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Orientation to mothers of children of the autistic spectrum about language and communication

Orientação a mães de crianças do espectro autístico a respeito da comunicação e linguagem

Keywords

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Descritores

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ABSTRACT

Purpose: To verify the results obtained by ten sessions of specific instruction about language and communication to mothers of children of the autistic spectrum. **Methods:** Subjects were 26 mother-child dyads. The children attended language therapy in a specialized service. Five pre-planned instruction sessions and five accompanying sessions to small groups of mothers parallel to the children's language therapy were conducted. **Results:** The focus directed to the child's communication allowed the identification of essential elements to the determination of successful interactive situation as joint attention, latency to answers and child's individual interests. The individualized analysis has shown that all subjects presented progress at least in one of the assessed areas. **Conclusion:** There was a positive impact of the systematic orientations to mothers about language and communication, conducted at the same time as language therapy (and not alternatively). The formal planning and recording were flexible enough to allow adjustments to group specific needs and demands.

RESUMO

Objetivo: Verificar os resultados obtidos após a realização de dez sessões de orientação específica para mães de crianças do espectro autístico a respeito de comunicação e linguagem. **Métodos:** Participaram 26 díades mãe-criança. As crianças eram pacientes de um serviço de Fonoaudiologia especializado em Distúrbios do Espectro Autístico. Foram realizadas cinco sessões de orientação e cinco de acompanhamento para pequenos grupos de mães, paralelamente à manutenção do processo de terapia fonoaudiológica das crianças. **Resultados:** O foco direcionado à comunicação, possibilitou a identificação de elementos como a obtenção da atenção da criança, a iniciativa de comunicação ou de alguma atividade conjunta, a latência para a resposta e o uso de materiais ou brinquedos de interesse da criança como essenciais para o estabelecimento de interações bem sucedidas. A análise individualizada mostra que todos os sujeitos apresentaram progresso em pelo menos uma das áreas investigadas. **Conclusão:** Houve um impacto positivo do procedimento de orientações sistematizadas voltadas às questões de comunicação e linguagem, realizadas juntamente com o processo de terapia de linguagem das crianças (e não em substituição a ela). Embora as sessões de orientações tivessem roteiros de funcionamento e registro, elas permitiam ajustes às necessidades e demandas de cada grupo.

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INTRODUCTION

The actions directed towards families of autistic children, conducted by speech and language pathologists, require extreme caution so they keep the focus on the area that belongs to speech and language pathology and do not involve other areas that also deal with autistic manifestations.

In what refer specifically to studies about families with children with autistic spectrum disorders, a recent study⁽¹⁾ reviewed the articles published over the past five years in the three most traditional journals specifically addressed to studies about infantile autism (Journal of Autism and Developmental Disorders, Focus on Autism and Other Developmental Disorders and Autism). The study revealed interesting data: less than 5% of the 1096 papers published refer to this theme, which certainly was not expected when we consider the impact of autistic children in family dynamics or the importance of family for diagnosis, intervention and education processes. On the other hand, more than half of these articles were published in the last 18 months.

According to the study, among the 39 articles published about research involving families with autistic children, some themes were more frequently addressed: emotional difficulties were addressed by 13 of them, support groups and quality of life, the characterization of the families and family members and the perspectives of parents regarding their children was the subject of seven studies each; intervention procedures were addressed in five articles. Even though many studies address or compare more than one subject, the number of articles involving the intervention process in the families or parental involvement is very small.

The review also points out that only five papers describe or evaluate the results of parental involvement in treatment programs. Two of them^(2,3) describe the results of residential programs for behavioral intervention based on parental performance, with respectively 27 and 53 participants. In both of them the parents report good results, especially in longer intervention programs. Two other studies^(4,5), with 18 and 33 subjects respectively, address the parent cooperation in therapeutic processes focusing interaction and social skills. The results describe progress and management of major areas of interest. The last study⁽⁶⁾ has 68 participants and describes a daily residential intervention program called Floor-Time, lasting between eight and 12 months, which gives good results but with a high cost.

The speech and language therapeutic process can be improved by specific orientations about the development of communication and language processes strongly focused on the individual profiles of abilities and inabilities of each mother-child dyad. But there are no reports of experiments conducted in this area. The focus on a particular population, treated at a speech-language specialized service has guided several researches, always considering its applicability to this population.

Thus, we propose an initial study involving a systematic orientation to mothers of children of the autistic spectrum who attended weekly at the service and the verification of the results by the observation of the patients' development the quality of

life reported by the mothers. It was hypothesized that systematic and specific orientations, held for short periods of time and with the possibility of return, may not only contribute to the communicative environment of the autistic child but also the understanding of the capabilities and difficulties of each child by their families.

