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

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Keywords: Motor Skills Disorders; Translational Medical Research; Rehabilitation; Pediatrics; Family

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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 behavioural changes when managing their child's health condition.
Methods : A mixed-methods, before-after-follow-up design guided by the theory of planned behaviour was employed. Data about the knowledge, skills and behaviours of parents of children with DCD were collected using questionnaires prior to completing the module, immediately after, and three months later. One-way repeated measures ANOVAs and thematic analyses were performed on data as appropriate.
Results : Fifty-eight participants completed all questionnaires. There was a significant effect of time on self-reported knowledge [F(2.00,114.00)=16.37, p=0.00] and skills [F(1.81,103.03)=51.37, p=0.00] with higher post- and follow-up scores than pre-intervention scores. Thirty-seven (65%) participants reported an intention to change behaviour post-intervention; 29 (50%) participants had tried recommended strategies at follow-up. Three themes emerged to describe parents' behavioural change: sharing information, trialing strategies and changing attitudes. Factors influencing parents' ability to implement these behavioural changes included clear recommendations, time, and 'right' attitude. Perceived outcomes associated with the parental behavioural 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 outcomes long-term.

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December 16, 2015

Editors-in-Chief
Disability and Health Journal

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

Dear Editors.

Enclosed please find the research article entitled "*Using an evidence-based online module to improve parents' ability to support their child with Developmental Coordination Disorder*"– for consideration by Disability and Health Journal. The article consists of a mixed-method, before-after trial with a three-month follow-up. In this trial, parents of children with Developmental Coordination Disorder (DCD) completed an online evidence-based module providing information and strategies to manage this prevalent and potentially disabling chronic health condition.

This manuscript will be of interest to your journal as the families of children with motor delays, or "suspected DCD", typically visit physicians and many other health care professionals to find out "what is wrong with their child". Previous papers have suggested that providing evidence-based information to families is a key strategy in equipping families to support their children with DCD. However, no specific intervention has been tested so far to evaluate the impact of providing information to families. This study evaluated whether an evidence-based online module could increase parents' self-perceived knowledge and skills to manage DCD; parents' behavioural changes at three months; the perceived outcomes of these changes; and the factors influencing these changes. As you will note, our study found positive and important results suggesting the utility of this type of evidence-based online module as an intervention to improve health outcomes of children with disabilities such as DCD.

We declare that this manuscript is original and has not been previously published and has not been submitted elsewhere. There are no similar publications of this study by the authors. All individuals listed as authors meet the appropriate authorship criteria (CC, CM, DA and KST designed the study; CC, VF, CGB and JB collected and analysed the data; CC drafted the manuscript and all authors revised it). Nobody who qualifies for authorship has been omitted from the list. Contributors and funding sources have been properly acknowledged. Authors and contributors have approved the acknowledgement of their contributions. All authors had complete access to the study data that support the publication. Written permission was obtained from all persons named in the Acknowledgments and participant consent was collected.

Thank you for considering this manuscript for publication in Disability and Health Journal
Sincerely,

Chantal Camden and co-authors

***Title page (with author identifiers)**

Running title: Online evidence-based module on DCD

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

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 behavioural changes when managing their child's health condition.

Methods : A mixed-methods, before-after-follow-up design guided by the theory of planned behaviour was employed. Data about the knowledge, skills and behaviours of parents of children with DCD were collected using questionnaires prior to completing the module, immediately after, and three months later. One-way repeated measures ANOVAs and thematic analyses were performed on data as appropriate.

Results : Fifty-eight participants completed all questionnaires. There was a significant effect of time on self-reported knowledge [F(2.00,114.00)=16.37, p=0.00] and skills [F(1.81,103.03)=51.37, p=0.00] with higher post- and follow-up scores than pre-intervention scores. Thirty-seven (65%) participants reported an intention to change behaviour post-intervention; 29 (50%) participants had tried recommended strategies at follow-up. Three themes emerged to describe parents' behavioural change: sharing information, trialing strategies and changing attitudes. Factors influencing parents' ability to implement these behavioural changes included clear recommendations, time, and 'right' attitude. Perceived outcomes associated with the parental behavioural 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 outcomes long-term.

