

Life stories of autistic adolescents: contributions to Speech-Language Therapy and Pediatrics

História de vida de adolescentes autistas: contribuições para a Fonoaudiologia e a Pediatria

Historias de vida de adolescentes autistas contribuciones para la fonoaudiología y la pediatría

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ABSTRACT

Objective: To analyze the dialogic processes of six autistic adolescents during speech-language therapy about their life stories, searching for support for pediatricians and speech-language therapists to work with their families in order to improve their development.

Methods: Data collection was carried out from video recordings of two speech-language therapy sessions with six subjects diagnosed with global development delay (three with autistic disorder and three with Asperger's disorder). The recordings were transcribed and data were separated into five themes. The analyses were based on qualitative research approach, in the context of the historical-cultural theory and the semiotic-indiciary paradigm.

Results: The following categories emerged from data collection: leisure, school level, social group, childhood facts, adolescence experiences and interests. Such categories reflected the experiences lived by the subjects and the way they signify the world and are signified by others. These categories allowed us to list the difficulties experienced by these subjects and their families.

Conclusions: The patients' indications reveal the need for continuous guidance about the aspects outlined in the categories, from the very moment that diagnosis is received, allowing the individual to have a more effective social participation and linguistic-cognitive development. The

pediatrician and the speech-language therapist are the professionals to provide such guidance, once they are the first to work with autistic children and to actively participate of their lives, from the moment of diagnosis until adolescence.

Key-words: child development disorders, pervasive; language; social group; adolescent.

RESUMO

Objetivo: Analisar os processos dialógicos de seis adolescentes autistas, durante terapia fonoaudiológica a respeito de suas histórias de vida, buscando subsídios para o pediatra e o fonoaudiólogo trabalharem com a família, a fim de impulsionar o desenvolvimento desses sujeitos.

Métodos: A coleta de dados foi realizada a partir da videogravação de duas sessões fonoaudiológicas com seis sujeitos diagnosticados como transtorno global do desenvolvimento, sendo três com transtorno autista e três com Asperger. As gravações foram transcritas e os dados, separados em eixos temáticos. As análises foram respaldadas na perspectiva qualitativa de pesquisa, sob a ótica da teoria histórico-cultural e o paradigma indiciário.

Resultados: Obtiveram-se as seguintes categorias a partir da coleta dos dados: lazer, escolaridade, grupo social, fatos da infância, vivências da adolescência e interesses. Tais categorias elucidaram as experiências vivenciadas pelos sujeitos e o modo como eles significam o mundo e são significados

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pelos outros, permitindo elencar dificuldades vivenciadas por esses sujeitos e seus familiares.

Conclusões: Os apontamentos dos sujeitos mostram a necessidade de orientações contínuas sobre os aspectos destacados nas categorias, desde o momento da descoberta do diagnóstico, proporcionando ao indivíduo uma participação social e um desenvolvimento linguístico-cognitivo mais efetivo. O pediatra e o fonoaudiólogo são os profissionais indicados para tais orientações, uma vez que são os primeiros a atender as crianças autistas e os que participam diretamente do momento da descoberta do diagnóstico, acompanhando os pacientes até a adolescência.

Palavras-chave: transtornos globais do desenvolvimento infantil; linguagem; grupo social; adolescente.

RESUMEN

Objetivo: Analizar los procesos dialógicos de seis adolescentes autistas, durante terapia fonoaudiológica, respecto sus historias de vida, buscando subsidios para que el pediatra y el fonoaudiólogo trabajen con la familia a fin de impulsar el desarrollo de esos sujetos.

Métodos: La recolección de datos fue realizada a partir de la realización y grabación de video de dos sesiones fonoaudiológicas con seis sujetos diagnosticados como Trastorno Global del Desarrollo, siendo tres con Trastorno Autista y tres con Trastorno de Asperger. Las grabaciones fueron transcritas y los datos separados en ejes temáticos. Los análisis están respaldados en la perspectiva cualitativa de investigación, bajo la mirada de la teoría histórico-cultural y el paradigma indiciario.

