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Occupational therapy for children with down syndrome – a case study

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Abstract

The purpose of study was to outline a client-centred model of practice framework that can be used in occupation-based practice for children with Down syndrome (DS). We considered as a case study a 13 years old boy with DS and we used the Canadian Occupational Performance Measure as a standardized tool to evaluate our intervention. After assessment, we decided on a neuro-physical theoretical approach to intervention, utilizing exercises and functional activities. During the programme of occupational therapy, our client covered the recommended sessions and at the end we concluded that beneficial effects were a direct result of our intervention project.

Keywords: case study, children, Down syndrome, occupational therapy;

1. Introduction

The best practice interventions in occupational therapy (OT) for children with Down syndrome (DS) must effectively support their meaningful and satisfactory involvement in current life activities and contexts. The purpose of study was to outline a client-centred model of practice framework that can be used in occupation-based practice with children with DS.

The framework must provide a tool for therapist to organize the processes of assessment and intervention, in the condition of recognizing that client-centredness pervades all stages of service delivery, taking into account the client-derived priorities (Rodger, 2010). For such cases it is highly recommended to consider children as occupational beings, both from occupational therapist and family perspective.

2. Material and methods

We used as theoretical basis the Canadian Practice Process Framework (CPPF) model and the Canadian Occupational Performance Measure (COPM) as a standardized tool to assess and evaluate interventions by identifying: seating issues, goals important to the client and self-rate performance of the client (Davis et al., 2007). The CPPF model is an instrument with eight key action points which was proposed in order to enable the

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occupational therapist to facilitate client-centred, evidence-based practice, as well as participate in reflective practice (Davis et al., 2007).

The COPM is an individualized tool that allows detecting self-perceived change in occupational performance problems over time, based on a rating importance that cover the interval 1 to 10 for each item, regarding performance and satisfaction. The assessment is based on client-centred principles and can be used in initial assessment and in measuring change (Law et al., 2005).

Our approach was an occupation-centred one, taking into consideration especially the occupational performance issues, tasks and environment rather than underlying performance components, as would be the case when a 'bottom-up' approach is used (Rogers, 2004).

Understanding the cultural, physical, personal, social, virtual and temporal environment or context of occupational performance is crucial (Townsend & Polatajko, 2008), so we used another tool, the Person–Environment–Occupation (PEO) model, in order to identify areas of occupational performance concerning the case of our client (Christiansen & Baum, 1997).

We conducted a case study on a boy with DS and we considered relevant the following data: biographical information (the history of pregnancy, delivery, the history of personal development, the history of school achievement), assessment of the physical, psychological and social status, evaluation of the family and social context, evaluation of occupational profile and of occupational performances.

3. Findings

We considered as a case study a 13 years old boy, premature born at 34 weeks with DS. He lives with his parents in a residential area, in a large house, in a family with high income and he studies at a normal school, despite his medium mental retardation. He has delayed language development and slow motor development, with muscular hypotonicity and obesity. He has most of the common dysmorphic features of DS, but his family and personal medical history is non-significant and usually he is not on any medication.

Our client experienced significant impairments in communication across a range of skills including articulation, morphology, syntax and semantics; his both receptive and expressive language is impaired, affecting his interactions with family, peers, and community members. He is an independent child and he used to work a lot at school and at home in order to be like his colleagues. He has a lot of problem in writing, reading and mathematics, but he likes very much to play football in the class team and after school program, even his colleagues often reject him.

The child reported feeling frustrated, angry and anxious about not being able to do many school tasks himself. He is a solitary child at school, standing on the sidelines because he is not accepted in children's games. During his school years, he was stigmatized by peers who derided his weight, intellectual disabilities and poor physical coordination. During out-of-school hours, he spends long periods of time in front of the television set.

He feels very frustrated due to his physical condition and he is not able to play his favorite sport and take part in his favorite hobby (e.g. playing soccer). He also reports feeling anxious that he is not able to complete his school tasks.

Regarding the environmental factors, our client find as exhausting to perform some intense physical activities (like climbing the stairs or participating in sport games). He has to limit his activities on the playground, even though he prefers to participate with his colleagues in sports and socializing activities. The family is very supportive, but his parents work a lot in business area and they have not enough time to spend with their son. Our client is registered in a four hours after school program that offers him facilities for study, some sedentary leisure activities, meals and rest with permanent supervising. Unfortunately, he doesn't like this situation, he fills very bored and lonely and he wants to stay more with his family.

We identified the key tasks/activities that comprised the child's roles and what performance difficulties the child had with these tasks: physical restraints for soliciting activities (like climbing stairs) and functional restraints for complex leisure games.

Because he had low language and communication abilities, we asked his parents to help him to recognize his occupational performance issues, to prioritize these and to identify realistic intervention goals.

In terms of participation issues regarding mobility, communication and personal self-maintenance and based on the assessment results and clinical observations, our client required assistance with the following instrumental activities of daily living: climbing stairs (performance score 3, satisfaction score 4) and sustaining other intense physical efforts like walking long distances, running, lifting/carrying heavy objects etc. Regarding the leisure activities, the most important problem for him was the participation in football games, at school and outdoor the school (performance score 2, satisfaction score 3). Improvement of performance of the two identified problems (climbing stairs and football playing) is considered as the goal and this process forms the basis for the program planning.