Therefore, the purposes of this study were to investigate the interference of orientations offered to mothers in the process of communication and language development of autistic children and in their communicative and social-cognitive performance and to verify the interference of these orientations on the way these mothers observe their child, according to an adaptation of the Questionnaire of the World Health Organization Quality of Life.

METHODS

This research and the consent form were approved by the Ethics Research Committee under number 0787/07.

Subjects

Subjects were 26 mother-child dyads who met the inclusion criteria and completed the entire study period.

Inclusion criteria: diagnosis included in the autistic spectrum, mother being the main responsible for bringing the child to speech and language therapy; child systematically attending weekly a specialized speech and language therapy service for at least six months; no interruptions larger than one week; age under 11 years (so that none of the subjects was characterized as a teenager at the end of study); consent form signed by the responsible adult.

The mother groups were organized according to the children's therapy schedule. The average age of mothers at the onset of the study was 38 years and 1 month (min. 23, max. 51) and the children's average was 8 years and 2 months (min. 5, max. 11). In what refer to educational level, the majority of mothers had completed high school.

Procedures

Children were filmed in regular speech and language therapy, playing with various types of toys with their therapist. These recordings were used to collect data on the functional communicative profile and social-cognitive performance of each child.

Mothers were interviewed individually by specialized speech-language therapists that work in the laboratory for over two years and therefore are known by them. During the interview they were asked to sign the consent form and answer the protocols on quality of life and functionality.

To avoid the need for mothers to attend to the interviews at other times at the Speech and Language Pathology Service (and therefore avoiding the interference of economic and transport issues), the orientations were offered in 30 minute periods during their children's therapy. The completion of counseling sessions in pairs or triads provides more symmetrical com-

munication situations since there is a common theme and a shared position. Thus, mothers were grouped according to the time of their children's therapy, regardless of their children's performance.

Each group was conducted by two speech and language therapists who were postgraduate in this specific area. There were five consecutive sessions of orientation, with each group of mothers. They were shown videos of their children interacting with the therapists, already known to them. The mothers who agreed or wished could also be videotaped with their children so that this material was discussed in this small group.

The goals of these orientation sessions were:

- Presentation of the proposal, identification of "strengths" and "weaknesses" of each child; suggestion that each mother identify pleasant and unpleasant situations in every-day activities.
- Identification of situations of productive and unproductive interaction between children and therapists; suggestion to compare them to everyday situations; resolution of doubts.
- Identification of key elements in successful and productive situations and suggestions of possible expansion, multiplication or transfer; resolution of doubts.
- Identification of key elements in the communication breakdowns and proposals for alternative procedures; resolution of doubts.
- Individual reports on the impact of the orientations; solving questions.

After the initial five consecutive sessions, five other follow-up sessions were scheduled with a three-week interval. These sessions dealt about the same subjects of the initial sessions, according to the needs of each small group.

After the last follow-up session, individual interviews were conducted with each mother, to resolve remaining questions.

Two weeks after the last follow-up session the children were videotaped again with their therapists and various types of toys. These recordings were used to collect data on the functional communicative profile and social-cognitive performance of each child.

Training the coaches

The coaches were speech and language therapists with experience and postgraduate training in care of children and adolescents within autistic spectrum. All of them received training regarding the implementation of protocols of the Socio-Cognitive Performance and Functional Communication Profile. The questionnaire about the quality of life was presented by one of the coaches, which was using that in her master's research and so could discuss it further.

Filming the children

Each child was videotaped with the therapist in a play situation routine one week before the beginning of his/her mother participation in the groups. When the mothers expressed interest in being filmed "playing" with their children, this was done during one therapy session in subsequent weeks. Few

mothers, however (only five), expressed this desire. These data was processed along with all the material.

Orientation sessions

The results of each session were recorded by the coaches of the groups after each session in the specific protocols and served as a basis for qualitative analysis of this process (Appendix 1).

Data analysis

The individual differences between autistic children justify the use of a methodology in which the child is his own control. Thus, the statistical analysis makes point by point comparisons, referring to the two moments to data gathering regarding the children's performance with respect to: number of communicative acts per minute, use of communicative space, communication interactivity, use of communicate means, communicative intent, imitation, tool use and play^(7,8).

The analysis of data concerning the quality of life used the Tukey test to determine the statistical significance of differences between the responses for the different areas analyzed.

RESULTS

Qualitative elements

Results obtained in the orientation and follow-up meetings

The proposition of ten sessions with 26 mothers of autistic children, i.e. 260 meetings, required extreme care in the recording of data. The qualitative analysis will not be completed in this paper.

To the analysis of the sessions the recorded data included the identification of the discussed theme and the intervention, or the dynamics established by the group during the discussion. There was great variation in the each group's functioning. In some of them, certain participants seemed to play a certain leadership role, proposing themes for discussion or talking more than the others during the meetings. On the other hand, other mothers seemed to comfortably accommodate less active positions in the groups, although these were always small (two to four participants).

