

Surveying Parental Experiences in Receipt of a Diagnosis of Developmental Coordination Disorder (DCD)

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Abstract

Being diagnosed with developmental coordination disorder will have a major impact on the children as well as their parents. After receiving a confirmatory diagnosis as developmental coordination disorder, the whole family is affected and majority of broken family has a history of growing up a child with DCD. But still a little information is documented on the experience of parents in having a child diagnosed with developmental coordination disorder (DCD). In the current study, 200 parents were enrolled and they have completed online survey regarding their experience of having received a diagnosis of DCD for their children in Indian context. Results of the current study demonstrated that after two and half years parents initiated the help from professionals with regard to their child's difficulty in motor coordination. When the satisfaction rate was evaluated, the results produced a mixed pattern. Majority of the parents included in the study were dissatisfied and only 20% of parents were satisfied. Parent's satisfaction over the diagnostic method and procedure were examined with factors like stress of the diagnostic method, the manner in which the diagnostic method applied, after the diagnostic process the support provided to the parents, time taken to complete the diagnostic process. Parents reported dissatisfaction in the post diagnostic provision and majority of the parents surprisingly didn't undergo any follow up appointments after the provisional diagnosis. The results of the current study suggest that there is a need for greater impact of DCD if not facilitated with early identification.

Keywords: DCD, Diagnostic method, parent's perception, survey on parents, satisfaction of parents.

Introduction

Characteristic feature of Developmental coordination disorder (DCD) includes difficulty in executing fine motor and gross motor skill. However the difficulties in executing the skill, impacts every activity of daily living as well as academics. Children and adults with DCD exhibit defects in executing the task that demands motor skill coordination¹. Majority of the children were diagnosed as DCD based on their performance in academics skills. Children encounter frequent failure in academics and in sports. Parents of children with DCD initially finds their coordination problem as normal and they will learn to wear their shirt and open the lunch box on their own as they

age and they fails to recognize that their child have difficulty in executing the tasks that demands coordination of bilateral upper and lower extremity. Teachers identify the children with DCD at school as they isolate themselves and prefer to be alone and avoid physical activity. Frequent isolation and trouble in interacting with peer group children at school needs consideration at the early stage of development. If not identified early, these children will have psychological disorders and few may engage in antisocial activities too. Suicidal risk was higher among adults with DCD as from the younger years of development they used to compare their growth and development with peer group children. When they exhibit difficulty in executing simple tasks like wearing the shirt and buttoning up the shirt, difficulty in tying the shoe lace will further deteriorate the child's development and they have enhanced suicidal risk. They need timely intervention and early diagnosis to avoid secondary complications.

The results of frequent failure in learning sports and academics deteriorates the child's ability in learning, thus in the due course of time, the child feels isolated and avoids the peer group children and others and prefers to be alone. Teachers in school identify the children who isolate themselves from others during physical activity sessions². Avoiding physical activity will enhance the problem behavior. In the past, researchers used to label the children with motor coordination difficulty as clumsy child, dyspraxia child and specific developmental disorder of motor function. These kinds of various terminologies used by the researchers lead to confusions in setting up the diagnostic methods and in designing rehabilitation methods.

Without the label, these children were left without a formal diagnostic method. Later in 2013, American psychiatric association labeled these children with motor coordination difficulties as Developmental coordination disorder. APA coined the difficulties faced by children with DCD and they highlighted that these children exhibit trouble in dressing, undressing and in handling utensils³. Difficulties in handling as well as gripping the pen as well as pencil are having a greater impact on writing outcome. Reduced participation in physical activities and green land play will deteriorate the child health and wellbeing. In our previous research, we have evaluated the vitamin D level in developmental coordination disorder children and concluded that due to poor participation in sports with peer group children, there is reduced exposure to the sunlight and poor green land play is quoted as a reason for vitamin D deficiency among children with DCD. At the early stage, parents and teachers must recognize the key features and difficulties exhibited by children to prevent psychological consequences in the developmental stages of the child.

