



Evaluation of health-related quality of life among parents of children with developmental coordination disorder

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ABSTRACT

Developmental coordination disorder (DCD), is a vastly reported disorder with a prevalence estimated of 7-8% in children aged 5 to 10 years. There is a false perception of parents of children with DCD that their children will come out of the motor coordination defects as they age (Adults). This false perception affects the child directly, and they will not outgrow of the problem, however, becomes socially isolated. Motor difficulties reported in children with DCD are heterogeneous. When the HRQOL focuses on children's, it is mandatory to include the domains that elaborate the illness, mental health aspects, comfort ability of the child and also the effects on their parents. The study aims to evaluate the health-related quality of life (HRQOL) among parents of children with developmental coordination disorder (DCD). Thirty parents of children with and without DCD were enrolled in the study and HRQOL of the parents was examined using the 12-Item Short-Form Health Survey (SF-12), Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI). When considering the HRQOL among parents of children with and without DCD, there occur different results among father and mother. However, parents of children with DCD had significantly lower HRQOL ($p < .05$). This study provides evidence that DCD significantly affects multiple HRQOL domains among the parents of children with DCD.



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INTRODUCTION

Developmental coordination disorder (DCD), is a vastly reported disorder with a prevalence estimated of 7-8% in children aged 5 to 10 years. Motor difficulties reported in children with DCD are het-

erogeneous ([Sankar and Monisha, 2019](#)).

Motor coordination defects presented by children with DCD are mild when compared to children with neurological problems. Due to the motor impairment, academic and vocational performance of the children is affected. When children with DCD were not delivered with an early intervention program, these children experience behavioural problems and other psychiatric illness ([Ganapathysankar and Saritha, 2005](#)).

There is a false perception of parents of children with DCD that their children will come out of the motor coordination defects as they age (Adults). This false perception affects the child directly, and they will not outgrow of the problem, however, becomes socially isolated ([Shankar and Monisha, 2019](#)).

Researchers in concern with children are present-

ing the complaints of DCD, aims to enhance motor proficiency, functionality, and improve well-being. Till date, there is no gold standard assessment tool to measure and document the changes in motor proficiency and functioning in multiple domains that is related to balance, gait, and handwriting, fine motor and gross motor defect. So, measures used by a physiotherapist and occupational therapist are instruments that lag consistency in measurements (Sankar and Monisha, 2018b).

Researchers were interested in examining the difficulties experienced by the child with DCD in multiple domains. Few studies also examined how DCD affects health aspects. However, the development of multidimensional assessment tool is in greater demand among the health care worker and researchers. The HRQOL questionnaire is used often as a valuable outcome measure of treatment /therapeutic interventions. These questionnaires elaborate on the patient's perception, and perceived effects of the treatments received. Current HRQOL instruments were focused on assessing the mental health, patient-perceived health and well-being. When the HRQOL focuses on children's, it is mandatory to include the domains that elaborate the illness, mental health aspects, comfortability of the child and also the effects on their parents (Sankar, 2020b).

When interviewing parents of children with DCD, it has been revealed that there is a higher level of stress, devaluation sense and blaming others were happening on their daily life, and these psychiatric symptoms affect their quality of life as well as health status. When mothers were evaluated, they have higher levels of health problems present, when compared to fathers of children with DCD. However, poor HRQOL was mostly reported in parents of children with severe neurological disorders to date.

Little knowledge and research exist for HRQOL in parents of children with DCD (Bukstein *et al.*, 2000). Since there is a debate, whether HRQOL will change when there is an enhanced motor ability of children with DCD. The current study was designed to compare HRQOL between parents of children with DCD and a control group of parents of children with typical development.

METHODS

Parents of children with DCD were invited to participate in the study through mails; participants were selected from 1 therapy centres and 3 Primary schools in and around Kattupakkam. Criteria of selection of participants were parents should have a child diagnosed as having DCD and residing

in the same household for years along with the child and absence of psychological disorder. The parents involved in the study can withdraw anytime from the study if they were responsible not only for the child with DCD but also have to be involved in caring of elders in the DCD group were excluded if they were responsible for any patient in their family (Sankar, 2019).

For a child with DCD, one parent, either father or mother, is recruited. Thus, the total number of mothers/ fathers recruited is 50 with the mean age of 45.7 years (age range= 25 to 50 years). Control group included parents of typically developing children. A total number of 50 participants were recruited from 3 primary schools.

For typically developing children, criteria for selection of parents are parents should have a healthy child with typical development and residing in the same location. Parents were excluded if they have any previous medical diagnosis of developmental, intellectual, psychiatric, or physical disabilities. Thus, the final sample of parents in the experimental and control group is n = 100.

DCDQ- developmental coordination disorder questionnaire was used to screen children with DCD. QOL Measurement in Parents was assessed using 12-Item Short-Form Health Survey (SF-12), Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) was used to assessing the HRQOL of parents in both the DCD and typically developing children. The SF-12 was used to generate scores for the physical component summary (PCS-12) and the mental component summary (MCS-12). The SF-12 has been used to measure the well-being of caregivers for relatives suffering from various medical conditions.

The 21-item BDI gathers information related to various depression symptoms, and the scale is scored from 0 to 3. A higher score indicates depression (Sankar, 2020a). BAI is used to analyzing anxiety symptoms on a Likert-type scale from 0 to 3; a higher score indicates increased anxiety level.