Introduction

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 teachers and parents[10]. Likewise, some rehabilitation centres 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 behaviours[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 centre website; preliminary results highlighted improvement in self-perceived knowledge and skills but no information was available with regards to change in behaviours [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 increase self-perceived knowledge and skills and that this increase would be maintained over time. Given that the online module proposed practical strategies, we also

intended to document participants' self-reported behavioural changes with regards to how they managed their child's DCD. We also aimed to explore the outcomes of the behaviour change, as well as the factors influencing parents' ability to change behaviour.

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-follow-up mixed methods design with a collaborative approach guided by the Knowledge-To-Action (KTA) model[22] to examine the uptake of evidence 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 behaviour[23] was used to guide the data collection. Core concepts of this theory stipulate that attitude, subjective norms and perceived behavioural control influence behavioural intention, which in turn influences behaviour. More specifically, we used 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 behavioural control. We included additional questions in the post-intervention questionnaire to document changes participants wished to implement with regards to how they manage DCD (their behavioural intentions). In the follow up phase, questions documented changes reported three months following completion of the module (the behaviour changes). Interpretation of results was informed by the theory of planned behaviour[23] to explore how behavioural changes, outcomes and factors influencing changes related to participants' attitudes, subjective norms and perceived behavioural 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 Ontario[20]. 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 (instead of in English). The online module takes about 1-2 hours to complete and includes information about: 1) Characteristics of DCD, 2) DCD at school, 3) DCD at home, 4) DCD during play time, 5) Strategies to manage DCD, and 6) Spread the Word - which contains additional resources to learn more about DCD. The module builds on effective knowledge translation strategies including the use of multimodal interactive components[24–28] and includes a case scenario, videos, experiential exercises, PDF resources, and links to other websites. The French DCD online module was posted on *CanChild's* website (http://dcd.canchild.ca/Fen/dcdresources/workshops.asp) and was freely accessible to visitors.

Setting and Participants

A convenience sampling method was used. Parents who self-reported having a child with a confirmed or suspected diagnosis of DCD, spoke French and had never seen the DCD online module before were included in the study. Participants were recruited between November 2014 and February 2015 through three different strategies: 1) a pop-up ad presenting the study opened when visitors came to the DCD website; 2) health professionals from two Quebec rehabilitation centres offering services to children with DCD invited their clients. Pamphlets about the study were also posted in the waiting room and on their websites; 3) the Québec parent association for children with DCD invited parents and disseminated information about the study in newspapers, and on their website and Facebook page. Parents also used social media to share information. All

of these recruitment strategies referred potential participants to an electronic consent posted on Survey Monkey®. Following electronic consent, participants were automatically referred to the first of three questionnaires.

Outcome Measures and Analysis

The pre-, post- and follow-up questionnaires included closed and open-ended questions to document self-reported: knowledge about DCD, skills in managing DCD, intention to change how they managed DCD, behavioural changes in managing DCD three months after completing the module, perceived outcomes of these changes and factors influencing their ability to change. Although some questions varied across questionnaires, 8 of 11 items about knowledge and skills were included in all questionnaires to document change over time (see Table 3). These questions used a 7-point Likert scale (ranging from 1=not at all to 7=very well). All questionnaires were based on those used in previous DCD studies[20,29] and were reviewed by health professionals and parents. Overall, the pre-intervention questionnaire contained 40 items (37 close-ended questions and 3 open-ended), including background information (e.g., children's age, services received); the post-intervention questionnaire contained 32 items (28 close-ended questions and 4 open-ended), and the follow-up questionnaire included 42 items (33 close-ended questions and 9 open-ended). Questions to document behavioural intentions were included in the post-questionnaire only (e.g., following this online workshop, do you intend to change something about how you manage your child with DCD? Please explain). Questions to document behavioural changes (e.g., please provide examples of things you changed, or tried to change), factors influencing behavioural changes (e.g., please describe anything that could have influenced, positively or negatively, your ability to implement desired changes) and perceived outcomes associated with these changes (e.g., please describe the impact of these changes on your child, your family and

your environment) were included in the follow-up questionnaire only.

