

Title: Evaluation of a web platform aiming to support parents having a child with developmental coordination disorder: Brief report

Abstract

Objective To explore the effects of a web platform, aiming to support parents of children with developmental coordination disorder (DCD), on parental knowledge and skills. **Method** A randomized pilot trial was undertaken (Clinical trial XX). Parents of children 5-12 years old with suspected or diagnosed DCD were recruited. The intervention group (n=15) had access to a web platform (including resources, forum and virtual interactions) for three months. The control group (n=13) only had access to resources. The primary outcome was measured pre- and post-intervention with the Parent Knowledge and Skills Questionnaire. Pre- post-questionnaires evaluated secondary outcomes (parents' sense of competence, children's strengths and difficulties, and children's occupational performance). **Results and discussion** All outcome measures improved over time for families of the intervention group. However, those improvements were not statistically significant (p 0.075–0.414). **Conclusion** Web platforms supporting parents of children with DCD are promising and need further evaluation.

Key words

Developmental coordination disorder; Online intervention; parental support; web platform

1. Introduction

Developmental coordination disorder (DCD) is a neurodevelopmental disorder that impacts on the planning and execution of activities of daily living (e.g. dressing), school work (e.g. handwriting) and leisure (e.g. cycling).¹ Difficulties associated with DCD often lead to

numerous secondary consequences: restrictions to participation², academic difficulties³, , physical- (e.g. obesity, cardiovascular problem)^{4,5} and emotional problems (e.g. anxiety, depression, decreased self-esteem). Moreover, parents of children with DCD Best practices underline the importance of informing, supporting and coaching parents to enhance their knowledge and skills about DCD so they support their child occupational performance and reduce physical and emotional long term impact od DCD.^{6,7} Despite the unanimity on the need to support parents, there is a paucity of studies evaluating the effects of interventions aiming at supporting parentsof children with DCD .^{2,8} As parents often seek informations and support online,⁹⁻¹¹ web interventions should be explored while developing support services. To date, only one study explored the effectiveness of web information provision for parents of children with DCD.¹² This study looked at the effect of a website including static information for parents (e.g. text, video). This website allowed parents to increase their knowledge and skills about DCD, but parents felt they would have sometimes needed individualised support to implement learned information with their child.¹² Thus, we undertook a pilot trial to explore the effect of a web platform (including online access to a professionnal) aiming at supporting parents of children with suspected or diagnosed DCD . The primary outcome was parental knowledge and skills, while secondary outcomes included the parents' sense of competence, children's occupational performance and emotional strenghts and difficulties .

2. Method

2.1 Design

This pilot randomized controlled trial included two groups, with outcome measures taken at baseline and after the 3-month intervention. It is part of a trial registered with ClinicalTrial.gov (XX) and approved by the XX. Participants have given informed consent to the research. This

paper focuses on effect of the web platform; for more information on feasibility, recruitment, retention rate, platform use and satisfaction with the web platform see XX.

2.2 Participants

The target population included parents or legal guardians of a child aged 5-12 years old, with a medical diagnosis or a suspicion of DCD (i.e. referred by a family doctor and waiting for assesment by a specialist for further evaluation), a motor ability score $\leq 16^{\text{th}}$ percentile at the Movement Assessment Battery for Children-2 (MABC-2) or $\leq 5^{\text{th}}$ percentile on one of its three subscales (Manual dexterity, Aiming and Catching or Balance)¹³, without a concomitant diagnosis of mental or physical disability or autism spectrum disorder, and who had not received specialized rehabilitation intervention for DCD within the provincial public healthcare system. Participants were recruited in XX, via family doctors, hospital waiting lists, the XX association of DCD and social media. Screening was conducted over the phone to verify eligibility criteria. Moreover, an eligibility evaluation (MABC-2) was performed at the Research Center for children who had never been evaluated with this tool (children who had been evaluated by an occupational therapist in the previous year could send a copy of their evaluation).

