Rites of passage: Understanding participation of children with developmental coordination disorder

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Abstract

Children with developmental coordination disorder (DCD) experience difficulty participating in the typical activities of childhood and are known to have a more sedentary pattern of activities than their peers. Little research has been done to investigate the impact of these deficits on the lives of children with DCD and the importance of their participation in the typical activities of childhood. This qualitative study explored the impact of the disorder and the importance of participation for children with DCD from the perspective of the parent. Twelve in-depth interviews were conducted with parents of children with DCD who attended a university clinic specializing in using the Cognitive Orientation to daily Occupational Performance (CO-OP) approach, a cognitive-based intervention. Findings revealed that incompetence in everyday activities had serious negative effects for the children. Conversely, intervention that was focused on enablement at the activity and participation level had a significant positive impact on the children’s quality of life. Emerging themes highlighted the notion that performance competency played an important role in being accepted by peers and being able “to be part of the group”. As well, parents reported that successful participation built confidence in their children and allowed them to try other new activities. 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 that focuses on enabling children...
to choose their own functional goals in the area of physical activity has important implications for enabling participation and building the social networks of children with DCD. © 2003 Elsevier B.V. All rights reserved.

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I didn’t think that learning to be a better goalie was a good goal for therapy. I thought writing was the important thing. Well I have to tell you that in OT he learned to be a goalie, and then he made the school floor hockey team. They went on to the championships and won. He is living his dream! (Bob’s Mom)

1. Introduction

Participation in the everyday activities of childhood is integral to normal child development. Research findings have demonstrated that a child’s participation in the typical activities of childhood influences health, self-esteem and social adjustment (Kleiber, 1999; Larson, 2000). Children with motor problems are often restricted in their ability to participate in the typical activities of childhood (Bouffard, Watkinson, Thompson, Causgrove Dunn, & Romanow, 1996; Smyth & Anderson, 2000). When these problems are severe enough to warrant the attention of professionals, the children are often diagnosed with developmental coordination disorder (DCD).

Children with DCD have a marked impairment in motor coordination that interferes with academic achievement or activities of daily living, in the absence of neurological or sensory problems (APA, 1994). The motor deficits experienced by children with DCD are relatively mild compared to those experienced by children with neurological problems such as cerebral palsy and spina bifida, nevertheless, DCD negatively impacts the child’s daily functioning and can have significant long-term effects on academic, psycho-social and vocational outcomes (Cantell, Smyth, & Ahonen, 1994; Hellgren, Gillberg, Gillberg, & Ennerskog, 1993).

Children with DCD represent a significant proportion of school-aged children. According to international estimates, prevalence of DCD among children aged 5–11 years ranges between 6% and 10% (APA, 1994). Contrary to previous beliefs that this is a benign childhood condition, longitudinal studies have demonstrated that DCD continues into adulthood and can have serious long-term sequelae including increased risk of social, emotional, academic, and psychiatric difficulties and adverse vocational outcomes (Rasmussen & Gillberg, 2000). Secondary difficulties such as lack of fitness and strength, a vicious cycle of motor activity avoidance, depression and social isolation and decreased participation in physical activity are well documented (Rasmussen & Gillberg, 2000). However, little is understood about how these deficits, which are relatively mild, can have such long-term negative effects.
Recently, the World Health Organization (WHO) introduced a new classification system for understanding health and disability, the International Classification of Functioning, Disability, and Health (ICF, 2001). This new model provides a framework for classification at three levels including body function and structure (impairment), activity (activity limitations), and participation (participation restrictions). This model is based on the notion that impairments at the level of body function or structure influence a person’s ability to carry out activities and participate in everyday life. In the ICF, functional outcomes are seen as the result of interactions between body function and structure, activity, and participation, and influenced by health conditions and contextual factors. Contextual factors are identified as either social and physical environmental factors, such as social attitudes, legal and social structures, geographical structures; or personal factors such as gender, age, other health conditions, coping styles, social background, education, overall behaviour pattern, and character style (World Health Organization, 2001).

Through the application of the ICF model to children with DCD, it is reasonable to assume that the motor impairments experienced by these children result in activity limitations and participation restrictions, which, in turn, would affect the health and well-being of these children. Thus, it could be presumed that the activity limitations and participation restrictions contribute to long-range problems of children with DCD, rather than their specific impairments. If this presumption was true, the ICF could hold important implications for the management of these children’s difficulties. It would suggest, for example, that the management of this disorder needs to include a focus on enabling children at the activity and participation level, so these children can participate maximally in their worlds. The purpose of this study was to explore this possibility, that is, to gain an understanding of the impact of performance deficits and competencies on the lives of children with DCD.