Questionnaires were posted on Survey Monkey®. Following completion of the pre-questionnaire, participants were directed to the online module. Upon completion of the module, a pop up window appeared at the top of the screen inviting participants to respond to the post-intervention questionnaire. If needed, a research assistant sent an email reminder one week after completion. Three months later, participants received an email with a direct link to the follow-up questionnaire.

Analysis

Descriptive statistics (means, standard deviations and frequencies) were calculated as appropriate for each close-ended item. To eliminate potential sources of bias between lost-to-follow up participants and participants, paired t-tests were performed on self-reported knowledge and skills scores. For participants, total mean scores were computed for DCD knowledge and DCD skills, and repeated measures ANOVA including post hoc comparisons were performed using SPSS 22 to evaluate significant changes throughout the 3 time points. Thematic analysis of open-ended questions was conducted followed Braun and Clarke's principles[30]. Specifically, two co-authors (CG and VF) generated initial codes and met with a third reviewer (CC) to identify themes and achieve consensus. Qualitative information and quotations (translated from French) were interpreted based on the theory of planned behaviour to illustrate key themes around management of DCD. Since this is a mixed-methods study, qualitative data were used to provide a greater understanding of the descriptive statistics with regards to self-perceived changes in behaviours, and to explore outcomes and factors influencing changes.

Results

One hundred thirty-eight (138) parents consented to participate and completed the pre-questionnaires; 81 completed the post-questionnaire and 58 completed all three. There were no differences in knowledge ($p \geq 0.08$) and skills ($p \geq 0.16$) between those who completed only one or two questionnaires and those who completed all three.

Table 1 presents the socio-demographic details of the participants and Table 2 presents the services participants reported receiving prior to the study.

[Insert Table 1 and Table 2 about here]

Impact of the DCD online module on parental knowledge and skills

There was a significant effect of time on self-reported knowledge [$F(2.00,114.00)=16.37$, $p=0.00$] and skills [$F(1.81,103.03)=51.37$, $p=0.00$]. Post-hoc analyses showed post-intervention and follow-up scores (of both knowledge and skills) were higher than pre-intervention but there was no significant difference between post and follow-up scores. Mean scores and comparisons are presented in Table 3.

[Insert Table 3 about here]

Parents' intention to change how they manage DCD

Immediately after completing the online module, 37 (65%) of participants reported intention to change something about how they managed their child with DCD. Three principal themes emerged: understanding DCD better; changing attitudes (e.g., reducing expectations) and trialling strategies (e.g., breaking down the task). Parents wished to understand DCD but also wanted their child and the adults around him or her to understand the condition. They planned strategies to share this information and to help others understand better. Participants also mentioned the importance of having access to the information contained on this website soon after diagnosis:

> *If it was day 1 following diagnosis, the website contains everything I would have liked to know and what I have learned from different sources. This is an excellent source of information.*

> *Talking more with my child about his difficulties and the underlying causes (not only talking about his difficulties.)*

Parents' behavioural changes regarding how they manage DCD

Table 4 presents findings from close-ended questions about behaviours related to sharing information, seeking information and trialling strategies to better manage DCD. In open-ended questions, sharing information and trialling strategies also emerged as themes reported by participants, along with changing attitudes.

[Insert Table 4 about here]

Parents shared information with different people, including the child's physician. Most parents shared general information about DCD and the website (e.g., the internet link) but some shared

specific resources, such as information about how to diagnose DCD (with physicians), specific videos, PDFs or experiential exercises (e.g., with extended family). The goal for parents was to raise awareness about DCD and to have others understand the struggles faced by their children in completing simple motor tasks, such as writing and using scissors.

Parents reported having tried different strategies recommended on the online module such as adapting activities (e.g., choosing clothes that are easier to put on) and introducing adapted tools and technology (e.g., using computers to write). Some also reported having made a life-changing decision, such as modifying work hours. One parent even reported moving in order to change their child's school.

Parents reported changing their attitudes toward their child, trying to be more patient and modifying their expectations ("*he won't be an athlete*"). Parents reported focussing more on supporting their child (rather than repeating instructions) and paying more attention to how the child's difficulties impact on confidence.