The topic most frequently discussed was the difficulties with the child's behavior and the disruptions caused by them. The questioning about other professionals shared the second position among the most common topics with reports of new achievements. The school adjustment and doubts about it come right behind as one of the most frequently discussed topics. The reports on changes in medical management and their results, as well as on independence in relation to every-day activities, followed by observations about the process of speech therapy, and questions involving aspects of sexuality were also topics of the meetings.

In what refer to the intervention of the coach of each group and the dynamics established by the group, the reports revealed that interaction about the same theme was the most frequent situation, often due to the fact that one of the group members

brought shared themes. When participants brought individual questions, the coach sometimes answered directly, sometimes rephrased the question to include all (or most) of the group. In a few situations the participants assumed that the doubt brought by one of the members was common to the others, without the intervention of the therapist. In very few situations the account of a topic or question had to be reformulated by the participant. Frequently someone in the group tended to occupy part of communication when a time-out for thinking was proposed. Not all meetings ended with a conclusion and some participants showed frustration about it. Aiming to address what appeared to be a need for closure, an unplanned extra interview was conducted individually, to provide the opportunity to finish the process.

Quantitative analysis

Functional Communication Profile

The results referring to the number of areas with progress identified in each of the subjects in this study are presented in Figure 1. It can be observed that among the five possible areas 65% of subjects (17) had between two and four areas with progress. An individual analysis shows that 96%(25) of the subjects showed progress in increasing the interpersonal communication.

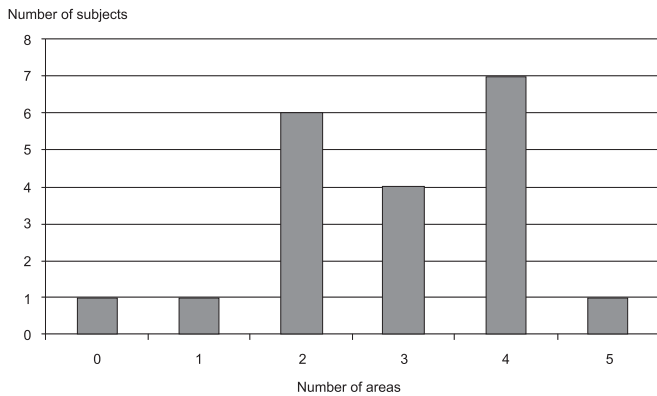


Figure 1. Number of subjects and number of areas of progress in the Functional Communication Profile

Socio-Cognitive Performance

Data about the number of areas with progress when we analyzed the Socio-Cognitive Performance are described in Figure 2. It is observed that among the seven areas surveyed, 61%(16) of the participants showed progress in two to four areas-

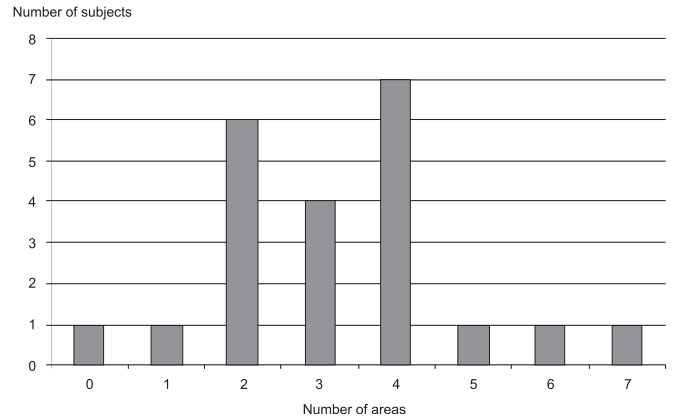


Figure 2. Number of subjects and number of areas of progress in the Socio-Cognitive Performance

as. At the Functional Communication Profile, only one subject showed no progress on any of the areas studied. However, the fact that this occurred on two different subjects, support the conclusion that 100% of the subjects showed some progress in the areas studied.

Protocol Quality of Life

There were statistically significant differences between subjects (mothers) in their answers to the questionnaire about Quality of Life (Table 1). This allows the assumption that the protocol is efficient to the characterization of each subject, which favors more individualized approaches.

No significant differences were found between the four domains investigated by the Quality of Life questionnaire (physical, psychological, social relationships and environment) (Table 2). Interestingly, the highest levels of dissatisfaction are related to the environment.

