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EC NURSING AND HEALTHCARE
Research Article

Down Syndrome Holders in the Special Education Context with a Systemic Approach Between School and Family

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Received: February 25, 2021; **Published:** April 29, 2022

Abstract

Special education is a context of insertion of psychologists in multidisciplinary team, with employment through SUS, APAEs systems. We approached a systemic case study with four Downs students, three boys and one girl, between the ages of 8 years/9 months, 7 years/7 months, 5 years/6 months and 4 years/3 months, with their respective school and family ties. The objective of the case study was to identify which family and school influences contributed favorably to the full psychosocial development of two students, and why the other students were significantly globally delayed. The methodological approach included individual interviews (mothers and students), home visits, classroom observation, individual play activities. Data were collected through clinical observation, parent meetings, individual interviews with each family, and home visits. Duly grounded in the systemic approach, involving school/team, students/families and their surroundings, in an integrative-inclusive dynamic with rescue of the parental affective function. The treatment of the information and the analysis of the data allowed us to verify the success or failure of the student's psychosocial development in different age groups, with the main focus being the González Rey (2002, 2003, 2005) [1] method, in which he states that Qualitative Epistemology is the possibility of researching subjectivity. It is pointed out with surprising prominence, in terms of psychological, cognitive, social and functional development, the 4-year-old child. It is the result of a work of observation, interaction, and reintegration of school and family, in a qualitative and exploratory research approach, which provided the opportunity to bring, to the present reality, new psychological intervention modalities with promising results, in Special Education. The choice of the method and the systemic approach were essential to reach the objectives of the study and provided a better understanding of the dynamics of families who have members with Down Syndrome..

Keywords: *Special Education; Parental Functions; Down Syndrome*

Introduction

This professional experience report, Psychological, was made from the behavioral and family observations of the students presented here, for two of them stand out in performance and evolution, despite the Down Syndrome. The Special Schools, APAEs, in neighboring municipalities, distance 16 km. School 01 with 77 students and School 02 with 96 students, under regulations and legal responsibilities of the same educational nucleus.

The theoretical basis and work with families, focus on the Systemic approach, from the perspective of new concepts and approaches, highlighting the multigenerational transmission, according to Celestino and B-Maluschke (Source: Victor RR CELESTINO Julia S. BUCHER-MALUSCHKE, -ISSN1516-6503 and ISSN2316-3402/2015) [2], which is a proposal to understand the process of repetition of relationship patterns in the family in successive generations and which is closely related to the family's emotional process, even before the individual's birth, which was observed in the reality of the families under study. And that, from the moment that these families were worked, results close to those referred to by the new look of the Systemic approach are identified, that is, that differentiation is fundamental for the individual's mental health, so that he can build his individuation and psychological functioning independent of family patterns.

Down Syndrome, according to the article of *Revista Brasileira de Psiquiatria* (2000; 22 (2): 96-9) [3], in addition to presenting developmental delays, other health problems may occur in the patient: congenital heart disease (40%); hypotonia (100%); hearing problems (50 to 70%); vision (15 to 50%); changes in the cervical spine (1 to 10%); thyroid disorders (15%); neurological problems (5 to 10%); obesity and premature aging. In terms of development, Down syndrome, although sublethal in nature, can be considered genetically lethal when considering that 70 - 80% of cases are eliminated prematurely. Regarding the prognosis, it appears that the prevalence of the condition has increased in the general population as a result of increased survival. Treatments and therapies, especially early stimulation with physiotherapy and speech therapy, show an unequivocal contribution to better development and social performance of Down syndrome patients.

Study Objectives

The objective of the case study was to identify which family and school influences contributed favorably to the full psychosocial development of one of the students and why the other students were significantly globally delayed. The methodological approach included individual interviews (mothers and students), home visits, classroom observation, and individual play activities. The families of four Downs students (3 males-X-W-Z and one female-Y (fictitious names X, W, Z, and Y)) were asked about previous and current care arrangements and which factors were decisive for the full healthy development of two students and which factors hindered the healthy development of the other two students in a similar age group.

What factors were decisive for the full psychoneurofunctional development of student X and mainly, of student Z? (Fictitious names X and Z).

Methodology

The research for this case study was carried out in psychology, based on behavioral and family observations of the students presented here, because two of them stood out in performance and evolution, despite Down's Syndrome, and two did not. The method is simple: interviews and data collection with family members, conversation circles, collection of medical records, and anamnesis updates. The Special Schools, APAEs, in neighboring towns, distance 16 km. We will name them APAE ZA, Salto do Lontra/PR, with 77 students and APAE RI, Nova Prata do Iguaçu/PR, with 96 students, under the rules and legal responsibilities of the same educational center. A brief literature review was made on Down's Syndrome and the Systemic approach. We made home visits, interviewed the parents and observed the students in their family environment. At school, we observed the students individually and in groups. With the parents, meetings with the parents in a conversation circle and, with the mothers, review of the clinical anamnesis and daily life.