2. Method

A qualitative approach, using in-depth interviews with parents of children with DCD, was chosen to explore the impact of DCD on the lives of children. Qualitative research is especially suited to the study of complex interactions such as those between the individual and the environment (Yerxa, 1991). Further, qualitative methods are considered to be the most effective means of studying the lived experience; they provide the researcher with an opportunity to understand life experiences from the perspective of the individual (Marshall & Rossman, 1995). Finally, interviews are the preferred method for collecting data about people’s thoughts, feelings and perceptions (Marshall & Rossman, 1995).

An important consideration in qualitative research is the issue of trustworthiness. Trustworthiness involves establishing credibility, transferability, dependability and conformability (Lincoln & Guba, 1985). In this study, credibility was established through the use of semi-structured interviews and the completion of a member check to ensure accuracy of research results. Furthermore, detailed descriptive information about the informants and their children was compiled to address transferability.
Dependability and confirmability were addressed through a field journal that was kept by the primary author. In addition, an audit of the transcripts by two experienced researchers was completed. The researchers have been involved in this setting for seven years and have established prolonged engagement.

2.1. Participants

The participants for this study were recruited by the primary author from among the families of children attending a university-based clinic that specializes in treating 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-centred, problem solving approach that enables skill acquisition and performance through a process of guided discovery and strategy use (Polatajko et al., 1995).

To be eligible for the study, the family had to have a child, who met the criteria for DCD outlined in the Diagnostic and Statistical Manual of Mental Disorders [4th ed.](American Psychiatric Association, 1994), and at least one parent who was fluent in English and willing to participate in an in-depth interview with the primary author. Twelve parents (10 families), meeting the above criteria, agreed to be interviewed for the study. All of the families lived in an urban setting, were middle class and very motivated to have their children succeed. All were dual parent families, with at least one parent being a professional or businessperson. In each case the child with DCD had at least one sibling, in some cases two. The children with DCD ranged in age from 7 to 12 years and 9 of the 10 children were boys (see Table 1). All children were clients of the university-based clinic and had completed their treatment or were in the final segment of their treatment. All the children had become competent or were close to becoming competent in three activities of their choice (see Table 1).

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<th>Table 1 Study participants</th>
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2.2. Information gathering

An interview guide consisting of a grand tour question and probes (McCracken, 1988; Spradley, 1979) was constructed to gain an understanding of the impact of DCD on the lives of children and their families. The purpose of using a grand tour question is to encourage participants to talk and elaborate on the topic of interest (Spradley, 1979). The grand tour question for this study was: Why do you think it was important for {your child} to learn how to {child’s treatment goals}? The planned probes were: How did learning {the child’s treatment goals} affect {your child} at home, at school, and with their peers? As well, information given during responses was used to construct additional probes.

All interviews were conducted at the university clinic by the primary author. In most cases the mother alone was interviewed; in two cases both parents participated in the interview (see Table 1). All interviews were initiated with a general question designed to put the parents at ease before the grand tour question was posed. At the outset of the interview, the parents were asked: What brought you to this clinic? The interviews lasted from one to one and a half hours. All interviews were audio taped and transcribed verbatim by a paid assistant.

2.3. Analysis of information

Analysis and interpretation of the data was conducted in stages. Firstly, open coding was carried out by the primary author (Strauss & Corbin, 1998). Initially all the data was coded using the constant comparative method (Glazer & Strauss, 1967). The transcripts were read in their entirety and all meaningful sections of the data were conceptually labeled. The third author then reviewed these codes and suggested changes or additions. Finally, the second author read and coded the transcripts, independently, and discussed these with the first author. At this point the stage of axial coding was begun. Working together, the authors identified larger themes and patterns and organized these into a picture of the impact of motor-based (in)competencies in the lives of children with DCD.

After the analysis and interpretation was completed, the primary author conducted an informal member check. Where possible, a summary of the results was discussed on an individual basis with parents who were returning to the clinic for post-testing. Parents agreed wholeheartedly with the results, reiterating many of the themes identified.

