

Life Impact of Developmental Coordination Disorder: Qualitative Analysis of Patient and Therapist Experiences

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DCD are one of the more commonly occurring forms of Developmental disorder managed by therapists and their teams worldwide. The impacts of this disorder are not restricted to limitation in activity of daily living and participation in sports and academic activities with peer groups, but may also result in long term physical co morbidities, psychological, and social consequences. There is currently no gold standard assessment tool in the identification of DCD; however specific patient-reported outcome measures DCDQ remains in practice. This analysis aimed to develop a conceptual framework of life impacts of developmental coordination disorder from the experiences of caregivers and parents who have DCD Children as well as the health professionals who treat them. A qualitative investigation was done using semi-structured interviews with people (n=12) who had handling children with DCD (Caregivers/patients) and Therapists (n=6) who treat children with DCD. Interviews with caregivers were recorder and 1 therapist has been individually allotted for transcribing each phrase and codes them. The recorded and coded phrases were finally grouped in categories. Experience of health professionals ranged from 1 year to 15 years working with people with DCD. Health professionals included a pediatrician (1), physiotherapists (2), psychiatrist (1) and an occupational therapist (1). The conceptual framework derived from interview data included five themes (Physical, Occupational, Psychological, Daily Living, and Social). Therapist responses did not reveal any additional items, but majority of responses focus on physical and occupational therapy scope. The nature of life impact following DCD affects many areas of life. The findings from this research have provided an empirically derived conceptual framework from which a gold standard outcome measure can be designed for a geographic location.

Keywords: DCD, Therapist, ADL.

Developmental coordination disorder (DCD) have an impact on ADL and children very often experience difficulty participating with peer groups in playing as well as in the typical activities of childhood and are known to be isolated and they have a more psychiatric illness. No research has been done to investigate the impact of these deficit on the lives of children with DCD. There is a need to assess the participation level and the

characteristics of children with DCD and the therapist have to advertize the caregivers about the importance of their participation with the peer groups in the typical activities of childhood¹.

This qualitative study explored the perspective of the caregivers about the life of children with DCD and the impact of the disorder with educating the parents the importance of participation in sports and ADL for children with

DCD. One to one interviews were conducted with parents of children with DCD who attended a semi structured interview in the rehabilitation center in and around Chennai. In interview it has been revealed that these children experience a serious psychiatric illness as a result of incompetence in everyday activities².

There are serious negative side effects experienced by the children with DCD. Interventions which focus on the well being of children with DCD have positive impact on the participation level of children with DCD; conversely it increases the quality of life of these children. Therapist interviewed the caregivers have highlighted the theme that performance competency plays a vital role in being accepted by peer group of children. Parents reported during their one on one interview session with therapist that successful participation have developed greater confidence in children and allowed them to try and participate in new task. The World Health Organization's International Classification of Functioning, Disability, and Health provides a unique framework for analyzing and understanding the impact of the physical disability on the lives of families with children with DCD. Results illustrate how intervention plays an important role that focuses on enabling children to participate in ADL with peer groups³.

Child diagnosed with Developmental coordination disorder have complex motor coordination difficulties. This difficulty in motor coordination is exhibited as an derangement in motor performance sequencing and organizing. These children were reported by the caregivers and teachers as to be socially awkward and clumsy and they have poor social acceptance among the peer groups too. These children isolate themselves from the family members, they experience difficulty to communicate the needs and they end up with psychiatric illness. These children have innumerable difficulties like frequent fall, bumping and hitting on the objects nearby when they experience any new unfamiliar environment, thus they face much difficulty with the normal activities of daily living⁴.

Motor in coordination is exclusively present in all the activity of daily living in children with DCD despite of having IQ of greater than 70%. Simple activities like closing or opening a box, writing, eating with fork and spoons, jumping,

jogging, running along the track are difficult for these children and they depend on support from parents or from the peer groups. Because of the difficulty they experience in common activities of daily living, these children's tends to avoid their peer group members and they experience social isolation and they were physically inactive and tend to be sedentary in their activity of daily living⁵.

None of the researchers has paid much attention to the psychological distress in children with DCD in addition to their motor coordination problem, these children experience psychological distress due to their difficulty in motor sequencing, timing and organization. They have anxiety and depressive symptoms as they experience poor academic outcome due to their poor handwriting skill and reading. These children much more difficulty with academic achievement. (Ganapathysankar, monisha.R, 2018) Poor performance in academic and in sports make these children with DCD to get prone to social isolation, negativism and other psychiatric illness

METHOD

In order to explore the difficulties faced by children with DCD, A qualitative approach, one to one interviews with parents of children with DCD, Qualitative research is especially suited to the study of complex interactions such as those between the individual and the environment (Yreka, 1991). These researches bring the lively experiences of the teachers, parents and caregivers and their statement and suffering they experience and monitored in children with DCD. These researches provide the researcher a wider understanding of the living experiences of the parents and caregivers as well as in children with DCD. Through semi-structured interviews data about caregiver's perception has been obtained. By using semi-structured interviews the issue of credibility has been fulfilled. An important consideration in qualitative research is the issue of trustworthiness.

