

ORIGINAL ARTICLE



# Physical Education Intervention in a Child with Dravet Syndrome: A Case Study

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## ABSTRACT

**Background.** Dravet syndrome (DS) is an early-onset epileptic encephalopathy that leads to deficits in gross and fine motor skills. **Objectives.** This study aimed to evaluate the results of a motor intervention program in a child with DS. **Methods.** We analyzed uma child with DS during the 3-year intervention in Physical Education. For data collection, interviews with the child's mother and the teachers' class diary were used. **Results.** Information was collected on emotional, behavioral, social, and quality of life aspects, using the Bruininks-Oseretsky Motor Proficiency Test to verify the child's development. **Conclusion.** The intervention program contributed positively to the improvement of motor proficiency, namely, in the balance and manual agility, as well as also verifying positive results regarding the development of the emotional, behavioral, social, and quality of life aspects of the child, in addition to the significant decrease in the number of seizures presented.

**KEYWORDS:** *Physical Education Program; Dravet Syndrome*

## INTRODUCTION

Charlotte Dravet described Dravet syndrome (DS), which was known as severe myoclonic epilepsy of infancy (1) is an early-onset epileptic encephalopathy caused by variants of the SCN1A gene (2, 3), often refractory to anticonvulsant treatment (4). It is displayed in the first year of life and is often confused with febrile seizures or other forms of epilepsy (5). It is a rare syndrome (5) that results in cognitive, behavioral, motor, communication, and social skills impairment (6, 7), affecting mental health, bone, and sleep (8). There are also problems with the quality of life related to health, attention, aggression, and withdrawn behavior, in addition to anxiety and depression (9).

Regarding motor aspects, children with DS have deficits in global and fine motor skills, difficulties in coordination, balance, hypotonia, and atypical gait (5, 10). Yet, even in light of all these issues, no specific work was found in the

literature regarding Physical Education for these children.

Nonetheless, researchers highlight the importance of Physical Education (PE) for individuals with epilepsy, showing that they are less active compared to other individuals who do not have this problem (11). Factors such as fear of injury risk (12) are considered, as well as prejudice, overprotection, ignorance, stigma, fear of inducing seizures, and lack of knowledge on behalf of health professionals (11), as those responsible for the low adherence of people with epilepsy to Physical Education programs, despite the positive correlation between mental well-being and self-esteem in children with epilepsy (13).

Concerning the benefits of PE for people with epilepsy, an improvement in cognition is emphasized (14) in mood, physical condition, social interaction, and quality of life. This is

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mainly because physical exercise strengthens neuronal protection mechanisms related to biochemical and structural changes, which have an inhibitory effect on abnormal electrical activity. Thus, epileptic discharges can decrease or disappear during exercise, reducing the recurrence of crises (11), in addition to lowering cardiovascular problems, lung diseases and contributing to the conservation of bone mass that can be impaired due to the use of antiepileptic drugs (15).

As for the type of activity to be proposed, there is no universal recommendation apart from the importance of checking one's age, the type of epilepsy, and the frequency of crises (14), to propose the proper activity in each case.

Considering the importance of Physical Education for individuals with epilepsy, the objective of this study was to evaluate the results of a motor intervention program in a child with Dravet's Syndrome. It is considered that the observations made in this work may become fundamental for reflection on the importance of Physical Education for children with DS and other conditions of epilepsy.

## MATERIALS AND METHODS

This research was carried out through a case study that, for Ventura (2007, p. 383), "aims at investigating a specific case, well delimited, contextualized in time and place so that a detailed search for information can be carried out."

The pedagogical intervention in Physical Education with a female child that presents Dravet Syndrome was analyzed within the Department of Sport Sciences of the University of Beira Interior, Portugal, for three years. The research was approved by the Human Research Ethics Committee of the University.

**Participant Characteristics.** At the beginning of the pedagogical intervention, the child was four years old, presenting a picture of Dravet Syndrome, attested by the Pediatric Hospital of Coimbra. According to reports by the mother, around four months of age, seizures started to appear several times a day and then decreased with medication use. At the beginning of the intervention, the child had 1 or 2 mild seizures, resulting in walking, balance, strength, postural control, and coordination. The relationship with other children was not the best, as she threw many tantrums and confronted her

colleagues, the kindergarten teacher, and her teacher's assistants.

**Documents for Collecting Information.** For the beginning of the pedagogical intervention, an interview was carried out with the child's mother, trying to understand the personal tastes, the potentialities, and the main limitations of the child, to adapt the planning to the characteristics presented.

At the end of each academic year, new interviews were conducted, which consisted of verifying the most and least favorable points of the intervention, allowing for a better reformulation of the objectives and methodology. Also, at the beginning of the remaining school years, the child's work team reported the losses and gains in skills during the vacation period.

Information was also collected on the emotional, behavioral, social, and quality of life aspects of the child to verify possible changes during the pedagogical intervention.

A Class Diary was used, which is the document used by the child's teachers to collect information about the pedagogical intervention. The objectives and methodology of each class were recorded, and the final reflection of the work was carried out each day.