2.3 Intervention

The intervention was designed based on intensity gradation principles to promote the use of general information by parents first, before encouraging them to seek more individualised information as needed.⁷ All participants (intervention and control group) had access to an informational resource page consisting of links to websites related to DCD including a validated evidence-based module (www.elearning.canchild.ca/dcd_workshop/fr/index.html).¹² Parents in the intervention group could also access a forum moderated by an occupational therapist who was available to answer questions and could provide information on DCD-specific topics.

Participants of the intervention group were also informed that they could directly and privately contact the occupational therapist via a chat function. If deemed necessary, the occupational therapist could also propose an appointment for videoconferencing via Cisco WebEx[®]. Parents of the two groups were provided with a username and a password to access the web platform, which was online for three months.

2.4 Study procedures and outcome measures

The battery of pre-intervention questionnaires, including the sociodemographic characteristics are detailed below and were completed by parents and children online prior to group allocation. A research coordinator, not involved in assessing participants applied a computer-generated random allocation sequence of 2:4 blocs, in order to assign participants to the intervention or control group (1:1). Study investigators and the research assistant in charge of outcomes evaluation remained blinded to participant's assignment. All measures were collected online via REDCap[®]. Links to questionnaires were sent to parents by email two weeks before the start of the intervention and immediately after the completion of the study three months later, with up to two weekly reminders for uncompleted questionnaires.

2.4.1 Primary outcome: Parent Knowledge and Skills Questionnaire (PKSQ)

Parental perception of their knowledge and skills about DCD was assessed with the Parent Knowledge and Skills Questionnaire (PKSQ). The PKSQ comprises 22 questions evaluated on a seven-point Likert scale. A total score and three sub-scores can be calculated, providing information about parental ability to: 1) Manage their child's condition, 2) Understand the impact of coordination difficulties on their child, and 3) Understand and apply knowledge about DCD. Higher scores indicate higher perceived knowledge and competencies from parents. This

questionnaire has been developed specifically for parents of children with DCD and has been used in other projects.¹²

2.4.2 Secondary outcome: Parenting Sense of Competence Scale (PSCS)

Self-perceived parental competence was evaluated with the Parenting Sense of Competence Scale (PSCS), a 17-item questionnaire using a six-point Likert scale and giving a total score out of 96. Higher PSCS scores indicate higher parental sense of competence, with scores <47 indicating a low sense of competency. This questionnaire is validated for parents of children over 6 years-old.¹⁴

2.4.3 Secondary outcome: Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) was used to assess the child's emotional and behavioural difficulties, hyperactivity and relational issues (Goodman, 2005). The parental version is validated for parents of children 4-17 years old and includes 25 questions evaluated on a three-point Likert scale giving a total score out of 40. Higher scores indicate more difficulties.¹⁵

2.4.4 Secondary outcome: Child Occupational Self Assessment (COSA)

The Child Occupational Self Assessment (COSA) was used to explore the impact of the platform on the child's occupational performance. The COSA is a clinical goal setting tool used with children 6-17 years of age.¹⁶ COSA responses are associated with a four-point Likert scale ranging from "1= I have a big problem doing this" to "4=I'm really good at doing this", generating a total score. Previous research studies using the COSA reported good test-retest reliability.¹⁷

2.5 Statistical analysis

The completion rate was calculated for each questionnaire (i.e. completed pre- and post-questionnaires divided by the number of randomized participants in each group). Missing data for pre- or post- questionnaires were excluded from statistical analysis. Based on the PKSQ previous published results, a sample size of 13 per group was needed based on calculations with $\alpha=0.05$, $\beta=0.2$, $\sigma_{\text{diff}}=19.33$ and $\mu_1-\mu_2=15.4$.¹² Normality assumption wasn't met and nonparametric analyses were performed. The U-Mann Whitney, Fisher exact and χ^2 tests were used to compare demographic data at baseline. The U-Mann Whitney test was used to compare change from baseline to post-intervention between groups. Wilcoxon signed rank test was performed to determine within-group differences over time (baseline to post-intervention). All test assumptions were verified. All statistical analyses were performed using SPSS (IBM SPSS Statistics 24). Statistical significance was set at $p<0.05$.

