Long-term pediatrician outcomes of a parent led curriculum in developmental disabilities

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A B S T R A C T

Previous research has demonstrated high satisfaction and perceived relevance of Project DOCC (Delivery of Chronic Care), a parent led curriculum in developmental disabilities, across a sample of medical residents.

Aims: The influence of such a training program on the clinical practices and professional activities of these residents once they are established in their careers as physicians, however, has not been studied; this was the aim of the present study.

Methods: An anonymous follow-up survey was designed and disseminated to physicians who participated in Project DOCC during their one-month developmental disabilities rotation as part of their pediatrics or medicine/pediatric residency between 2002 and 2010. Fifty-eight physicians completed the survey.

Results: The findings suggest that participation in a parent led curriculum during medical residency had a lasting impact on physicians’ relationships with families. Specifically, a majority of the physicians espoused a family-centered approach to care, a sensitivity to the interactional effect that caring for a Child with Special Health Care Needs (CSHCN) has on family members, the need for physicians to have a prominent role in community resource coordination, and the importance of an integrated approach to health care provision.

Conclusions: Use of a parent led curriculum as a means to increase the provision of family-centered care by physicians is supported.

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1. Introduction

A family-centered perspective in the provision of medical care has been shown to have positive health outcomes for families and children with special health care needs (CSHCN) (American Academy of Pediatrics, 2012; Kuhlthau et al., 2011; Kuo, Bird, & Tilford, 2011). This perspective acknowledges the family as the foundation and one of the few traditional constants in a child’s life and, as such, a crucial member of a collaborative health care team (Johnson & Kastner, 2005).
For health care to be delivered in an effective manner, primary care physicians must develop a close relationship with the family so that they can collaborate with each other and other professionals in providing effective care for CSHCN, realizing that satisfaction and health outcome is greatest if joint parent-physician involvement in treating the child occurs (American Academy of Pediatrics, 2002; Ziring et al., 1999; Rossignol, 2015). Despite these findings, the implementation of family-centered practices by primary care physicians is perceived by many parents as lacking. In the 2009–2010 National Survey of Children with Special Health Care Needs, only 62.7% of parents of CSHCN reported they were “very satisfied” with the communication among their child’s doctors and other allied health care providers, 53.1% with communication between their child’s doctor(s) and school when care coordination is needed, and 57.8% with receipt of assistance to help coordinate care among different doctors or community services when needed (Smalley, Kenney, Denboba, & Strickland, 2014).

As a means to address the lack of family-centered care in medical education, Project DOCC℠ (Delivery of Chronic Care) was developed in 1994 by a group of parents to educate physicians-in-training about what families with CSHCN experience at home and outside traditional hospital and clinic settings. The authors of Project DOCC℠ developed a structured curriculum, directed and delivered by parents, with a Parent Interview, Home Visit, and Grand Rounds presentation as the central components (Appell, Hoffman, & Speller, 1994). By 2009, this parent led curriculum had been presented to over 1000 students at more than 20 hospitals and medical schools across the United States (Associated Press, 2009).

The Parent Interview consists of a guide of 50 interview questions about the pregnancy, birth, early development, and current status of the child with a disability or chronic health condition. The interview also includes questions about relationships among family members (e.g., siblings), the home environment, school, and other elements of the child’s culture and world. This one-hour interview is conducted in a clinical setting with one parent trainer.

The Home Visit is an experiential learning component conducted by two parents, the host family and a parent from a second family, who provide a variety of different viewpoints to the residents. The host family takes the residents through their home and talks about a day in the life of the child and family. The residents are shown medical equipment, adaptations, accommodations, and the child’s room with emphasis placed on barriers and solutions to common problems faced by the child, parents, and family. Parental, marital, and sibling issues are discussed as well as behavioral problems, financial and insurance issues, school problems, and community resources. The second parent is an agency director, teacher, or advocate who also has a CSHCN and has worked with families with a broad range of disabilities. To extend the family perspective beyond that of the host family, the second parent speaks about different needs and long-term concerns pertinent to other families of CSHCN. A third component, Grand Rounds, is periodically organized as a project overview by the clinical supervisor of the residents and the coordinator of Project DOCC℠. The presentation is developed for all pediatric residents and many practicing pediatricians at the local medical school.

In 2002, Project DOCC℠ was introduced into the pediatric and medicine/pediatric residency programs at the University of Tennessee Health Science Center (UTHSC). The experience was coordinated by developmental pediatric and parent faculty of the Boling Center for Developmental Disabilities and delivered during the residents’ one-month required Developmental-Behavioral Pediatrics rotation. Project DOCC℠ is supported through the Boling Center for Developmental Disabilities’ Leadership Education in Neurodevelopmental and related Disabilities (LEND) project. A cadre of approximately 25 families who are at least two years post-diagnosis participate in the program on a rotating schedule. Common chronic health and disability conditions represented within families include Autism Spectrum Disorder, Intellectual Disability, Down and VATER Syndromes, ADHD, Learning Disabilities, Spina Bifida, and Cerebral Palsy. Families receive a modest stipend for their participation. In part, because of its high prevalence rate (Centers for Disease Control and Prevention, 2010), the majority of participating families have a member with an Autism Spectrum Disorder. This has been instructive to residents, considering that a majority of parents of children with autism have reported their primary care physician does not address a majority of autism-specific, family-centered needs (Carbone et al., 2013).

Kube, Bishop, Roth, & Palmer (2013) evaluated the short-term outcomes of the curriculum in a sample of 112 residents immediately after completing their rotation. Residents were highly satisfied with the curriculum and believed that the experience would be relevant to their future practice. These findings are consistent with the few, smaller studies that exist in the literature and support the assertion that this type of training program could have a positive impact not only for residents (Wysocki, Gururaj, Rogers, & Galey, 1987) but also mixed groups of medical students and residents (Blasco, Kohen, & Shapland, 1999).

The Project DOCC℠ program continues to be an essential component of resident education at the Boling Center. However, the degree to which participation in a parent led curriculum in developmental disabilities during medical residency impacts physicians’ subsequent relationships with families and their role within the community is not known. The aim of the present study was to survey former residents, now practicing pediatricians, to evaluate the long-term outcomes of this program with respect to their current practice in developmental disabilities. It was hypothesized that physicians would rate their DOCC℠ experience during their pediatric and medicine/pediatric residencies as relevant to their current professional activities and clinical practice.
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