

Research Paper

Using an evidence-based online module to improve parents' ability to support their child with Developmental Coordination Disorder

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Abstract

Background: Developmental Coordination Disorder (DCD) is a prevalent neurodevelopmental disorder. Best practices include raising parents' awareness and building capacity but few interventions incorporating these best practices are documented.

Objective: To examine whether an evidence-based online module can increase the perceived knowledge and skills of parents of children with DCD, and lead to behavioral changes when managing their child's health condition.

Methods: A mixed-methods, before-after design guided by the Theory of Planned Behavior was employed. Data about the knowledge, skills and behaviors of parents of children with DCD were collected using questionnaires prior to completing the module, immediately after, and three months later. Paired *T*-tests, sensitivity analyses and thematic analyses were performed on data as appropriate.

Results: One hundred-sixteen, 81 and 58 participants respectively completed the three questionnaires. For knowledge and skills, post- and follow-up scores were significantly higher than baseline scores ($p < 0.01$). Fifty-two (64%) participants reported an intention to change behavior post-intervention and 29 (50%) participants had tried recommended strategies at follow-up. Three themes emerged to describe parents' behavioral change: sharing information, trialing strategies and changing attitudes. Factors influencing parents' ability to implement these behavioral changes included clear recommendations, time, and 'right' attitude. Perceived outcomes associated with the parental behavioral changes involved improvement in well-being for the children at school, at home, and for the family as a whole.

Conclusions: The online module increased parents' self-reported knowledge and skills in DCD management. Future research should explore its impacts on children's long-term outcomes. © 2016 Elsevier Inc. All rights reserved.

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Providing information to families is a key strategy to effectively manage many childhood chronic conditions, including Developmental Coordination Disorder (DCD).^{1,2} DCD is a prevalent (5–6%) health condition that

impacts on children's everyday functioning in self-care (e.g., dressing), academic tasks (e.g., handwriting) and motor activities (e.g., riding a bicycle).^{3,4} Without appropriate support, these children are at increased risk of depression, anxiety, decreased self-esteem and physical fitness, and childhood obesity.^{5,6} Despite the fact there is a consensus on the importance of providing information to families to raise their awareness about the condition and build their capacity to manage the health condition,^{1,2} parents of children with DCD often report having a lack of information,⁷ which echoes parental reports for other childhood disability conditions.^{8,9}

Relatively few interventions have been developed specifically to increase parents' awareness of, and capacity to manage, DCD. Information sharing between clinicians and parents is often part of service delivery models, such as the Partnering for Change model, where occupational therapists share information and build capacity in

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teachers and parents.¹⁰ Likewise, some rehabilitation centers provide parents with information sessions to help them better understand DCD.¹¹ However, in such interventions, sharing information is perceived to be part of the general responsibilities of therapists and the outcomes related specifically to sharing information with parents are not documented. Physicians and rehabilitation professionals can, however, use specific interventions to increase parents' awareness of DCD and build their capacity to manage the health condition. These professionals are ideally positioned not only to provide information about DCD, but also to recognize and facilitate its diagnosis as families often consult with them about coordination difficulties, failure to develop motor skills or problematic behaviors.^{12,13} Nevertheless, busy clinicians do not always take/have the time to discuss these issues thoroughly with parents and to provide them with all the information they need.

Many families rely on the Internet to look for information and understand their health issues,^{14,15} especially in relation to chronic conditions.¹⁵ The quality of the information found on the internet can be highly variable, and therefore it has been suggested that health professionals should be proactive in directing families to high quality, evidence-based sources,¹⁶ and provide feedback on information their patients discover on the internet.^{17,18} In the DCD field, very little research has been done to investigate how the internet could be used to increase DCD awareness and build capacity. In one study, a virtual platform with suggested readings was provided to parents and a clinician was available to speak with family by phone. Parents were satisfied with the intervention but no other outcomes were evaluated.¹⁹ Likewise, a DCD online module was developed and posted on a childhood disability research center website; preliminary results highlighted improvement in self-perceived knowledge and skills but no information was available with regards to change in behaviors.²⁰ In childhood disability in general, a systematic review of internet-based self-management interventions for youth with chronic health conditions found conflicting evidence regarding the interventions' ability to improve disease-specific knowledge and quality of life.²¹ Authors of this review concluded that we are just beginning to understand how internet-based resources could improve outcomes for children with disabilities.

This study investigated whether an evidence-based online module would increase parents' perceived knowledge of, and skills in, managing their child's DCD. We hypothesized that the module would have an immediate and a short-term impact on self-perceived knowledge and skills, and thus knowledge and skills scores would be higher immediately after viewing the module and three months later compared to scores before viewing the module. Given that the online module proposed practical strategies, we also intended to document

participants' self-reported behavioral changes at three months with regards to how they managed their child's DCD. We also aimed to explore the outcomes of the behavior change, as well as the factors influencing parents' ability to change behavior.

Methods

This project was approved by the Rehabilitation Interdisciplinary Research Center and the Hamilton Integrated Ethics Research Board.

Design

This knowledge transfer (KT) intervention study used a pre-post mixed-methods design with a collaborative approach guided by the Knowledge-To-Action (KTA) model²² to examine the uptake of evidence by parents in the management of DCD. Specifically, this study addressed one of the last phases of the KTA cycle – evaluation of the outcomes. The Theory of Planned Behavior²³ was used to guide the data collection. Core concepts of this theory stipulate that attitude, subjective norms and perceived behavioral control influence behavioral intention, which in turn influences behavior. More specifically, we used the extent of DCD knowledge to document attitude (because beliefs are related to the understanding of the disability) and self-perceived skills to manage DCD to document perceived behavioral control. Data about beliefs and self-perceived skills were collected before, immediately after and three months following viewing the module. In the post-intervention questionnaire, we also included questions to document changes participants wished to implement with regards to how they manage their child's DCD (*their behavioral intentions*). In the three months follow-up questionnaire, questions documented changes reported following completion of the module (*the behavior changes*). Interpretation of results was also informed by the Theory of Planned Behavior²³ to explore how behavioral changes, outcomes and factors influencing changes related to participants' attitudes, subjective norms and perceived behavioral control.

Intervention

The evidence-based DCD online module was a French translation and Québec adaptation of a self-help tool developed by international experts at *CanChild* that had been piloted successfully in Ontario²⁰ (although both are Canadian provinces, English is the spoken language in Ontario while French is the spoken language in Québec. Moreover, health care systems are of provincial jurisdiction and thus services differed across provinces). Adaptations to the module were minor, as an advisory committee composed of clinicians and parents perceived that the information was relevant for individuals in Québec. Modifications included providing information about the services in Québec (rather than in Ontario) and adding resources written in French

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