Procedure

The SRM College approved this study of Occupational therapy, SRM Institute of science and technology. After getting informed consent signed from the parents, the principal investigator visited the parent(s) of children with DCD at home or school then distributed the HRQOL questionnaire to the participants. Parents were instructed to fill up the questionnaire without mentioning the name. The filled up questionnaire was mailed back to the primary researcher by the parents of children with DCD.

Details of the parents include name, age, marital status, educational qualification were assessed at the baseline during the first home visit (Table 1).

Sample t-test was used to analyze the homogeneity of demographic variables in groups. The SPSS software package was used for all statistical analyses, and a p-value of less than .05 was considered statistically significant. To determine the difference that exists between groups, effect size (Cohen d) was calculated by dividing the difference between the means for the typical development and DCD samples by the SD of the typical development sample.

RESULTS

Table 1 analyzed the distribution of demographic Profile of the parents of children with DCD, and the current study did not significantly differ between the DCD and the specific development groups ($p > .05$). In the DCD group, five subgroups did not differ significantly in terms of age, gender, or family characteristics. The two groups of parents did not significantly differ in any demographic attribute (Table 1).

In Table 2, PCS-12 and MCS-12 scores were lower in parents of the children with DCD group than in parents of the typically developing children. Table 2 also shows that BDI and BAI scores were higher in parents in the DCD.

DISCUSSION

The current study adds scientific knowledge regarding the HRQOL and its impact on the Health-related quality of life among parents of children with and without DCD. In the Indian context, more researchers were focused on the effects of therapeutic intervention on children with DCD; this is the first study to analyze the HRQOL among parents of children with and without DCD (Sankar, 2019). Following the previous researcher Kirby, Edwards & Sugden, 2011, the current findings proved that DCD significantly affects both physical and psychosocial domains of HRQOL. The problems experienced by the children with DCD had a more significant impact over familial activities. But for the child with DCD, their parents, especially the mother, need to spend her whole 24 hours in a day with her child.

Previous researchers have assessed the perception of Indian mothers regarding their participation in physical activity and assessed their motivation level to engage their children in green land play. Indian mothers have negative/false perception regarding physical activity. When parents of children with DCD is questioned in one-to-one interview, it has been revealed that the mothers of chil-

dren with DCD want their children to focus on academic achievement and indoor play games like chess, carom (Lovell *et al.*, 2012).

They have negative belief and the misconception that a child with DCD will have difficulty to play in green land and ends with injury as they bump and hit over the objects when exposed to the park or playground. Parents of children with DCD prefer no physical activity, and thus they end up with psychological distress and poor social relationships. They also experience lower self-perceived QOL and poor self-perception of health (Magaña *et al.*, 2004).

As the child with DCD needs assistance in performing all the ADL- which teaches the motor activity. Necessary activities like bathing, feeding, toileting, dressing, playing needs monitoring by their mothers.

As a mother, she has to take proper nurturing care for her child with DCD, and simultaneously she has to do her daily routine like household works and also engaged in occupational activities. These mothers were exposed to stress and depression as they spend their whole day in helping and monitoring their child as an unpaid maid. Highest level of stress and other psychiatric disorders can be prevalent in this group of mothers (Sankar and Monisha, 2018a).

However, Indian parents have different perceptions of HRQOL. For example, studies proved that Indian mothers have negative perception over green land play, and they avoid participation in any physical activity. Thus, they reported having a higher incidence of stress and anxiety.

Discrepancies among father and mother, regarding how they analyze their child's difficulty in performing all the activities of the daily living task, will interfere with the family life and stays as the primary cause for family conflict. However, no self-reported HRQOL questionnaire exists for Indian parents, and it is not validated. Development of a gold standard questionnaire and validation is of increased demand.

The results of the current study proved that parents of children with DCD include both mother and father experiences impaired physical as well as psychological well-being. The results of the current study go in hand with the previous researchers Miodrag & Hodapp, 2010. The HRQOL domains were affected in parents of children with DCD as they frequently worry about their child status, and they were forced to spend maximum time and energy needed to meet their daily needs.

Table 1: Demographic Data of the Parents of Children with and without DCD

| Characteristic | DCD Group | Typically Developing Group |
|------------------------------------|-----------|----------------------------|
| Parent data | n=50 | n=50 |
| Age of Mother | 45.7 | 42.8 |
| Age of Father | 47.2 | 47.9 |
| Education status Any college | 25 | 30 |
| Education status High school | 10 | 10 |
| Education status Elementary school | 15 | 10 |
| Gainful employment Mother | 15 | 25 |
| Gainful employment Father | 35 | 25 |

Table 2: HRQOL subscales for Parents of Children with and without DCD

| characteristic | DCD (Mean) | Non-DCD(Mean) | p |
|----------------|------------|---------------|-------|
| Parent HRQOL | | | |
| SF-12 PCS-12 | 50 | 57 | .0001 |
| MCS-12 | 51 | 56 | .002 |
| BDI | 11 | 8 | .21 |
| BAI | 13 | 9 | .04 |

CONCLUSIONS

Parents of Children with DCD were found to have lower HRQOL compared to children with typical development. Among parents of children with DCD, HRQOL is an important outcome that has received little attention. There is a need to educate mothers regarding their child’s status, and Appropriate psychological counselling can help parents of children with DCD to improve their physical and psychological well-being

Conflict of Interest

The authors declare that they have no conflict of interest for this study.

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