Parents were the first to notice the Childs difficulty in motor coordination at the earlier stage but they failed to recognize it as a problem and if the child experience difficulty in dressing himself/herself parents used to assist them and fails to document their trouble in executing the simple activity were other children's of same age execute it without much difficulty⁴. Parents fail to report their trouble to the professionals and they failed to seek for help. In the current study we have investigated the experience and concerns as well as opinion of parents, who received the provisional diagnosis of developmental coordination disorder in Indian context. This study aims to evaluate the journey of parents who obtain diagnosis of DCD for their children and also to evaluate the parent's satisfaction in diagnostic methods.

Methodology

Parents were included in the study, if they found to have children diagnosed with developmental coordination disorder. They were invited to participate in the study through invitation emails sent through the child developmental centers. Emails were sent to various foundations for children and support groups for children. The details of the study and the purpose of conducting the research were clearly explained by the primary researcher to the parents through mail. Advertisements of the project and suggestions were mailed to the researcher throughout the study. Target population can engage in the study at any time after signing in the informed consent form. Participants were recruited from in and around Chennai, Tamilnadu, India

. 200 parents completed the survey and the final sample included in the study is 150 were 20 samples were removed from final list and the remaining 20 samples were removed as they failed to obtain the provisional diagnosis of DCD. 10 parents withdraw from the study for personal reasons. Final sample included in the study was 150. Mean age of parents at the time of survey is 42 years and the mean age of children included was 11 years. It has been observed that from the sample 60% were presented with multiple diagnosis and they were commonly diagnosed with learning problems, physical disability and autism spectrum disorders. Majority of the parents seek help privately and failed majority of times before being diagnosed as DCD they underwent false positive diagnosis as ADHD, Autism and Learning disorders. We have initiated online survey with closed ended questions and the questions comprises of demographic data which includes age, gender and ethnicity.

The questions also include parents information on their work and time spent with the child. When they were diagnosed as DCD and the type of services they seek for and their location at the time of DCD diagnosis. Child age and co-morbidities were collected through series of closed ended questions. The series of questions examined the pathway from when parents identify the child's difficulty to formal diagnosis as DCD. After their consultation with the specialist, the series of closed ended questions were gathered from the parents. Which includes the role of professionals seen and how the treatment and assessment benefitted them? Whether the parents were referred to other therapists, outcome of the referral? Whether the parents were asked not to worry and stress about the child's diagnosis of developmental coordination disorder.

The questions were targeted at the alternative routes too and that includes a text box where the parents can provide a free text on the child's status. Child's difficulties in executing the activities of daily living and the parent's queries on the child's diagnosis were documented in the free text. Parents were answered about the reassessment procedure and the diagnosis received during the reassessment varies or not? Satisfaction with the diagnosis was questioned with the parents. Whether the diagnostic process is satisfactory, the professionals executed the diagnosis either clarified the doubts on the diagnostic methods. 5 point Likert response scale was used to document the satisfaction of the therapy sessions. Perceived knowledge and the stress parents experienced were also rated on the Likert scale. The survey was evaluated by website with the questions and details were visible with a brief summary of the results. Ethical approval was obtained from SRM Medical college Hospital, Kattankulathur, India.

Results

Table 1: Percentage of Professionals seen at initial consultation and subsequent referrals

Professionals assessed	First consultation n=200	First referral n =150	Second referral n =100	Third Referral n =80
Physician	20	-	-	-
Pediatrician	100	100	40	40
Teacher	20	-	-	-
Physiotherapist	10	10	-	-
Occupational therapist	20	30	40	40
Neurologist	10	10	20	-
Others	20	-	-	-

Table 2: Areas were the children with DCD experience difficulty

Domains	percentage
Object attachment	20%
Dislike to change	10%
Sleep problem	5%
Behavioral problems	5%
Social isolation	30%
Problem schooling	29%
Delay in communication	1%

Table 3: Outcome made by therapist after initial consultation and referral %

Outcome	First consultation	First referral n =150	Second referral n =100	Third referral n =80
Diagnosis made by therapist	100	80	40	60
Referred to others	20	10	20	10
Referred for lab test	10	-	20	-
Diagnosed as no problem	20	40	20	10
Diagnosed as no problem and asked to return if problem persist	50	20	-	-
other	-	-	-	-

25% of parents reported that their initial trouble was to identify the child's difficulty in executing movements (Table 1). 50% of parents had concerns on both in diagnosis and in difficulty while executing movements. Other 25% were not related to diagnosis at all (Table 2& 3). Parents were enquired with the list of movement related and non movement related problems and they were asked to select the concerns related to their child development.