Resultados: Emergieron las siguientes categorías a partir de los relatos de los datos: ocio, escolaridad, grupo social, hechos de la infancia, vivencias de la adolescencia, intereses. Tales categorías elucidaron las experiencias vividas por los sujetos, el modo como ellos significan el mundo y son significados por los otros y permitieron listar dificultades vividas por los sujetos y por sus familiares.

Conclusiones: Los apuntes de los sujetos muestran la necesidad de orientaciones continuas sobre los aspectos destacados en las categorías desde el momento de la descubierta del diagnóstico, proporcionando al individuo una participación social y un desarrollo lingüístico-cognitivo más efectivo. El pediatra y el fonoaudiólogo son los profesionales indicados a tales orientaciones, una vez que son los primeros profesionales a atender a los niños autistas y los que participan directamente del momento de la descubierta del diagnóstico y siguen los pacientes hasta la adolescencia.

Palabras-clave: trastornos globales del desarrollo infantil; lenguaje; grupo social; adolescente.

Introduction

Autism is a developmental disorder in which those affected suffer from problems interacting with people and with the world, abnormal language function, stereotypical behavior, aggression directed at themselves and at others and eating and sleeping disorders^(1,2). Autism covers a spectrum of symptoms that can vary from an intense form of manifestation, classified as Autistic Disorder (299.00) to, when mild, Asperger's Disorder (299.80)⁽³⁾. The nomenclature currently employed for autism is that of Pervasive Developmental Disorders (PDD)⁽³⁾, but here the term autism is also used. Current epidemiological data show that there are about 5 people with Pervasive Developmental Disorders for every 10,000 births⁽¹⁾. The diagnostic criteria state that the pathology manifests by the time the child is 3 years old and remains until death⁽³⁾.

In addition to the disorders inherent to the pathology itself, studies have shown that these people's social and family lives are also compromised, because their mode of functioning causes stress in the family and problems with the way they act⁽⁴⁻⁹⁾. These problems are caused by the fact that society is organized to accommodate normal patterns⁽¹⁰⁾, and does not offer sufficient resources or opportunities either for people whose development is bound to some sort of deficiency or for their families. All of the problems faced by the family and the social group who live with people with PDD start with the onset of symptoms, are aggravated by diagnosis and can be lifelong.

If one considers that the family is the first social group of which children are members, the group that provides them with learning and development, the group of which they become active participants and the group that inserts them into other social groups, such as schools, churches, leisure activities etc., then it is clear that these problems can have negative consequences for the development of autistic children, further exacerbating the pathology^(10,11).

Pediatricians are normally involved in the discovery of PDD, since they are the medical specialists dedicated to caring for children and adolescents at all levels of complexity⁽¹²⁾. Furthermore, since they are the first doctors that children have, pediatricians become important to their families as sources of information and guidance on the care and type of treatment that children should be receiving at home.

Language abnormalities tend to be the first symptoms to concern families and pediatricians, and the first referral^(13,14) is

usually for speech therapy, before resorting to psychiatrists and neurologists later on. Therefore, the pediatrician and speech therapist are very often the first health professionals to take part in the process of suspicion and diagnosis of an autistic disorder meaning not only that knowledge of the initial symptoms is relevant, but an understanding of all the problems that will be experienced throughout life is also needed in order to be in a position to advise and guide the family along the most effective paths to the development of their autistic family member.

In the light of the above, the objective of this study was to analyze dialogues of people with PDD diagnoses talking about their life histories, seeking a basis for pediatricians and speech therapists to guide and propel the social, linguistic and cognitive development of these patients.

Methods

This research project was approved by the Research Ethics Committee at the Medical Sciences Faculty of the *Universidade Estadual de Campinas*. The parents of all participants signed a free and informed consent form. Analyses are all conducted using the qualitative method, which is concerned with the search for clues and with explanation and interpretation of human products. This type of research considers that human beings to be part of a phylogenetic, ontogenetic and microgenetic process, which is both historical and subjective, and therefore believes that they are not quantifiable. This perspective is supported theoretically by microgenetic analysis⁽¹⁵⁾ and the evidential paradigm⁽¹⁶⁾.