Participants

Informed consent has been signed by all the participants who were given a voluntary consent after getting a clear explanation from the primary author of this study. The participants were recruited from among the rehabilitation centers in and around Chennai by the corresponding author

Table 1. Details Of The Study Participants

S. no	Name of the Child	Age	Gender	Treatment Goals	Parent Interviewed
1.	Arun	7	M	Riding A Bike	Mother
2.	Balan	7	M	Cutting A Paper	Father
3.	Chandru	7	M	Riding A Scooter Board	Father
4.	Damodaran	8	M	Holding A Pen	Mother
5.	Dayanidhi	8	M	Holding The Desk And Writing	Mother
6.	Krishnamoorthy	9	M	Cursive Handwriting	Mother
7.	Sarath	9	M	Drawing	Father
8.	Sankaran	8	M	Organizing The Desk	Mother
9.	Sathish	8	M	Writing	Mother
10.	Surya	8	M	Painting	Mother
11.	Vigneshwar	9	M	Riding A Scooter	Father
12.	Sathya	10	M	Painting	Father

Table 2. Sample Questions From The Semi-structured Interview

Question Number	Sample Question
1.	How Is Your Childs Activity Of Daily Living
2.	How Did That Makes You Feel
3.	How Is Your Child Participation In Sports
4.	How Is Your Childs Eating Habit, Using Spork And Spoon
5.	How Your Child Reacts To A New Unfamiliar Environment
6.	How Well Your Child Communicates To You
7.	Sleeping Habit

of this study. Participants were educated regarding the need for conducting the interview sessions and this analysis will directly or indirectly will help their children with motor-based performance problems. "A primary focus of the clinic is to teach children to become competent in the activities of their choice. The clinic uses the Cognitive Orientation to daily Occupational Performance (CO-OP) approach, a client-centered, problem solving approach that enables skill acquisition and performance through a process of guided discovery and strategy use" (Polatajko *et al.*, 1995). Inclusion criteria for the study includes that parents who were with the children of DCD should meet the criteria for DCD as outlined by the Diagnostic and Statistical Manual of Mental Disorders [4th ed.] (American Psychiatric Association, 1994), and the parent who is fluent in English and willing to portrait all the details of their child is included in the study, then the parents were participated in an in-depth interview

conducted by the primary author, the interview questions and answers revealed has been recorded and transcribed. A total of 12 families meeting the criteria and proceeded to the interview sessions, majority of 7 families were from Kanchepuram district Tamilnadu, they were located from the village setting and with poor income but motivated well enough to get improvement in their children's successful future. By individually analyzing each children's family history, it has been observed that each family is with a child with DCD had at least one sibling, in some cases two. The children with DCD were of age group from 7 to 10 years and all the children were boys (Table 1).

Analysis of data

An interview questions was constructed to gain an understanding of the impact of DCD on the lives of children and their families. The purpose of open ender interview is to encourage the parents to talk and elaborate on the difficulties faced by

children. Initially the parents were asked: Why do you think it necessary for your child to take learning goals and therapy sessions?

Focused questions which were oriented towards the academic activity of child were gathered by using the questions like: How did learning affect the child's behavior at home, at school, and with their peers? Similar questions which cover all the 5 major domains were addressed by the respondent.

All interviews were conducted by the primary author in the rehabilitation center. In most cases the mother alone was interviewed; in two cases both parents participated in the interview (Table 1). All interviews were initiated with a general question designed to put the parents at ease before the grand tour question was posed. All interviews were audiotaped and transcribed verbatim by a physiotherapist. Analysis and interpretation of the data was conducted by the second author, who reviewed and coded the transcripts in stages. Finally discussed with the first author, who then revised and verified the responses. By organizing all the interviews conducted, authors identified the detailed impact on the lives of children with developmental coordination disorder. The organized picture of the impact of motor-based (in)competencies in the lives of children with DCD were later explained to the parents, when they visited the therapy sessions on the consecutive days following the interview sessions. Finally a summary of the results was discussed on an individual basis with parents on post-testing days. Parents agreed to the therapists decisions.

RESULTS

The nature of life impact following DCD extends beyond short term impacts on ADL and discomfort into many areas of life. The findings from this research have provided an Qualitative data, through which further impairment specific patient and teacher as well as therapist reported outcome measure can be developed.

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