Outcomes associated with behavioural changes

The outcomes associated with these behavioural changes were closely interwoven with a greater understanding of DCD and specific to the change implemented, either at school or within the family, and lead to greater well-being for the child.

At school, better understanding of DCD by educators led to more adaptive strategies with the child with DCD, in class and for homework:

When exercises are done in big group, [the teacher] doesn't ask him to write and listen at the same time. I have the feeling she doesn't ask him as often as before to copy what is on the blackboard.

We now understand his difficulties better, what he says; we don't think anymore he is wasting his time, we know he is simply tired at the end of the day. He doesn't have the energy to write during homework, so we do it for him. We use a writing board and don't focus on the writing but on the content of the sentence and the spelling.

At the family level, better understanding of DCD by parents and the extended family led to modifications to families' daily routines and perceptions of their child, and improved quality of life.

Our family stopped saying "he is only clumsy, don't worry" or "he simply has no more energy"; they are more receptive and understand better his errors or his behaviours. They are more patient.

Everybody is happier and less stressed. DCD will always be there but we need to adapt as a family if we want to be happy.

Children with DCD benefited from these adaptations made at school and at home, and increased their well-being and self-esteem:

Academic results are spectacular, very nice school report, better self-esteem; he is also less reluctant to try new activities.

Factors influencing behavioural changes

Overall, participants reported in the follow up questionnaire that the information contained in the online module responded to their child's needs (mean=5.7/7; standard deviation= 1.2), covered what they believe is important for their child (m=5.8/7; SD=1.2) and contained practical recommendations (m=5.9/7; SD=1.2). When asked to rate factors influencing behavioural changes, participants felt that they had the necessary time and resources to implement the strategies recommended in the online module (m=4.9/7; SD=1.4) and that adults in the child's environment were open to implementing new strategies (m=4.8/7; SD=1.4). However, only half of the participants (n=29; 50%) reported having tried to implement new strategies. They mentioned having been able to only partially implement the strategies they intended to (m=4.8/7; SD=1.2) and being relatively satisfied with the outcomes of the change implemented (m=5.1/7; SD=1.3). Three themes emerged from the open-ended questions that reflected parents' responses about factors that affected their ability to make changes in how they manage DCD: having access to information with clear recommendations, being supported and finding time, and having the "right" attitude. Having the right attitude appeared to be the most important theme, and referred both to parents' attitude (i.e. developing resilience and patience) and others' attitude. Others' attitude appeared particularly important at school, where parents needed to rely on educators' willingness to implement strategies and make accommodations. Most parents reported openness and collaboration with schools, but some had negative experiences (e.g., a parent reported that one teacher said she was experienced enough and did not need more information or to be told what to do).

Discussion

This study demonstrated the impact of an online resource in increasing parents' knowledge and ability to manage DCD - an increase that was maintained at three months' follow-up. Parents reported having shared evidence-based information with others, trialled strategies, and noticed positive outcomes for the child and family. This KT intervention – the evidence-based online module on DCD – is easily accessible. Referring parents to and ensuring that they access evidence-based education could be a way for physicians and health professionals to provide families with the information they need to self-manage this chronic childhood health condition.

Previous study that piloted the English version of the DCD module reported parental satisfaction and change in knowledge and skills following completion of the website[20,29] The amount and direction of the changes reported in this study are similar to the ones found in the previous study. The qualitative information provided by this study about behavioural changes and outcomes at three-month follow-up confirms the clinical significance of these changes. The combination of the quantitative and the qualitative findings describe how targeted information (i.e. providing access to an evidence-based website) provided as a stand-alone intervention (i.e. not as part of a broader medical or rehabilitation follow up) can have a significant impact on families' lives. This finding has major implications for the delivery of service to this population. It is important for healthcare professionals, specifically physicians, to be proactive and to refer families to evidence-based websites following a diagnosis. This referral could save time, support the patient-health care professional relationship, and prevent the negative consequences associated with poor quality health information[14,15].