This methodological perspective considers that data on a person or group of people do not only represent individual issues, but also the concepts circulating within the social group⁽¹⁷⁾. This theoretical perspective is less concerned with generalizations and more concerned with the depth and scope of understanding of the study object. This statement is supported by the following considerations, published in Portuguese by Minayo and presented here in translation⁽¹⁸⁾: *It is through individuals, groups or classes that the fundamental totality is expressed in the perennial marriage between mind and body, matter and spirit; so that in the apparent simplicity of a statement about health, individual people project their visions of society and nature, the historicity of relationships and conditions of production inscribed in their bodies, their bodological space, their social temporality, their cultural infinity, their fetishes, their personal demons and their anxieties of transcendence. Therefore, qualitative research recognizes the subject as an author who is, under specific conditions, capable of both "portraying" and "refracting" reality.* (p.252) In Minayo's terms, the content of autistic adolescents' speech encapsulates their

ways of thinking and of understanding their lives and the ways in which society signifies them and treats their feelings.

When choosing the subjects to make up a sample, the same author states that it is necessary to select social groups that have the attributes that the researcher intends to investigate. The choice of subjects should privilege diversity, in order to make it possible to observe differences and similarities. The number of subjects should meet the criteria of saturation; i.e. when information recurs in the data⁽¹⁸⁾. Qualitative research is not concerned with statistical treatment of data, but it is of fundamental importance to be as transparent as possible when defining the profile of the population to be studied and the number of subjects.

With relation to the profile of the population studied here, it can be stated that all of them had been diagnosed with Pervasive Developmental Disorders, were living in the same provincial city in the state of São Paulo (200,000 inhabitants), were adolescents aged 13 to 18 years who lived with their families, were enrolled at normal or special school [depending on which study group they belong to] and are all middle-class. Therefore, it is understood that these sample provides valuable information for this population profile and can be generalized for similar populations who will have similar experiences with meanings circulating in similar contexts.

With regard to the number of patients studied, an initial survey was made of the number of possible subjects registered with the health and education services of the city in question, finding 44 people with pervasive developmental disorder diagnoses. Fourteen of them met the research criteria and ten were selected for the first stage of data collection; five enrolled at normal schools and diagnosed with Asperger's disorder⁽³⁾ and five enrolled at special schools and diagnosed with Autistic Disorder⁽³⁾. In the course of the interviews it was observed that after interviewing three subjects from each group, the data began to repeat, since all of their discourse was related to issues of leisure, education, social group, facts from childhood, experiences from adolescence and interests. While there were individual peculiarities, the themes recurred, meeting the criterion of saturation⁽¹⁹⁾ proposed by the method employed.

Data collection took place during two individual speech therapy sessions with the six patients with diagnoses of Pervasive Developmental Disorders⁽³⁾. Sessions were conducted by the lead researcher and privileged the subjects' life stories, elicited with the help of photographs of the subjects and their families at different stages of life. Each session lasted 45 minutes and the patients and their families were free to tell their own stories, starting from the photographs they were

shown. The researcher directed the dialogue, with questions about experiences, as the subjects told their stories.

The six participants were classified into two groups, Group 1 and Group 2, with the inclusion criteria for the first being: diagnosis of Pervasive Developmental Disorder, subtype Autistic Disorder and enrollment at a special school. The criteria for membership of the second group were: diagnosis of Pervasive Developmental Disorder, subtype Asperger's Disorder and enrollment at a normal school.

The sessions with Group 1 members were conducted at their special school and Group 2 sessions were conducted at members' homes. All sessions were videos recorded and transcribed to allow for selection and analysis of episodes and subdivision of the dataset into analysis categories.

Results

The characteristics of the participants were as follows: the three patients in Group 1 studied at a special school dedicated to pupils with a diagnosis of autism and all three in Group 2 studied at normal schools, although two of them had attended special school and been transferred to a normal school 7 years previously, while the last had always attended normal school. With relation to their families, four of them, two in each group, live with both parents, one Group 1 member lives with the mother, who is divorced, and the third member of Group 2 lives with mother, sisters and step-father. With relation to siblings, one Group 1 member has siblings and two Group 2 members have siblings.