Justification

The study was done with four students (4) in which two (2) stand out healthily and two, at similar ages, are more cognitively and socially compromised. The psychological clinic activities began at ZA School in March/2015, presenting, in the form of a lecture, to parents and the entire school team, the format of the work program in the Systemic and Cognitive-Behavioral modality. With the formation of groups (students and parents), and individual consultations, both for clients and their families. This is how I got to know the four students in this case study and their families. I met student Z, who was one year and two months old, already walking, but with marked tantrum

traits, usually hiding under a table. I conquered his attention and affection in such a way that he became attached to me, whenever he met me in the hallway or at the reception, he would run to my lap, and when he passed in front of my classroom, he would come in and never wanted to leave. He learned to dominate the pencil and pen, to draw his hands, to make little balls, to make big wave-shaped scratches, with firmness in the tracing. I usually use a clipboard, which he takes and crosses out all the blank sulphite sheets. He recognizes dolls in the family -white head he points and says it's Grandpa. He learned to come to school last year (2017) by bus with other classmates. When I go to his classroom, he asks the teacher to put on a DVD of Galinha Pintadinha and, gesticulating with his hands, arms, and legs, he dances and sings. He has an incredible visual memory, a quick and assertive psychomotor body control. This agile and quick way of learning and showing what he has learned in gestures and rudiments of words aroused my curiosity, in relation to his Downs peers, older ones who do not speak, and the walking is compromised with immense delay in the case of student Y and student W, who has not developed speech and the walking is insecure at the age of 9.

At APAE RI, where I started my activities, with the same program of activities and performances, I met student X, independent in walking and talking, active and participative in all school activities. These two students from different schools and families aroused my curiosity to know more closely what they have in common and what helped them to develop earlier than the others.

In reviewing and updating the clinical anamneses of these students, what caught my attention was the family life history, gestational history, and medical condition of each.

Introducing the case study students

In respect for the confidential treatment of their identities, each one is identified by special letters: 1-W, 2-X, 3-Y, 4- Z, in the respective numerical and alphabetical order (1-w, 2-x, 3-y, 4-z).

Pupil W (date of birth, 06/08/2009) APAE ZA (S. Lontra), just turned 9 years old, not breastfed. Son of parents with 39/40 years old, schooling, the 1st grade, she 2nd grade, they live in the rural area. They have one brother, 3 years older. He has been attending APAE since he was 2 months old. Gestational history: The mother reports that during gestation she sensed something strange with the baby, but never told anyone about it; she felt insecure. She had normal prenatal care, was born by c-section (9m), and the pediatrician was the one who told them that her son had Down's syndrome, in a very rude way, says the mother, who was in shock, and took time to get used to it and accept it. He was never sick, but presented muscular hypotonia, with delayed speech development to this day (he did not develop speech), he walked close to 3 years old. He is shy, refuses to participate in many activities at school, with isolated behavior, limits himself to looking with a slight smile. Today, after many interventions with the family and school, he begins to get involved in group activities. Distant family relations.

Pupil X (birth date 05/10/2010) APAE RI (N. Prata do Iguaçu), 7 years and 10 months old, was breast-fed until 8 months. Son of young parents (mother had him when he was 16 years old), parents' education was first grade, they live in the rural area. He has a brother aged one year and ten months. He has been attending APAE since he was 5 months old. Gestational history: normal gestation (9m), born in a normal delivery. Parents only found out he had Down's syndrome when he was 3 months old. Mother took him to the pediatrician for a routine consultation and the pediatrician informed her that she should take him to APAE. She was alone with her son, because her husband worked outside and didn't come home for days. She had no childhood diseases, crawled between 7 and 8 months, walked at 11 months, there was a slight delay in speech, today she communicates well. He has an active behavior, is skilled in acting, and loves music. Lives with grandparents, uncles, and cousins.