The analysis of the PEO transaction for football playing helped us to establish SMART objectives (S – Specific, M – Measurable, A – Achievable, R – Relevant, T – Time limited) for our client's rehabilitation: enabling him to play football for 20 minutes in a football school team, on a normal football field, by developing his ability to play short passes, to successfully drive passes over a long distance, to dribble, pass and shoot, his ability of decision making on the field and his spirit of collaboration with the other players.

The indirect service referred to improve the child's socialization skills through other leisure group activities and removal of stressors that could be interfering.

After assessment, including functional observations and standardized physical assessments under classical models (Decker & Foss, 1997), we identified some difficulties at the level of body structure and function and we chose to focus intervention at the activity and participation level. We decided on a neuro-physical theoretical approach to intervention, utilizing exercises and functional activities to help our client to improve his abilities for football playing. Thus, the OT program focused on roles, occupations, occupational performance and environment, by using functional activities that are required to successfully participate in school, sports, play, work and routine tasks of daily living.

The essential feature of the intervention process for our case was represented by the client-centred approach: the child identified goals which form the motivating focus of intervention. We designed a school based strategy of intervention that primarily involved the client, occupational therapist, school teachers, classmates and parents. Methods of intervention included environmental modifications, education, equipment recommendations and strategies related to improve joint and muscle flexibility (range of motion), strength, power, endurance, balance and proprioception (special positioning and coordination of limbs) in gentle work out routines.

We applied a daily occupational therapy session of 20 minutes initially, then progressively raising to 40 minutes, for 6 months consecutively, including diverse and alternative activities like football games, other equip games, technical instruction, video presentations and soccer video games. Each session required also 5 minutes of warming up and 5 minutes of cooling down, in order to satisfy the physiological basis of the approach.

During the OT program, we have permanently monitored the progress in collaboration with the client and the other team members in order to adapt plans as necessary until final evaluation. In addition, the monitoring of the client needed to take place to ensure that the intervention did not have an adverse effect on his medical condition (Addy, 2006).

Thus, for our case it was important to apply regular checks to monitor diet, weight, physical functioning and psychological status and to early detect eventual health problems. Moreover, it was important to monitor his performance and motivation for participation and to send information back to the intervention team.

At the final evaluation, after 6 months of OT, the improvement of performance of the two identified problems (climbing stairs and football playing) was significant, for both items obtaining higher scores at the COPM questionnaire (performance score 7 and satisfaction score 6 for climbing stairs and respectively performance score 6 and satisfaction score 5 for football playing).

The change in performance and satisfaction for our client following the OT intervention can be analyzed from table 1. Thus, the overall change in performance for the two identified problems (climbing stairs and football playing) was of 4 points gained. For the same perspective, the overall change in satisfaction was of 2 points gained.

After living the experience with our client, we can affirm that his adherence at the OT intervention was big because he was part of the decision-making process and because he felt in control over changes to his existence.

Table 1 – The evolution of our case between initial and final COPM evaluation

Occupational performance problems	Initial		Final	
	Performance	Satisfaction	Performance	Satisfaction
Climbing stairs	3	4	7	6
Football playing	2	3	6	5
Total score (Total performance or satisfaction scores / number of problems)	2.5	3.5	6.5	5.5
Change in performance (Final performance score – initial performance score)	4			
Change in satisfaction (Final satisfaction score – initial satisfaction score)	2			

During the program of occupational therapy, our client covered the recommended sessions and at the end we concluded that beneficial effects were a direct result of our intervention project. For him, the achieved goals referred to engage in sports (football game), to learn and to be accepted in a classroom, to be able to play with siblings and to become integrated in community.

Each achieved goal reflects an individual's desire to fully participate in society. Thus, it can be said that an important, perhaps universal outcome of OT services, is to enable people to participate in society through engaging in the occupations that are meaningful and important to them (Christiansen, Baum & Bass-Haugen, 2005).

4. Conclusion

The presented case study of a young boy with DS is representative for a disabled child who is unable to manage at home and at school in leisure physical activities and intensive efforts due to his reduced physical capacity, which affects his ability to proper function in his environment.

In such cases the intervention must be focused on those activities that bring meaning to child's life and we consider that the best therapists are his family members and his classmates - the people who spend every day with him, who understand him and show him affection.

This case study demonstrated the outcome of an intervention using the Canadian Practice Process Framework model and we think that numerous factors influenced the success of it: the occupational therapist's skill and knowledge with the assessments and therapy approaches, his clinical reasoning, knowledge of the evidence base and ability to use reflective practice to provide an individually tailored programme.

From this experience we had learned that intervention in case of a child with DS must be precocious and continuous applied in order to obtain maximum befits. We think that other relevant issue from our experience was the manner of creating a dialogue with a disabled person, in order to promote the building of a collective opinion. We ascertained that is important to consider a level of equality when dealing with disabled people, starting from the ideas that we are at the same level, despite of different competencies.

The rehabilitation goals for any children with developmental disabilities should be the same as that of normal children (McColl et al., 2003). The therapeutic project may need to be adapted as necessary due to each individual's condition, but the overall goal should be to provide as comprehensive treatment as possible (Rodger & Ziviani, 2006).

As other authors already have stated, the occupational therapist's role in such case should not only focus on extending occupational performance, but also to be proactive in enabling client to accept himself for who he is and become resilient to societal barriers (Addy, 2006). For the presented case-study further goals must be discussed and set, like continuing to attend outpatient physiotherapy and regular occupational therapy sessions, in these circumstances the long-term functional outcome looking positive.

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