**Intervention.** The pedagogical intervention took place over three consecutive school years, with the child enjoying two weekly motor stimulation sessions, each lasting 45 minutes. During school breaks, Christmas holidays, Carnival, and summer, there was no intervention. The child was assiduous, having attended all classes provided.

The motor intervention program was built according to the following assumptions: (i) the child's initial diagnosis, to understand her level of motor development and to adapt the type of exercises to be performed; (ii) individualization of classes; (iii) playfulness, using different tasks and materials; (iv) cognitive stimulation, through motor tasks; and (v) the pursuit of improving basic motor skills.

Thus, the child was submitted to a motor intervention program in the school gym she attended. Different types of portable materials (balls, bows, ropes, balloons, Swedish bench, mattresses) and a trampoline with 80 cm in diameter. The double task was also used to stimulate the child at both a motor and cognitive level and determine communication and relationship with her peers.

At the beginning of the first school year, there was a meeting with the parents to prepare a motor intervention program to help the child reduce her deficits. We sought to know the child's tastes, difficulties, and potential and, after the initial assessment, a specific intervention program was designed for the child with DS.

The following objectives were defined for the 1st year: to perform jumps with the feet together; to throw a ball at a fixed target from a short distance; to walk on top of a Swedish bench, and jump independently on the trampoline.

Different tasks were created to achieve these goals. However, the child was unable to jump with her feet together and walk on the Swedish bench independently, showing great enthusiasm for jumping on the trampoline.

Given the difficulties and little development presented by the child, the objectives were maintained throughout the following years. Still, as she then acquired some motor skills, more demanding tasks were being requested; for instance, in the case of throwing to reach a target, the distance from the target was increased.

Another aspect that was worked on was socialization. The first four sessions of the intervention were in individualized teaching and, subsequently, in each session, a classmate was chosen to do the activities with the child. In the second and third years of the intervention, two colleagues from the room accompanied her in the activities. This strategy favored motivation and developed socialization and respect for colleagues.

This strategy contributed to improving her motivation in carrying out the proposed tasks and developed socialization skills and respect with her classmates.

**Motor Assessment.** To evaluate the child's performance and to prepare the planning, in addition to defining the objectives of the work, the Bruininks-Oseretsky Motor Proficiency Test - second edition - BOT-2 (16) was used, in a reduced form, to verify the child's development in moments before and after the intervention, at the beginning and end of each school year. This test assesses fine and overall motor skills and indicates levels of motor proficiency, taking into account the child's age and gender.

## RESULTS

Table 2 presents the results of the tests proposed for the child during the three school years, with scores recorded at the beginning and end of each year. Based on the data presented in Table 2, it is possible to verify that there was no development of any kind in the items that make up fine motor precision and refined motor integration over the three school years. According to Wirrell et al. (2017), children with DS show deficits in fine motor skills and coordination, and manual dexterity. This fact can help to understand the low score registered by the child in these subtests. However, it should be noted that, during the intervention, no specific work was carried out at the level of fine manual control, which may also justify the fact that there was no development in this area (17).

**Table 1. Bruininks-Oseretsky Motor Proficiency Test, in Reduced form (BOT-2)**

| Subtests                                     | Description                                   |
|--|---|
| <b>Subtest 1 - Fine motor precision</b>      |   |
| 1  | Filling in a star                             |
| 2  | Drawing a line through a path                 |
| <b>Subtest 2 - Fine motor integration</b>    |   |
| 3  | Copying overlapping circles                   |
| 4  | Copying a diamond                             |
| <b>Subtest 3 - Manual dexterity</b>          |   |
| 5  | Stringing blocks                              |
| <b>Subtest 4 - Bilateral coordination</b>    |   |
| 6  | Touching nose with index finger – eyes closed |
| 7  | Pivoting thumbs and index fingers             |
| <b>Subtest 5 - Balance</b>                   |   |
| 8  | Walking forward heel-to-toe on a line         |
| <b>Subtest 6 – Running speed and agility</b> |   |
| 9  | One-legged side hop                           |
| <b>Subtest 7 – Upper-Limb coordination</b>   |   |
| 10   | Catching a tossed ball – one hand             |
| 11   | Dribbling a ball – alternating hands          |
| <b>Subtest 8 - Strength</b>                  |   |
| 12   | Knee push-ups or full push-ups5               |
| <b>Total Motor Composite</b>                 |   |

Table 2. The score of the Tests Proposed over the 3 School Years.