The following categories emerged from the two speech therapy sessions, conducted with an emphasis on the patients' life stories: leisure, educational level, routine, social group, memories from childhood, experiences from adolescence, interests and religion. These categories were not preestablished, but emerged from the dialogues with the subjects, and are not viewed as peculiar to autistic people, but are part of everybody's life histories. The results are presented in Charts 1 and 2.

Discussion

All of the participants in this study described taking part in leisure activities and their speech revealed that they took pleasure in these situations. Considering that development is the product of social experiences, it can be said that these experiences allow individuals to appropriate themselves of the ways of doing and saying of a culture, which are levers for their learning and development⁽¹¹⁾. It is important to point out that five subjects said they went on trips with their parents, aunts

and uncles and sometimes cousins. Just one described taking part in leisure activities with parents' friends, sisters, brothers and sisters in law and friends. This observed situation reinforces the problems that autistic adolescents, in common with those with functional deficiencies, have in growing up and taking on the correct attitude for their age, participating in groups of people with similar ages⁽²⁰⁾. This observation cannot be considered as typifying PDD, since adolescence itself is a period of both physical and cultural changes⁽²¹⁾. Furthermore, the way in which autistic adolescents behave socially, which is a result of physical and social problems, means that they do not easily mix with people of their own age group and so they are left with the family context as the default option. It is therefore the responsibility of the professionals involved to provide the families of people with PDD with guidance to help them experience the features of different phases of life to as full an extent as possible.

In the education category it could be observed that situations that involve school are very significant for these subjects, since all of them mentioned this type of memory when telling their life stories. Five subjects mentioned positive experiences both at previous schools and at their current schools while one subject from Group 2 dealt with negative features of a previous school. The literature shows that schools are important spaces for learning and development for autistic people, since they are places where they have the opportunity to interact with normal children, who they can use as models, and to experience situations that are richly permeated by language and culture⁽²²⁾. This became clear when they talked about parties, fancy dress, sports days and the subjects they study at school, talking about what they have experienced in their lives. Notwithstanding, there are many different barriers to inclusion for these children, ranging from a lack of receptivity and qualifications of the part of teachers to structural incapacities of the education system. If such complications are to be minimized, it is necessary that autistic children be included right from the first years of life, when they first attend infant school⁽²³⁾, and this is an important recommendation for pediatricians and speech therapists to make.

Another notable feature in the data is the negative memories of a previous school described by one of the members of Group 2. This has been described in the literature before⁽²³⁾, showing that high-functioning autistic people, including those with Asperger's Disorder, are sensitive to inadequate conditions at school and interpret them as rejection, which can compromise the following years at school. This did not take place with the individual described here since his speech showed that he is happy at his current school. Nonetheless, it is important that professionals who deal with

CHART 1 – Synthesis of data from individual speech therapy sessions with GROUP 1, according to analysis categories.

Leisure	Education	Social group	Memories from childhood	Experiences from adolescence	Interests
1 - Taking part in trips to the beach, to the park, to the zoo and to go shopping.	1 - Stories from other schools they have attended: parties, previous teachers.	1 - References to parents, grandparents, aunts, uncles and cousins.	1 - Knowledge about mother's pregnancy, birth. Statements, although restricted, about activities related to this, for example, hospital and cesarean section.	1 - Demonstrated knowledge that they are becoming teenagers, that they are no longer children and should be engaging in adolescence activities, but no activities specific to adolescence appear in their discourse.	1 - Football team
2 - Traveling to visit relatives in other cities	2 - Stories from the time they spent in daycare when they were younger.	2 - Statements about both parents, about the father's current wife and her daughter.	2 - Stories about childhood: drank from a bottle, sucked thumbs, played with a tricycle.		2 - Pets
3 - Visits to amusement parks.	3 - Statements about their current special school, focusing on activities, parties, teachers, other pupils and feelings.	3 - References to siblings (the other two participants have no siblings).	3 - References to having been very small when babies.		3 - Painting on canvas
4 - Parties and family events.		4 - Social group at the special school (teachers and other pupils).	4 - Cared for by mother, grandmother and aunts when babies.		4 - Music, radio, CDs and singers.
5 - Trips and leisure activities with parents or with groups of pupils and teachers from the special school where they study.		5 - Statements about the mother of another pupil.	5 - Stories about learning to walk and clapping hands when shown photographs from first birthday.		5 - Easter bunny and chocolate eggs.
6 - Sometimes, grandparents, aunts, uncles and cousins take part in their leisure activities.					6 - Food.