This is the first study to explore the benefits for children with DCD with regards to parental support through web-based information. A few other studies of the use of web-based information with other chronic conditions of childhood were found in a systematic review[21]. Results indicated most interventions involved the provision of direct services through the internet (e.g., monitoring) and evaluated disease-specific outcomes related specifically to the child's condition (e.g., pain). Our findings suggest that the outcomes of using evidence-based websites about childhood chronic conditions might be broader, and could include child and family well-being as shown through participant report of greater self-esteem and satisfaction at both the child and family levels. Website information should address child and family needs, but also target the broader environment to change societal norms, including others' attitudes. Societal norms are an important concept in the theory of planned behaviour that might greatly influence parents' intentions and their ability to change behaviours. This is illustrated particularly well in this study by parents' struggle with 'others' attitudes' that might reflect the social norm with regards to typical development and how children are expected to perform motor-related activities at home and at school. Individual and group interventions targeting parents of children with DCD might contribute to changes in their perceptions of these societal norms. However, population-based interventions raising awareness about DCD might be even more effective at changing societal norms and expectations, and ease the implementation of recommended strategies to manage chronic health conditions such as DCD.

Interestingly, when asked about their behaviour changes, parents referred to attitudes and beliefs, which in the theory of planned behaviour are considered to be separate concepts from behaviour changes. Attitudes and behaviours were, however, closely interwoven for participants, which might suggest that even in the absence of clear behaviours (i.e. tangible actions), we might

improve children's outcomes and prevent secondary consequences by working at the perception levels.

Study limitations and strengths

The use of open, online recruitment strategies and data collection limited our ability to calculate a response rate. Moreover, the data collection used self-report information and did not control for other events or interventions not related to the website. The questionnaires used were not validated cross-culturally; however, they were based on questionnaires used successfully in other DCD studies.

An important strength of the study is the involvement of our collaborators. The fact there is a DCD parent association in Québec and that rehabilitation centres offer health services to children with DCD imply that DCD is a health condition warranting attention. The integrated KT approach raised awareness among health professionals about the informational needs of families with DCD. The use of the theory of planned behaviour to ascertain behavioural changes that occurred following the intervention and after a three-month follow-up provided us with knowledge about how families used the information, and the outcomes and factors influencing their ability to change how they manage DCD. This is a strength of the study given that theoretical grounding and formal evaluation of outcomes are often missing in KT studies[31,32]. Moreover, the study aimed at evaluating an evidence-based online module on DCD; the results might be generalizable to evidence-based modules about other chronic childhood disabilities and can guide KT research in the field of rehabilitation. This study, however, justifies the need for more research using standardized measures to document parents' behavioural changes and children's outcomes.

Conclusion

This study identifies directions for practice, policy and future research in KT and the use of technology to improve health outcomes and the experience of care. Physicians and health professionals should be aware of, and refer their patients to, evidence-based websites that are useful for self-management of disabilities and chronic health conditions, such as DCD, when a diagnosis is given. Planning of services should include provision of information to families, and using evidence-based websites could offer a cost-effective solution. Future research should objectively evaluate the impact of the recommended strategies on children's lives.

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Table 1. Demographics of participants who responded to the questionnaires (n=58)

Demographics characteristics	N (percentage)
Relation to child	
Mother	49 (84.5%)
Father	9 (15.5%)
Region	
Eastern Townships	12 (20.7%)
Quebec City	6 (10.3%)
Other regions in Quebec (i.e. outside our partners' territory)	35 (60.3%)
Europe	5 (8.6%)
Child's age	
0-5 years old	9 (15.5%)
6-12 years old	44 (75.9%)
13-17 years old	3 (5.2%)
18 years old and over	2 (3.4%)
Child's sex	
Boy	41 (70.7%)
Child's having a diagnosis of DCD	
Yes	53 (91.4%)
Other diagnoses and health issues	
Attention deficit disorder with/without hyperactivity	27 (46.6%)
Learning difficulties	18 (31.0%)
Sensory difficulties	15 (25.9%)
Speech and language difficulties	18 (31.0%)
Behavioural issues	4 (6.9%)
Other (such as migraines and muscular difficulties)	4 (6.9%)
No diagnosis at all	2 (3.4%)
Autism spectrum disorders or Asperger's syndrome	0 (0.0%)
Membership	
Québec DCD provincial association (AQED)	21 (36.2%)
Another DCD association	6 (10.3%)
Another parental association	7 (12.1%)
Not a member of any association	29 (50.0%)
Knowledge about DCD association/websites	
Québec DCD provincial association (AQED)	50 (86.2%)
SOS Dyspraxie (i.e. a Québec website about dyspraxia)	37 (63.8%)
CanChild (a Canadian website about childhood disability)	11 (19.0%)
Referred to the module/study by	
My child's clinician	3 (5.2%)
The AQED	27 (46.6%)
Found on the CanChild website	2 (3.4%)
Facebook	17 (29.3%)
Other (such as word of mouth or through an internet search)	9 (15.5%)