Discussion

However majority of the parents reported that they waste their money and time in searching for the proper therapeutic sessions for their child with developmental coordination disorder. Few parents inspite of knowing their children had significant difficulty in completing the activities of daily living task fails to reach for the professional help and they perceive that their children when turning adults will outgrow on their own from the difficulties in executing tasks that demands motor coordination⁵. The diagnosis if received formally at the age of five and seven years the motor problems exhibited by the children become more pronounced. Majority of the parents waste their time and money over inappropriate treatments and false diagnosis. The intervention as well as the referrals done by majority of the therapist fails to match the diagnosis and in Indian context, the major drawback is the lack of gold standard assessment tool to diagnose the children with developmental coordination disorder.

Thus without the screening or diagnostic tool, therapist fails to evaluate the child's difficulty in major domains. The domains were the children with developmental coordination disorder exhibits difficulty is fine motor, gross motor skill, balance, bilateral coordination, in hand manipulation, gait. Where the child with DCD even if exhibits IQ score of more than 80% they finds it hard to execute the tasks that demands coordination of bilateral upper limb. The difficulties exhibited by children were predominant in writing tasks and previous researchers have documented that children with developmental coordination disorder have poor in hand manipulation and intrinsic muscle strength. Through handwriting difficulty evaluated by primary school teachers majority of the referrals were made to therapist after explaining the difficulties faced by children during their school hours.

The diagnosis and the methods as well as the tools used in the diagnostic process vary from country to country. For the formal diagnostic process there is a need for collection of information of the past events, the present events and the range of perspectives of the child events in their life. Movement ABC2 and other screening tools were used in the diagnostic process⁶. Multiple sources of information were used in the diagnostic process. Parents were anxious to understand their child's difficulty and they were curious to get a formal diagnosis of their disorder. Due to the delay in the diagnostic process, parents frequently find it as a huge relief once their children were identified appropriately⁷.

The delay in identification of their Childs difficulty triggers other psychological distress like fear, stress and suicidal tendency. Without early identification methods parents were stressed and they feel guilty that they failed to identify the early diagnostic methods and missed the crucial time for intervention. The results of the long term negative consequences were delay in identification of the Childs motor coordination and intervention⁸. The factors like stress and depression leads to dissatisfaction and loss of confidence for the parents. The issue that sustains for the longer

period of time is the trouble in diagnosis and management for DCD. Without gold standard diagnostic methods researchers use more assessment tool and end up with false positive results⁹.

Parents often expect that they should receive awareness about the diagnosis of developmental coordination disorder and also in recognition of their child's difficulties at the early stage. They also expect that there is a need for enhanced contact to service delivery centers with a clear analytic criterion and examination¹⁰. Parents believe that they need to have a better understanding of their child's difficulty and the available therapeutic methods that enhances the child's motor coordination skills. Data that confers with the treatment methods that enhances the execution abilities of daily activities and participation level were not adequately documented in the literature search and majority of the parents demands the data to be made available for planning appropriate therapeutic intervention for their children¹¹.

Conclusion

The study concludes that there is a growing need to promote awareness about developmental coordination disorder among professionals like general health care practitioners and teachers. This will enhance early recognition and referrals. Appropriate referrals will reduce the waiting time for assessment as well as intervention. Effective communication is in need between the parents and therapist to help support children with DCD appropriately.

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Availability of data and other materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request. Please mail and reach us in monisha_ravikumar@srmuniv.edu.in

Ethics approval and consent to participation

The study was approved by the Institutional Ethics Committee (Human Studies) of the SRM Institute of Science and Technology, Kattankulathur with Approval No. 1755/IEC/2019. Written informed consent for interviews was obtained from all participants. The privacy and confidentiality of all the participants was strictly maintained.

Competing interests

Authors declare no conflict of interest

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