CHART 2 – Synthesis of data from individual speech therapy sessions with GROUP 2, according to analysis categories.

Leisure	Education	Social group	Memories from childhood	Experiences from adolescence	Interests
1 - Trips to the city's nature park.	1 - Negative experiences at previous schools, where subject was called a "loser".	1 - Refer to parents, grandparents, aunts, uncles and cousins.	1 - They talked about the houses they used to live in	1 - They demonstrate that they are beginning to become interested in the girls at school. One of them only says that a certain is girl is pretty because eh wears glasses and is blonde, while the other explicitly states that he wants a girlfriend.	1 - Pets
2 - Trip to the beach.	2 - Subject shows that they are enjoying their current school.	2 - They approach people at school (teachers and other pupils).	2 - They described games they used to play as small children.	2 - Concerns about the future, about the desire to get a job, earn a salary and gain greater independence.	2 - Superheroes, like Batman, Superman and Spiderman.
3 - Ride on a steam train.	3 - State they have no desire to take part in extracurricular activities, such as parties and excursions.	3 - Their lives are shared with neighbors, parents' friends, brothers and sisters in law, schoolmates.	3 - They remembered that they used to go to amusement parks with their fathers, play catch-a-thief, tag and hide-and-seek and used to play football in the street with a childhood friend.	3 - They explain that they are becoming teenagers and so they have given some of their toys to other children.	3 - Fixation with dates
4 - Favorite activity is going shopping - to buy shoes and clothes.	4 - Used to go to special school.	4 - They sometimes visit the people mentioned.	4 - They talked about their mothers' pregnancies, their own births and the care they received from their families.		4 - Christmas
5 - Trip times are fixed.	5 - School as a significant space.	5 - They can't remember the people in the photographs of their birthdays and previous schools.	5 - Stories about using a pacifier and bottle .		5 - Playing with Lego
6 - The same trips are repeated every week.	6 - They don't like writing.		6 - Knowledge of when they stopped wearing diapers.		6 - Sport (basketball)
7 - Trips are always in the company of parents, sisters and parents' friends.	7 - Favorite subject is history.		7 - Say they don't remember having friends when they were young children.		7 - Cycling, music (Roupa Nova and Chitãozinho and Xororó).
					8 - Likes Fiat cars and the car owner's manual. 9 - Video games.

autistic schoolchildren remain alert to ensure that they have good participation in school spaces and make changes where necessary.

With relation to social group, it was observed that all subjects made references to several people in their social circles, including parents, siblings, aunts, uncles, cousins and grandparents, in many different situations, both in the past and in the present. These statements raise a paradoxical discussion, since whilst autistic people are understood to be people with abnormal social relationships⁽²⁴⁾, they nevertheless show themselves to be sensitive to others, including their “others” in their discourse and delineating the importance of other people in their life histories. It is pertinent to mention that none of the subjects remembered people who were not part of their family but did appear in the photographs. This finding could be interpreted as another symptom of autism, but the historical cultural theory understands the memory to be charged with meanings and necessarily harnessed to social practices, which, in turn, appear in speech. With normal children, this occurs as they appropriate themselves of their language, but in the case of autistic children, experiences must be interpreted, experienced and spoken about by parents and relatives before they can be understood, making them meaningful and memorable. This probably did not occur; the situations passed and the memories drain away without becoming the subject of these autistic subjects’ speech and emotions.

In the category “memories from childhood”, it was observed that all of the participants said they knew about their mothers’ pregnancies, about their own births, what they did when babies, such as pacifiers and bottles, diapers, learning, the care they received from their families, the difference in size between infancy and their current ages, for example. These data show that even though these families are involved with the issues of autism, they place value on important stages in their children’s lives, providing them with the information that makes up their life stories. This is of fundamental importance for their development as individuals, since the human constitution keeps on going as a person is signified and becomes part of another person’s discourse⁽¹¹⁾ in addition to making it possible for them to appropriate themselves of their own life stories and take part in the act of narrating facts, taking a great leap in linguistic-cognitive function⁽²⁵⁾. Additionally, this category also provided the observation that some of the children described how they used to like to play and named the games they played when small children and that one of the members of Group 2 remembered that he had a childhood friend with whom he played football.