Table 2

Table 2. Services children and families were receiving at the beginning of the study

Description of services received	**N (valid percent)**
Do you receive health/rehabilitation services or support? (n=58)	
Yes	49 (85%)
What organization(s) provide(s) you services and support? (n=49)	
Rehabilitation centre	22 (45%)
School	26 (53%)
Private clinic	16 (33%)
Community-based centre	5 (10%)
Other (e.g., hospital)	10 (20%)
What professional(s) provide(s) you services and support? (n=49)	
Physical therapist	12 (24%)
Occupational therapist	40 (82%)
Specialized educator	28 (57%)
Speech and language therapist	28 (57%)
Social worker	8 (16%)
(Neuro)psychologist	23 (47%)
Other (e.g., nutritionists, child psychiatrists and specialist in psychomotricity)	13 (27%)
Did your child have an individualized service plan(s) in the previous year? (n=58)	
Yes	44 (76%)
Where was/were the intervention plan(s) held? (n=44)	
School	43 (98%)
Rehabilitation centre	8 (18%)
Other (e.g., daycare)	3 (7%)
Were you present at the intervention plan(s)? (n=44)	
Yes	40 (91%)

Table 3. Perceived level of knowledge or competence with the following skills (n=58)

SELF-REPORTED DCD KNOWLEDGE AND SKILLS	Pre (n=58)	Post (n=58)	Follow-up (n=58)	F value (p value)	Change score & Post-hoc analysis when relevant		
	Mean (SD)				T2 vs T1	T3 vs T1	T3 vs T2
Recognizing typical characteristics of DCD	5.1 (1.3)	5.9 (1.1)	5.9 (1.0)	N/A†	+ 0.8	+ 0.8	0.0
Understanding the challenges facing the child	4.9 (1.3)	5.9 (1.1)	6.0 (1.0)	N/A†	+ 1.0	+ 1.1	+ 0.1
Understanding the impact of DCD on the child's:							
• Ability to accomplish daily tasks at home	5.4 (1.8)	6.2 (1.3)	5.9 (1.7)	N/A†	+ 0.8	+ 0.6	- 0.3
• Participation in physical activities at home	5.4 (1.7)	5.9 (1.8)	5.9 (1.9)	N/A†	+ 0.5	+ 0.5	0.0
• Participation in physical activities at school	4.7 (2.0)	5.8 (2.0)	5.7 (2.1)	N/A†	+ 1.1	+ 0.9	- 0.2
• Participation in physical activities in the community	4.9 (1.9)	6.0 (1.7)	5.8 (1.9)	N/A†	+ 1.0	+ 0.9	- 0.2
• Ability to accomplish tasks at school	5.5 (1.5)	6.0 (1.7)	6.2 (1.5)	N/A†	+ 0.5	+ 0.7	+ 0.1
• Self-esteem	5.5 (1.7)	5.9 (1.8)	6.1 (1.4)	N/A†	+ 0.5	+ 0.6	+ 0.1
TOTAL KNOWLEDGE SCORE	5.2 (0.2)	6.0 (0.2)	5.9 (0.2)	16.4 (0.0)*	+ 0.8	+ 0.8	0.0
Explaining the child's:							
• Specific motor difficulties at home	4.8 (1.5)	5.9 (1.1)	5.7 (1.3)	N/A†	+ 1.0	+ 0.9	- 0.1
• Specific motor difficulties at school	4.9 (1.4)	5.7 (1.3)	5.7 (1.3)	N/A†	+ 0.8	+ 0.8	0.0
• Specific motor difficulties in the community	4.5 (1.5)	5.7 (1.2)	5.5 (1.3)	N/A†	+ 1.2	+ 1.1	- 0.1
• Useful strategies at home	4.6 (1.7)	5.6 (1.3)	5.6 (1.4)	N/A†	+ 1.0	+ 1.0	0.0
• Useful strategies at school	4.5 (1.5)	5.6 (1.3)	5.3 (1.4)	N/A†	+ 1.1	+ 0.8	- 0.3
• Useful strategies in the community	4.1 (1.6)	5.5 (1.3)	5.3 (1.4)	N/A†	+ 1.4	+ 1.2	- 0.2
Using their current knowledge of DCD to:							
• Respond to the child's needs at home	4.8 (1.4)	5.9 (1.2)	5.8 (1.0)	N/A†	+ 1.1	+ 1.0	- 0.1
• Respond to the child's needs at school	4.3 (1.3)	5.4 (1.4)	5.3 (1.3)	N/A†	+ 1.1	+ 0.9	- 0.1
• Respond to the child's needs in the community	4.1 (1.3)	5.3 (1.3)	5.3 (1.2)	N/A†	+ 1.2	+ 1.3	0.0
