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Children with Rare Diseases in the School: Social and Communication Difficulties



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Abstract

Human beings are able to develop their social and communicative competences. However, we have to consider some difficulties, specifically in the socio-communicative functioning that people with rare disease have. Those diseases, which hinder their social and communicative development, are noticed in their facial expressions, speaking or movement impairment. The purpose of this study is to analyse the communication deficit, social skills and the inclusion process of students with rare diseases in the school context. Looking into the process of social and communicative competences acquisition that these students undergo according to their teachers' opinions, and they also take part in the improvement of their socio-communicative process. This study was applied to a total of 50 active teachers in Early Years (Reception) and Primary School (KS1- KS2) in Spain. According to the findings, the Hermeneutic Unit (ATLAS.ti 7 Software) of the Verbal Report data shows that the main communicative difficulties, students must face, are the following:

- a) "Understanding what the student said, due to his/her articulatory problems".
- b) "Lack in teachers' training in educational children's diversity. Guidelines to be followed or aspects that must be taken into account to foster good communication with them."
- c) "Lack of the student's attention".

Keywords: Rare diseases; Facial expression; Communicative competence; School; Special Education needs

Introduction

Human beings are able to develop their social and communicative competence. Children with special education needs and disabilities comprise some of the most vulnerable in our societies. However, we have to reflect on the difficulties, especially on the socio-communicative sphere that those with rare diseases have. Regarding to the EU definition of minority of rare diseases and orphan or rare diseases that refers to "those life-threatening diseases or chronic, debilitating diseases with a prevalence of less than 5 cases per 10,000 inhabitants in the EU [1,2]. This paper shows that there is an effort to recognize these diseases from a very important aspect "identification with accurate information to professionals and affected people". The social competence is "the ability to maintain good relationships with others" [3,4]. The authors express that can be mastered the social skills, the respect for others, the receptive and expressive communication, the

sharing emotions, cooperation, assertiveness, etc. Those illnesses which hinder their social and communicative development and are noticed in their facial expressions and speaking or movement impairment [5,6]. Through the teaching action, teachers must improve the inclusion in the classroom as well as the social and communicative competence of these students [7,8]. The anguish and frustration associated to these rare illnesses may cause social and family problems [9], and in our case, school problems. Living with this kind of illnesses may lead to severe identity crisis and inhibit personal growth. If friends, classmates, family members and even teachers are constantly simplifying and ignoring the illness, the difficulties for these children may increase. The perception and development of socio-communicative competence by the teacher perspective is of importance, especially with children with a disease or rare syndrome and /or disability. In this

review we present the methodological processes that will allow to improve the social and communicative competence of the students with these rare illnesses. The facial expression of these students is affected and that makes it difficult for them to communicate with their peers, teachers and family [10]. For this, we have taken into account the experience and data collected in two researches [11-15] a rare congenital disorder of varying severity, involves multiple cranial nerves and is characterised predominantly by bilateral or unilateral paralysis of the facial and abducens nerves. Facial paralysis causes inability to smile and bilabial incompetence with speech difficulties, oral incompetence, problems with eating and drinking, including pocketing of food in the cheek and dribbling, as well as severe drooling. Other relevant clinical findings are incomplete eye closure and convergent strabismus. The authors report on 48 patients with Moebius and Moebius-like syndromes seen from 2003 to September 2007 (23 males and 25 females, mean age 13.9 years refers to the rare illness of Moebius syndrome (a congenital paralysis which stops facial control and lateral eye movement) and the other one refers to Melkersson-Rosenthal syndrome (oedema or swelling as a result of inadequate secondary lymph drainage of the upper lip, reappearing facial paralysis and fractured tongue) [16-18].

Discussion

There are three main difficulties encountered by teachers to communicate and be related to these students:

- a) "Understanding what it said, due to the articulatory problems."
- b) "Lack of diversity training of teachers. Guidelines to be followed or aspects that must be taken into account to foster good communication with them."
- c) "Lack of attention of students."

The process of communication in the school of people with disease or syndrome is indicated that the linguistic aspects must be worked on, are:

- a) Carrying out exercises that are focused on promoting the buccolingual skills development, auditory discrimination and breathing.
- b) Carrying out exercises designed to teach to these students the correct articulation of all sounds and their integration into spontaneous or conversational speech.
- c) Introducing an alternative system of communication when verbal communication is not possible.

In relation with the psychomotor aspects, laterality, space-time location, balance, gross motor experiences, eye-hand

coordination (gross and fine motor), the eye-pedal coordination, social interaction and body schema should be worked.

And in relation with the social aspects should be worked: self-esteem, conflict resolution and social skills to achieve objectives such as:

- a) Promote the distinction between self-image from what it's received from others.
- b) Develop attitudes of acceptance and tolerance towards oneself and others.
- c) Develop communication skills.
- d) Promote the development of emotional bonds.
- e) Promote the constructive resolution of conflicts that may arise in interpersonal relationships in the classroom.
- f) Encourage the development of attitudes of dialogue, tolerance and cooperation within the group.
- g) Develop attitudes of respect and appreciation towards other groups, customs and values.

The implications for professionals working with students with disease or syndrome affecting his/her factions. Teachers say that these students have difficulties in all aspects of education and also say that resources to improve teaching-learning process are: support for specific teachers for diversity, specific support material, pictograms, diversity of activities, additional communication resources.

Conclusion

Teachers working for the first time with students who have a disease or syndrome that affects their factions are afraid of not knowing how to teach, mainly because of their lack of training to meet the educational needs. They work with the student to behavioural problems and / or learning difficulties primarily affect. They also say that the disease or syndrome makes it difficult to his adaptation to their class group because they often have trouble with their communication. It also prevents him from properly developing the teaching-learning process. That's why It is important to be empathetic and act taking into account student characteristics, their potential and adapt to their context and positive verbal environment with by steps for establishing a positive verbal environment [19]. A positive verbal environment is one in which children feel valued [20] It is necessary to work social skills and use various resources to improve students' teaching-learning process. Individualized instruction is the strategy that best fits their characteristics. Teachers must make decisions about strategies for the development of social competence [21,22].

The student's school mates accept it, but at the same time they ignore or reject them in their games or group activities and they sometimes suffer verbal abuse [23]. The support and collaboration of other students promotes personal and social development and improvement of the teaching-learning process.

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