Janet E., PhD, et al. "Pediatrics." Comprehensive Primary Care for Children with Special Health Care Needs in Rural Areas 116.3 (2005): 649-56. Print.
2. Homer, Charles, et al. "A Review of the Evidence for the Medical Home for Children with Special Health Care Needs." Pediatrics, Vol. 122 Issue 4, October 2008.
3. Rafferty, Judith S., MD, et al. "The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model." Pediatrics 113.5 (2004): 1507-516. Print.
4. Ruucci, Paola, et al. "Measuring Parents' Perspective on Continuity of Care in Children with Special Health Care Needs." Int J Integr Care International Journal of Integrated Care 15.4 (2015): n. pag. Web