• Share relevant information in response to a need	4.5 (1.5)	5.7 (1.3)	5.7 (1.2)	N/A†	+ 1.3	+ 1.2	- 0.1
• Solve issues when they arise	4.0 (1.3)	5.5 (1.3)	5.3 (1.2)	N/A†	+ 1.5	+ 1.3	- 0.1
TOTAL SKILLS SCORE	4.5 (0.2)	5.6 (0.1)	5.5 (0.1)	51.4 (0.0)*	+ 1.1	+ 1.0	- 0.1

*Significant differences (at p = 0.05) between T2 vs T1 and T3 vs T1 but not between T3 vs T2.

† N/A = Non applicable (as ANOVAS were performed on Total scores only).

Table 4. Participants' behaviour with regards to sharing information (at three months)

Description of the behaviour	N (valid percent)
Did you share information with someone? (n=58)	
Yes	48 (83%)
With whom did you share the information? (n=48)	
Child's teacher(s)	30 (63%)
Rehabilitation professional(s)	11 (23%)
Members of their family	35 (73%)
Child's doctor	5 (10%)
Coaches or group leaders	7 (15%)
Other (e.g., friends, colleagues)	15 (31%)
Did you…? (n=58)	
Contact new parents' or DCD associations (yes)	41 (71%)
Participate in new web-based discussions about DCD (yes)	26 (45%)
Visit the *CanChild* website for the first time (yes)	23 (40%)
Read new articles or books about DCD (yes)	29 (50%)
Talk/request meetings to talk to your child's teacher (yes)	25 (43%)
Seek/receive rehabilitation services (yes)	19 (33%)
Seek/receive a medical diagnostic (yes)	11 (19%)
Other significant event (e.g., requested financial aid)	6 (10%)

***Guideline/checklist (see author information)**

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Included on page:
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4-5
Methods			
Study design	4	Present key elements of study design early in the paper	5-6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	7-8-9
		Case-control study—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls	N/A
		Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants	N/A
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed	N/A
		Case-control study—For matched studies, give matching criteria and the number of controls per case	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-8
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8
Bias	9	Describe any efforts to address potential sources of bias	(17-limitation)
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	N/A

		(*c*) Explain how missing data were addressed	N/A
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed	9
		Case-control study—If applicable, explain how matching of cases and controls was addressed	N/A
		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Continued on next page			
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	10
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10 (Table 1,2)
		(b) Indicate number of participants with missing data for each variable of interest	10
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	N/A (all follow up at 3 months)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	N/A
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	N/A
		Cross-sectional study—Report numbers of outcome events or summary measures	N/A
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	14

Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Title page