All of the data in this category emerged as the researcher interacted with the subjects and when they were shown the photographs, showing that mediation is important for recovering memories, organizing discourse and appropriating life stories. This is because human memory is not direct or autonomous, but is dependent on social situations, on the speech of others and on images; i.e. it is always mediated by signs⁽²⁶⁾.

With relation to experiences from adolescence, it is important to point out that the members of Group 1 made it clear that they know that they are no longer children, but did not refer to experiences appropriate for that age. In contrast, it was clear that members of Group 2 had changed their concerns, two of them showing that they already noticed the differences between themselves and the opposite sex. One of them clearly stated that he would like to have a girlfriend soon. Additionally, one of the subjects mentioned concerns about the future, about getting a job and earning a salary. It is known that adolescence is a stage during which society begins to attribute a different position than during childhood and during which the expectation arises of new behaviors, interests and responsibilities⁽²¹⁾. However, the social group’s expectations are different in the case of autistic people, who are permanently attributed the position of children, which compromises the formation of the identity of the adolescent and, later, the adult⁽²⁰⁾. However, the data analyzed here show that the members of both groups were in the process of passing from childhood into adolescence, since they were already aware that they had grown up (Group 1) and had already adopted new interests and concerns (Group 2), but were still living bound to the meanings of childhood.

This paradoxical situation, between childhood and adolescence, was also obvious in the subjects’ interests, when they said that they liked things that were appropriate for their age, such as football, music, painting, sport, video games, but also liked things that are the object of children’s interest, like the Easter Bunny and superheroes. Only one of the five subjects expressed excessive and fixed interest in Fiat cars and car owner’s manuals, but the same patient also demonstrated interests in a variety of other activities and objects. The data allocated to this category contradict one of the symptoms chosen for the diagnostic parameters⁽³⁾, which is the restricted range of interests. The data undoubtedly do not indicate that this symptom does not occur, but they trigger reflection on the social development of autistic people, showing that their interests are not preeminently the result of physical factors, but are incorporated from the interests of the social group and the prevailing culture⁽¹¹⁾.

The dataset also indicated that a diagnosis of Pervasive Developmental Disorder, whether of the Autistic or Asperger

subtype, is associated not only with the symptoms described in the diagnostic parameters, but also with problems of social insertion, of inclusion at school and of passing through the different stages of life (childhood to adolescence). In counterpoint to these problems, and understanding human development as a product of concrete living conditions, of past experiences and of the way in which individuals are signified by the social group, family guidance, from the point of diagnosis onwards, becomes of fundamental importance to ensuring that autistic people have satisfactory development, can live independently and have improved quality of life.

This research allows for the conclusions that autistic people should be provided with rich social and leisure experiences and new learning experiences, should be put into school as early as possible, should be given information about their own life histories, should be engaged in day-to-day activities that are appropriate for their age group, should be encouraged to form relationships with a variety of different people and should be allowed to conduct their daily activities in an autonomous manner. Furthermore, it can also be concluded that photographs are not only a speech therapy resource, where they function

as mediating signs that facilitate the act of remembering and narrating⁽²⁴⁾ and provide individuals with the conditions to master dialogue⁽²⁷⁾, but can also be important in a family context, serving to structure the life stories of people with Pervasive Developmental Disorders and, as a consequence, their constitution as human beings.

Since pediatricians are physicians responsible for caring for children from birth until adolescence and with whom families establish a relationship of trust, it falls to them to help these parents and to follow the stages of their patients' development, seeking to establish continuity of guidance, interacting with psychiatrists, neurologists and other health professionals such as speech therapists, physiotherapists, occupational therapists and psychologists, thereby optimizing the social, linguistic and cognitive functions of autistic patients and providing their parents and relatives with reassurance and comfort.

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