3. Results and discussion

In all, 39 children were assessed for eligibility between September 2016 and January 2017 (Figure I). Of those, 33 families were admissible to the study, with 28 families completing pre-intervention questionnaires and randomly assigned to the intervention (n=15) or control group (n=13). Six families (21%) did not complete the post-intervention questionnaires despite email reminders. No differences were found between groups for all demographic characteristics, motor scores and all primary or secondary outcomes at baseline (Table I).

[Insert table 1 about here]

All outcome measures improved from pre to post intervention for the intervention group. However, none of these improvements reached statistical significance when intragroup tests were performed for any measure in the intervention group (Table II) and no significant differences for

pre-post change between groups were found (p range 0.200-0.863). The study might have been underpowered to find significant changes. Another explanation, proposed by many authors, is that outcome measures currently available to evaluate the effect of intervention for children with DCD may lack sensitivity to detect changes for this specific population.^{12,18-20}

[Insert table 2 about here]

The only pre-post significant change was an intragroup improvement on parental knowledge and skills (PKSQ) for the control group ($p=0.038$). This result is consistent with studies on online modules without access to professionals, where online information is effective for increasing parental perception of their knowledge and skills.¹² However, it is surprising that this effect was not present in the intervention group, as our hypothesis was that the effect on parental knowledge and skills would increase if granted access to the entire platform (which included interactions with other parents and an occupational therapist). This might be explained by the relatively low level of activity on the forum and virtual interaction in a context of pilot trial with a small sample size (see XX for all details). In this context, because participants of the intervention group had access to more sections on the platform, they may have explored less the informational resources proposed. Moreover, the small sample size, associated with the lost to follow-up observed in the study (detailed in XX), affected the statistical power of the study. Future studies with larger sample sizes are needed to fully explore the effects of web platform aiming to support parents.

4. Conclusion

The aim of this paper was to explore the effects of a web platform aiming to support parents of children with DCD. Improvements were noted in the intervention group for all outcome

measures however, they did not reach statistical significance. Use of web platform to support parents of children with DCD is promising and needs further evaluation.

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Table I: Demographic characteristics

	Intervention group (n=15)	Control group (n=13)	<i>p</i> value
Child age, median y: mo	8:3	8:11	0.142 ^a
Child sex, n male	12	10	> 0.999 ^b
Parent sex, n female	14	13	> 0.999 ^b
Parent level of education, n >12 years	5	7	0.274 ^c
Diagnostic status, n medical suspicion of DCD	11	7	0.433 ^b
Concomitant health conditions, n yes	7	6	0.978 ^c
No access to health services, n	9	6	0.464 ^c
MABC-2, median percentile (range)	5 th (0.5-37)	9 th (0.5-37)	0.620 ^a

^a U-Mann Withney, ^b Fisher exact test, ^c χ^2

Table II: Intra-group comparisons of the effects of a web platform and control intervention on parent and children variables

	Intervention group			Control group		
	Pre	Post	<i>p</i>	Pre	Post	<i>p</i>
PKSQ, median (range) /154 (n=9-8*)	107.0 (80.0-134.0)	112.0 (100.0-116.0)	0.401	101.0 (81.0-138.0)	116.0 (102.0-142.0)	0.038
PSCS, median (range) /96 (n=8-9)*	66.0 (47.0-70.0)	68.0 (54.0-76.0)	0.075	67.0 (51.0-82.0)	66.5 (52.0-82.0)	0.397
SDQ, median (range) /40 (n=9-9)*	23.0 (9.0-27.0)	18.0 (9.0-24.0)	0.307	15.0 (8.0-28.0)	14.0 (8.0-28.0)	0.442
COSA, median (range) /108 (n=7-4)*	83.5 (82.0-87.0)	85 (83.0-87.0)	0.414	88.0 (85.0-96.0)	84.0 (79.0-89.0)	0.080

PKSQ: Parent Knowledge and Skills Questionnaire; PSCS: Parenting Sense of Competence Scale; SDQ: Strengths and Difficulties Questionnaire; COSA: Child Occupational Self Assessment.

*The number of participants varies across questionnaires; the first number refers to participants who completed the pre and post questionnaire in the control group, while the second number refers to participants who completed the pre and post questionnaire in the intervention group.