3. Results

The results are presented under three emergent themes. In each case the theme is described and illustrated by quotations from the participants. Each quote is attributed to the speaker. Since the primary reason for interviewing the participants in this study is that they were parents of a child with DCD, each speaker is identified as {child’s name’s} Mom or Dad. The names of the children (see Table 1) are fictitious,
3.1. Motor-based (in)competencies and the lives of children with DCD participants’ perspectives

All the parents who participated in this study seemed very eager to talk about their children’s lives. Although the intent had been to start the actual interview with the grand tour question after a general ‘ice-breaking’ question, in most cases, this first question was sufficient to get the parents to speak extensively about the impact DCD, with its inherent (in)competencies, was having on the lives of their children. Three basic themes capture the essence of what the parents had to say: consequences of the unimportant, when the ordinary becomes extraordinary, and turning points. Under each a number of sub-themes were identified (see Fig. 1). Together the themes indicate that achieving competency in the everyday activities of childhood is a rite of passage for children and failure in these seemingly unimportant activities can be devastating.

Roger’s Dad: There is no doubt about it, that for Roger, bike riding has been a lifeline, a lifeline into the social community, and a lifeline so far as his self-esteem it has definitely grown. It sort of was a rite of passage, a real marker for him.

3.2. Consequences of the unimportant

Children with DCD are generally competent in the essential developmental skills such as sitting, standing, walking, and talking. The performance problems experienced by these children are typically only evident in the everyday activities of childhood, many of which, in and of themselves, seem unimportant. The parents in this study seemed keenly aware of this.
Aaron’s Mom: He had started Grade 1 and he was having a very difficult
time on a number of fronts, but one of them was, for instance, his snow-
suit. He just, he would have a baby temper tantrum about getting his
snowsuit on and uh it struck me that it was just too much for his little
fingers and it was taking so long that he would just get frustrated, he just
wanted to get out and play.

Susan’s Mom: She has come home from school in tears a couple of times
because she couldn’t play tag games at school on the playground. And
you know that while that’s not a life threatening thing that to me is a
quality of life issue.

Parents reported that their children’s problems were considered unimportant be-
cause they were not as severe as those of other children. As a result their problems
are frequently trivialized.

Aaron’s Mom: The teacher said, ‘oh man I have kids who need way more
help than he does’ . . . so Aaron wasn’t anywhere near where he could get
any help.

Bob’s Mom: I went to the JK teacher and said I had concerns about his
fine motor, and she said oh no problem nothing to worry about. So I said
the same thing to the SK teacher and she said oh, he’s just a little boy, left
handed, born in November nothing to worry about.

As a result, the parents were frequently left on their own to deal with their chil-
dren’s problems.

Sam’s Mom: In grade one they felt he had ADHD and that’s what the
teacher told us. As it was we decided to go privately. And he was as-
sessed. So it was a motor problem not a attention problem at all.

Bob’s Mom: He hung out with two kids he would have said ‘were just like
me’, that weren’t getting help although one mother was secretly getting
some OT help when the child lived up in Ottawa, but you know no
one wanted to talk about that kind of help.

If the parents did manage to get the attention of a professional they were fre-
quently given the runaround.

Brian’s Dad: We did try to get OT to come in but it was explained to us
that they were only for high needs cases, for example CP, um wheel-
chairs, those kind of situations, that’s when an OT comes in not for
these circumstances. And if we wanted, there’d be a very long waiting
list.
3.3. When the ordinary becomes extraordinary

The parents were also keenly aware that it was important for their children to be competent in the everyday activities of childhood because of the extraordinary consequences that failure to acquire these simple skills had for their children.

John’s Mom: It is a self-esteem thing. They feel good when they can do it. They want to be like the other kids not centred out. It affects their self-confidence, their willingness to try. John likes to have friends, he likes to play and when he is late for recess because it takes him longer to tie his shoes or put on his coat it frustrates him and isolates him.

The parents talked about how they themselves had trivialized their children’s problems until they became aware of the consequences the failure had for their children.

Aaron’s Mom: When I was a little girl I was an excellent printer, was the best in the class and that was just me. And so I thought Aaron doesn’t have to be like me, he can be one of those guys with messy printing and that was my initial reaction, but then I saw how it was impacting how he felt about himself and I think that’s where the snowsuit thing really helped me to see...