| Subtest                            | Assessment |            |            |            |            |            |
|------------------------------------|------------|------------|------------|------------|------------|------------|
|                                    | 1stYear IA | 1stYear FA | 2ndYear IA | 2ndYear FA | 3rdYear IA | 3rdYear FA |
| <b>1 - Fine motor precision</b>    |            |            |            |            |            |            |
| 1                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| 2                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| <b>2 - Fine motor integration</b>  |            |            |            |            |            |            |
| 3                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| 4                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| <b>3 - Manual dexterity</b>        |            |            |            |            |            |            |
| 5                                  | 0          | 1          | 0          | 2          | 2          | 3          |
| <b>4 - Bilateral coordination</b>  |            |            |            |            |            |            |
| 6                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| 7                                  | 0          | 0          | 0          | 0          | 0          | 0          |
| <b>5 - Balance</b>                 |            |            |            |            |            |            |
| 8                                  | 0          | 1          | 1          | 2          | 1          | 3          |
| <b>6-Running speed and agility</b> |            |            |            |            |            |            |
| 9                                  | 0          | 0          | 0          | 2          | 2          | 4          |
| <b>7-Upper-Limb coordination</b>   |            |            |            |            |            |            |
| 10                                 | 0          | 0          | 0          | 0          | 0          | 0          |
| 11                                 | 0          | 0          | 0          | 0          | 0          | 0          |
| <b>8 - Strength</b>                |            |            |            |            |            |            |
| 12                                 | 0          | 0          | 0          | 0          | 0          | 0          |
| <b>Total Motor Composite</b>       | 0          | 2          | 1          | 6          | 5          | 10         |

Legend: IA - Initial assessment; FA - Final assessment.

The data presented in Table 2, regarding difficulties in manual dexterity and coordination, reinforce the statements of Wirrell et al. (2017), who describe the problems found in individuals with DS in these aspects, in which the score recorded by the child was shallow, being, in an initial phase, null. Nevertheless, improvements in manual dexterity were registered throughout the intervention program. It was also found that at the beginning of each school year, there was a delay in the values presented just after the holidays. This fact refers to the importance of Physical Education for developing manual dexterity and coordination in children with DS (17).

Regarding balance and bilateral coordination, the data presented in Table 2 also reveal a meager score, which is in line with what was reported by Barous & Heering (2018) (10), who highlight that children with DS have difficulties in these two aspects. Gait is severely impaired in patients with DS (18), which also helps justify the low level of balance presented. However, bilateral coordination, composed of two items, registered different variations. Therefore, item 6 written development from the second year of intervention. On the other hand, item 7 of the bilateral coordination subtest, which consists of keeping the eyes closed and rotating the thumbs and index fingers, remained unchanged.

In terms of speed, agility, and strength, there was no development in the child, and no reference

to the subject was found in the literature, making it challenging to analyze the reasons for such results.

Concerning motor proficiency, in children with typical development, it is positively associated with physical activity and negatively associated with a sedentary lifestyle (19). This factor was also shown in the presentation of the total result of the Motor Proficiency (MP) test of this study, as it was possible to notice that there were changes in the child over the three school years from the proposed intervention, having started with 0 (zero) points and ended with 10 (ten). There was a slight regression after the summer vacation stopped when the child did not practice physical activities. Based on the results obtained in the MP test and according to the protocol of Bruininks & Bruininks (2005) (16), it was possible to categorize that she maintained an MP well despite the child's score improving below the average. The results obtained showed a development trend, especially in terms of coordination and balance. It is essential to continue the motor intervention program to improve the child's MP profile.

In addition to the data presented, positive changes were recorded in the child's emotional, behavioral, social and quality of life aspects. These aspects were recorded in the teachers' Class Diary and described by the child's mother in the interviews. One of the most evident aspects

was the social behavior and acceptance of peers, as the child started to respect her classmate. Likewise, her colleagues began to appreciate her and understand and collaborate with her given the activities proposed in the intervention.

## DISCUSSION

According to the mother and the child's teachers, the child showed progress in tasks such as going up and downstairs and walking, which leads to an improvement in quality of life. In addition to the advances in these motor skills, the child has become more independent and confident when performing these motor skills. Inevitably the child's due quality has improved.

In addition to all these advances, it is essential to emphasize the decrease in the number and intensity of seizures that have started to occur very sporadically. The child spent weeks without attacks.

Because of the significant results obtained, it can be said that children with DS must be accompanied by a specialist in Adapted Physical Education, agreeing with Wirrell (2016), who mentions the importance of these children being cared for by a multidisciplinary team that includes a motor specialist (20).

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## CONCLUSION

We can conclude that, despite the three years of pedagogical intervention, the child with DS presented a low level of development because of the motor assessments carried out. However, the intervention program strategically designed for her contributed positively to the improvement of her motor proficiency, namely, in balance and manual dexterity, in addition to being fundamental for obtaining positive results regarding the development of emotional aspects, behavioral, social, and quality of life of the child, along with the significant decrease in the number of seizures presented.

The fact that it is a case study with only one child and the scarcity of research related to PE related to Dravet Syndrome in the literature becomes a limiting factor. It makes it more difficult to analyze it more to the results obtained in the motor evaluation. Still, the good results obtained concerning the child's quality of life stress the need to invest in PE programs for people with this Syndrome or with other cases of epilepsy, paying close attention to the integrity of the benefits of physical exercise and not only concerning motor aspects.

## CONFLICTS OF INTEREST

No conflict of interest.

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