Pupil Y (date of birth, 11/13/2012) APAE ZA, aged 6 years and 9 months, did not breastfeed. Daughter of mother 40 years old and father 43 years old, primary education (4th grade), reside in the urban area. Has a pair of siblings (F.21a and M.14a). Attends APAE since 30/09/2013, with many absences. Gestational history: troubled pregnancy, because of the pain that the mother felt (arm and right leg, usually at dawn), she was heavily medicated; in the 7th month of pregnancy she had an ultrasound and realized that the baby was not

normal, but she kept quiet, the doctor said nothing, and from then on she began to suffer from crying, insomnia, and fear. She was born by a long C-section delivery (mother spent 2 days in pain), was taken to the neonatal ICU, and stayed there for 10 days. Three days after the birth, mother was discharged and went to see her daughter in the ICU, she got a shock when she was notified by the doctor that her daughter was a Down's syndrome carrier. She went home without her daughter, triggered depression and couldn't bear for anyone to make a comment. At home she resented and did not accept the baby, conflicts with her partner emerged, and they separated. There were delays in global development, at one year of age she was hospitalized again for 17 days with double pneumonia. Today, after involving the mother in a conversation circle with other parents, the student started to take her first steps, clinging at home on the sofa and chairs, and at school on the jogging with someone on her side; she has not developed speech, but understands simple orders and can manipulate objects that fit together. The mother remade her life, with the example of other mothers, started making pasta, bread, and sweets to sell, did well in business, and opened a small business.

Pupil Z (date of birth, 27/01/2014) APAE ZA, aged 4 years and 6 months, was not breastfed. Son of parents with ages: mother 45 years and, father 53 years old, at the time of birth, residing in the rural area. Has 5 adult siblings. Has been attending APAE since he was 5 months old. Gestational history: diabetic mother, smoker, couldn't sleep at night; alcoholic father, retired due to illness. Unstable pregnancy, thought of and even attempted abortion, without result. Student Z was born pre-mature at 6 months, stayed 45 days in the Incubator of the Neonatal ICU; Down's syndrome carrier, with slight cardiac alteration. Mother expressed double feeling, accept-reject, thought: my God now a baby and what am I going to do; mother was hospitalized for 45 days, at the beginning of pregnancy, then another 45 days in the sixth month, in which a c-section delivery was performed, because of very high diabetes, both life-threatening. He was a robust, crying baby, attended APAE twice a week in the first year, learned to crawl and walk. Coincidentally, I started my activities at APAE with the Systemic and Cognitive-behavioral approach in March 2015. He was a baby with a closed facial expression, shy, used to hide under the table, lie down and hide his face. I started a conversation circle with the parents and group work with the students, with home visits. They all came to my classroom, with a mirror and tatami in front of them, a toy box, and they used to open the box and scatter everything on the floor; little by little he looked at himself in the mirror, was very agile on the floor, and searched everything around. I gained his attention in such a way that whenever he sees me in the hallway, he runs into my arms. He did, individual sessions with him and his mother. He has never been sick, he has always been strong and healthy. The community where they live is very united, he lives with his grandparents and uncles; he goes to their houses alone, he knows how to cross the street.

Results and Discussion

It was a field work with the families and the students, where it was possible to closely observe the interaction between parents and children, the history survey, since the gestational phase and how they live in their day to day life. It is understood that when our professional focus is on problem solving, we will always find healthy opportunities to better manage conflicts, aggressive situations or even, problematic contexts. My work with these schools has been a great portal for the visibility of the other, of the others and of myself in the context of that context. We are the voice and path of light, visibility and psychosocial reorganization of this clientele and their family and social context. Parents' meetings were initially fortnightly, then became monthly, and since last year they have been bimonthly. These are moments of conversation and exchange of experiences. It proved to be a unique opportunity for these families to escape from anonymity, social shame and fear of being ridiculed in the surrounding reality. There were reports of emotional parents, commenting on how much their children and, themselves, improved in their daily life, and that, they started to see their children with more respect and self-love.

Student W is from a well-structured family (rural area), very close and well-connected parents in the community, with the student always healthy. But one detail caught my attention: a shy mother, with worrying feelings about her son. He did not allow the student to leave the house, for fear that he would get hurt. W grew up afraid of everything, pets, plants and, without living with anyone outside the home and school.

Student X comes from a large family around him (rural area), grandparents, uncles, cousins. Since drinking, living and sleeping in the grandparents' house and, with an important differential: at school the team is active and creative in methodological interventions. He learned early to handle sound devices, is part of the School Musical Band and, parents stimulate at home, take care of his brother.

Student Y comes from a family in conflict (urban area), limited in space and bonds. She suffers emotional blocks since pregnancy. She was born fragile, sick. Without any external stimulus to develop, paternal absence, with strong maternal attachment.