The parents spoke at length about the long reaching emotional impact the DCD had on their children. They talked about their own children’s awareness of their difficulties and the sense of failure that developed as a result of repeatedly not being able to master everyday activities.

Susan’s Mom: Susan has come home quite upset that she couldn’t climb the ropes at school. And she told us in April and when I questioned her gym teacher about it, he said well we climbed ropes in February, so I think this is something that has stayed in her mind and she has stewed about it for a number of months before bringing it to my attention.

Roger’s Dad: I think we have gone through three or four bikes, and he outgrew them. It was again, each time it’s like a sense of failure, so it gets compounded.

The parents explained that failure made their children feel ‘stupid’, often to such an extent that the children stopped even wanting to try.

Doug’s Mom: You know, that seems to be a big thing, ‘I don’t want to look stupid’, it is safer not to try it than to try it and fail. ... I get this feeling that there is anger and frustration in the life that he possesses and it comes out verbally in a big way and it is always ‘I can’t do this and I can’t do that’.
Aaron’s Mom: But you know there is a certain level of ridicule that is hard to take and that is sort of baby stuff. You know not being able to do up your pants in the bathroom or not being able to use a snowsuit or having food around your mouth like a baby that kind of stuff is hard to take and he is a smart kid and he loves people and I think it really hurts his self-esteem and his willingness to try new things.

They also spoke about the social consequences their children experienced as a result of their difficulties, noting that children were very aware of each other’s performance and recounting instances where their children were left out, teased, or bullied.

Sam’s Mom: But you know at school you get graded emotionally by your peers, the kids that can read, the kids that can hold their pencil, the kids that can print letters they are the ones that are considered smart.

Paul’s Mom: Well at Cubs they did a bike rodeo. And we were outside setting up the cones and of course you could either ride a bike or rollerblade, which excluded him from both things {because he could do neither}. . . .He felt excluded and I know that he felt that because most of the kids turned up with bikes and I knew he felt he had a bike at home and he could not ride it and he had gotten too big for the one we had.

Bob’s Mom: There were times I knew he was frustrated especially if they had to do little exercises like jumping on one foot or in dance club they had to do very precise dance steps and he finally said I’m not going to do dance stuff, he had longed to dance, ‘cuz the girls were all there and his friends were there, but he just couldn’t do it.

3.4. Turning points

The focus of the interviews in this study was on children with DCD and the impact that performance difficulties with the everyday activities of childhood had on their lives. While parents described many negative consequences emanating from these difficulties, they also talked enthusiastically about the important positive impact eventual mastery had for their children. All the children in this had CO-OP treatment, during which they worked on skills they had chosen (see Table 1). In all cases the children succeeded in acquiring those skills and became competent in their performance. Based on the descriptions provided by the parents, achieving mastery was a turning point for the children.

Roger’s Dad: It [learning to ride his bike] has helped his socialization and self-esteem. Just the way it has made him feel good about himself because he was able to do that. He’s more adventurous in other aspects of it. I think having learned to ride the bike then he took ownership of it and moved on to trying other things. So that was good too because I see that
as part of the independence and growth and you know he is trying to go outside more than he normally used to.

While failure had left their children with a sense of failure and an unwillingness to try, achieving competency, the parents said, made their children proud of their performance and willing to try.

John’s Mom: He struggled with shoe tying and then it finally got down to a handful of kids who couldn’t tie their shoes and I couldn’t buy Velcro shoes anymore. When he finally got the grasp of how to tie his shoes, it was wonderful. Shoe tying is still a great thing for him, even in the morning he was tying his shoes and he said mom what do you think about this, do you see how smoothly I tie my shoes now. He was extremely proud and so that’s something that seems so insignificant to so many people, that was a major issue for him.

Sam’s Dad: Since he has learned to write, you know he has more confidence, like he is even starting to read on his own, and he is so proud of his writing, like today he was so proud to show you what he had done. . . . Now he plays games and things and he doesn’t get frustrated as he used to. When he is doing something else, he’ll spend more time at it, he’ll work with the smaller blocks which he wouldn’t do before.

Further, while incompetence had resulted in negative social consequences for their children, parents described their children’s new competencies as opening doors for them with their peers.

Bob’s Mom: Bob could right away do the handwriting and could carry on as if he had done it all his life, so it gave him enormous confidence, now he’s moved to the [private] school. So now he fits in and that was something if peers were judging you for the first time can he do what the other kids do, you know he loves to kick a ball, he loves to play soccer but that handwriting now people don’t recognize that he struggled with that in the past so now he has suddenly been raised up to the same level of playing field.

Roger’s Dad: It was funny, one day he came up and I was walking the dog and Roger was riding ahead of me and we came up our street and there was a group of kids he knew standing there and they all shouted “way to go Roger, good riding, good riding”. I thought that was great! He waved as he passed them and nearly fell off his bike because he let the handlebars go, he waved and he knew then he was very very good!

The parents’ reports suggest that just as incompetence in the everyday activities of childhood had far-reaching negative effects, achieving competence had far-reaching positive effects precisely because they were the everyday activities of childhood.
Bob’s Mom: I didn’t think that learning to be a goalie was a good goal for therapy. I thought writing was the important thing. Well I have to tell you that he learned to be a good goalie with you, and then he made the school floor hockey team. They went to the championships and won. He is living his dream!

4. Discussion

Children with DCD experience considerable restrictions in motor-based activity (Smyth & Anderson, 2000). In this study parents confirmed these restrictions, and identified the far-reaching negative consequences of these restrictions. The participants in this study shared their children’s stories and recounted how pervasive the activity restrictions their children experienced were in the lives of their children, negatively impacting their competence, sense of efficacy, and social participation. There were many stories of failure, inadequacy and exclusion. Interestingly, the parents also recounted stories of success, and expounded on the positive impact that finally achieving competency had for their children. They said that once their children were able to participate in activities with their peers, it changed their lives. The children gained confidence as they mastered their goals and, as a result, they were more willing to try new activities believing they could master them now. Progress toward their therapy goals seems to have led the children to believe that they were capable of performing activities of their choice and may have led to increased self-efficacy. Self-efficacy refers to personal beliefs or perceptions of specific abilities, that the child feels they are capable of doing or performing actions (Bandura, 1997). Sense of self-efficacy comes from mastery of skills and researchers have found that allowing children to set their own goals enhances self-efficacy and learning (Schunk, 1985). Self-efficacy beliefs have been shown to influence choice of activities, persistence and skill acquisition (Bandura, 1997). Children with low self-efficacy may avoid certain tasks and children who see themselves as efficacious participate more frequently and are more likely to persist when tasks become difficult (Schunk, 1991).

This study suggests that focusing treatment on the activities the children identified as goals achieved far more than simple acquisition of the skill; it seemed to give the children a new sense of efficacy, and an entree to their peer group. Clearly, the children had chosen activities that were important for social acceptance and participation. Acquisition of the children’s chosen skills led to changes amongst friendship, allowing the child to fit in and be part of the social network and participate with their friends.

Although traditional approaches to intervention focused on remediating impairment, rather than increasing activity and participation, the findings of this study speak to the importance that everyday activities have in the lives of children and provide strong support for the notion that treatment for these children should be focused at the level of activity and participation. The results of this study illustrate that focusing intervention at the level of activity promotes social connections and enables participation for the children with DCD.
The findings from this study indicate that the ICF model is useful in predicting the impact of DCD on the lives of children. It provides a model for understanding the relationship between the impairments of children with DCD, and the activity limitations and participation restrictions experienced by these children. Parents identified that their children’s motor impairments led to activity limitations and, in turn, to participation restrictions. However, parents also indicated that when intervention enabled their children to become competent, to reduce their activity limitations, their participation restrictions were also reduced and the children flourished. Not only were social changes identified, parents also reported personal changes in their children as a result of intervention. Further, when the children could participate in activities with their friends the effect of their impairment decreased, even though the motor impairment may not have been resolved.

Understanding the impact of DCD on the children and their families is critical for professionals who treat these children. Professionals need to consider social, emotional and physical outcomes when planning intervention. This study demonstrated the importance of understanding the relationship between impairment, activity and participation on the health and well-being of children.

5. Conclusion

In-depth interviews with parents of children with DCD provided insight into the experiences of living with DCD. The perspectives they had on the difficulties encountered, and the activity limitations and participation restrictions experienced by their children highlighted the far-reaching negative consequences of DCD. Activities that typically developing children master quite incidentally were extraordinary activities for these children. Intervention that focuses at the activity and participation level is important in the management of children with DCD and enables them to be accepted by their peers and to be a “normal kid”.

References