Student Z (rural area), despite his parenting origins in old age and sick (diabetic mother and sick father) and, the only one of the three students, of 6 months gestation, emerges with a lot of strength and strength for life. He learns easily, imitates everything and everyone, knows how to communicate between gestures, monosyllabic words that are still poorly understood and a lot of musical body expression. He knows how to handle objects, likes to watch cartoons, sings and dances with his whole body. He has firmness in his steps, with total psychomotor mastery, is selective in his choices, does not approach anyone. The parents say that he is very intelligent, he helps his mother with everything in the house. He likes to wake up early and go to his grandmother's house to kiss and have coffee with her.

Among the four students with Down Syndrome, student Z stands out, with a medical condition since pregnancy, high risk, born from a gestational period of 6 months, remains in the neonatal unit 45 days. And yet, despite muscle hypotonia, signs of initial cardiac pathology, develops naturally and healthily.

What or what are the facilitating elements, both internal and external, that enable their healthy development and active behavior involved?

In the case of student Z, the meetings of parents and individual visits to the mother, brought the family members closer and home visits reinforce the changes in behavior for a better interaction, with dialogue and more tolerance between them. The family of student Z is big and very festive, comments the father who, on weekends usually gather all uncles, grandparents, nephews and grandchildren, moment when, they play many musical instruments and dance, and that the son 'Z', participates in everything trying to play the guitar, sing and dance.

I emphasize here the importance of the management model within schools, which makes all the difference in the development of the clientele and approximation of families in the school. An open, welcoming management enables discussions, multidisciplinary meetings and inserts all school professionals in the focus of the school in the focus on creativity, involvement and pedagogical and psychopedagogical actions with methodology adapted to the and rediscutidas, aimed at the development of the clientele. For example: the insertion of the Psychologist in a Class Council meeting, where she may be contributing with technical clarifications pertinent to the behavior of the students. In a school, whether special or not, where there is no functional role of psychology professionals, there are reactions, on the part of educators, more at the superficial level, attributing the poor performance of the clientele, to themselves, to parents or even to the State:

- Possible answers for the healthy development of student X and student Z: factors of an internal nature: change in the habits and behavior of parents and, externally: very rich surroundings in family interrelationships, school with systemic actions (student Z), associated with the proactive personality traits of each student. And nowadays with reinforcement of systemic psychology active between school and family.

- Possible answers to the difficulties presented by the other two students: medical failures are identified. Any pregnant woman, currently, needs psychological follow-up during pregnancy and, when special child is suspected, there is an urgent need for psychological follow-up during pregnancy and after the birth of the baby is.

The result of this work makes me reflect on the other APAEs and, on how each colleague Psychologist acts, and does the performance contribute to the full involvement between school and family? I argue that the type of psychological intervention in APAEs is more efficient and effective in the Systemic approach. Our work becomes pleasurable, fun and satisfying, as the results emerge inside and outside the school, families become more participatory and confident.

And to finish the presentation, I board timely references from the School of Palo Alto (USA), in which some of its representatives diverged from the rigidity of academic circles, in the human way of communicating and interacting. Gregory Bateson's thinking stands out,

which began to preach an evolutionary and interdisciplinary epistemology, approaching other sciences, such as Sociology, Psychology, Psychiatry, (...); for him the mind, spirit, thought and communication are combined with the external dimension of the body to build the individual reality of the subject; so that communicating implies building a sense in interaction, a priority factor in the field of Systemic Therapy and Psychotherapy. He says, "Communication is what makes human relations possible". And Virginia Satir adds: "... I realized that something else was happening in families than was evident". Source: TOMO IV, FUNIBER/2017 [4].

Conclusion

This is a work of observation and interaction with the respective families, whose curiosity was to identify what leads certain children, despite having the same syndrome (Down syndrome), to develop with more skills and abilities of involvement and family and social interaction. This is a brief case study, with the method is simple, interviews and data collection with family members, conversation circles, collection of medical records, and anamnesis updates, which evidences the influential variants facilitating the full development of the initial bases of a child, in the domestic, cultural, social and educational family affective field, in childhood. These variants, identified in this study, of a subjective nature facilitating, departing from welcoming family life, stimulating and associated with professional (proactive pedagogical) and psychological interventions, in systemic and cognitive behavioral approaches, proved to be efficient and effective, for the learning and socialization of two study subjects. On the other hand, they revealed the blockades and obstacles of full child development, which involved communication failures (doctor and patient), interventions (doctor/patient, parents/children, educators/parents/technical team), precariousing and compromising the child's psychoneurofunctional development, in its early and later phases. From this sample, we can rethink strategies and new intervention methodologies, involving pregnant women, families, schools, doctors and psychologists, in the initial interventions and approaches with this special clientele.

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Volume 4 Issue 5 May 2022