DISCUSSION

The results concerning the qualitative analysis of the orientation meetings have important elements of consideration, as well as confirmation of some aspects previously reported. The fact that it was possible to observe that some mothers find it easier to identify weaknesses and unpleasant situations than the reverse, reflects the need to, in situations of initial interviews, identify motions that are contrary to the ones brought spontaneously by the families spontaneously. When the family only describes the problems, ask about the skills; and when the

Table 1. Comparisons between subjects for answers to the questionnaire Quality of Life

Analysis of variance						
Causes	GL	SQ	QM	F	Probability {>F}	
Block	21	111.71	5.32	6.03	0.0000*	
Treatment	25	197.78	7.91	8.96	0.0000*	
Residue	522	460.65	0.88			
Total	568	770.15				

*Significant values (p<0.01)

Legend: GL = linear module; SQ = correlation coefficient; QM = regression coefficient; F = coefficient of determination

Table 2. Areas investigated by the Quality of Life questionnaire (Tukey test)

Number of treatments	5	
Mean square of the residue	102.5	
Mean square	4	
Number of repetitions	26	
Significance level	5%	
Treatment	Mean	Tukey
Physical domain	79	a
Psychological domain	70.5	a
Social relations	66	a
Environment	58	a
Coefficient of variation (%)	14.3606	

family only describes the successes, ask about the difficulties⁽⁹⁾.

Most of the reported weaknesses refer to issues of communication and behavior and the unpleasant situations refer to times when the children present behavioral disorders (that mothers tend to associate with situations such as crowds, noisy or unknown environments and activities of daily living). These situations are the often described in the literature as characteristic of this group of patients and as a source of stress for parents^(3,6,10).

The importance of group situations to orientation activities for parents of autistic children also have been mentioned⁽⁴⁾ and confirmed by this study. Thus, it was interesting to note the mention of shared attention as one of the strengths observed in these patients because this is usually described as an element of difficulty for them⁽¹¹⁻¹³⁾.

The attention dedicated to the children's communication allowed the identification of elements such as obtaining the child's attention, the initiative of communication or of a joint activity, the latency for the response and the use of materials and toys that has the child's interest. Those aspects are essential to the establishment situations of successful interaction^(14,15) and their possibilities in every-day situations⁽¹⁶⁾.

The identification of the origins of communication breaks also proved to be productive, although there was the need of interventions towards the identification of the situations that maintained the difficulties^(4,6,17-19). The possibility to generate small changes in family routine that may foster communication responds to long-term goals for this type of intervention because it tends to generate results that are more comprehensive, lasting and multipliable^(3,5).

Regarding the results presented by the patients in the analysis of the Functional Communication Profile, the data from this study can be compared to previous studies, which worked with longer intervals⁽²⁰⁻²³⁾. The same can be stated about the analysis of the Socio-Cognitive Performance, in which almost all patients showed some progress^(1,20-23).

The results for the Quality of Life questionnaire can be compared to a recent survey of the same population, held at the same service, but with other participants. In this study⁽²⁴⁾ 150 caregivers of autistic spectrum children treated in ambulatory

regimen and institutions responded to the same instrument used in this research. In this study the greatest difficulties reported by caregivers of autistic children also refer to environmental issues.

CONCLUSION

The first objective of this research, to verify the interference of orientations offered to mothers about the processes of communication and language of autistic children, was hit. However it requires the exercise of caution in generalizing the results. All the participants of the study showed progress on at least one of the assessment rates proposed in a period of time in general lower than the observed in previous studies that involved the same therapeutic procedures and the same evaluation criteria. It is, however, a small difference, with a small set of data, which does not allow the complete determination of its causality. Unfortunately, practical difficulties make it hard to establish the procedures for more rigorous research, as would be required for this type of conclusion.

A study under more controlled conditions, with a homogeneous group of patients and caregivers, that could be divided into two subgroups (one that would receive orientations during a period in which the other received only speech therapy) and the positions would be switched after all the program, would undoubtedly answer much better to the posed questions. However, in the Brazilian reality, families get specialized care for their children at very different periods, access to therapeutic and educational services varies widely and even the age at which patients are diagnosed also varies. These aspects hinder the determination of homogeneous groups of patients. In large cities like Sao Paulo, difficulties related to distance and transport add to the problems caused by the subjects' behavioral difficulties. Therefore prolonged periods of intervention are usually marked by many absences and delays.

Thus, it is justified to carry out small studies, as presented here, because these data could be added to others, performed in other centers or with other groups in order to provide clearer evidence of interference among the processes of therapy language and family orientation.

The second goal of the research, to verify the interference of the orientation on the processes of communication and language of autistic children, in the way their mothers observe their performance, according to criteria adapted from the Questionnaire of the World Health Organization Quality of Life was not fully reached. The answers provided by the mothers did not allow analysis related to the group. Apparently there was an unanticipated interference, possibly the fact that these questionnaires were applied in the same service in which the children receive therapy may have determined too high responses. The questionnaires reflect satisfied mothers, without big problems with their children (here the question of the difficulties of transport appears as an exception because there are systematic references to it). It is assumed that if the questionnaires were applied outside the environment of care, or at least by people unidentified people with it more realistic results could have been obtained. Anyway, even if it was not possible to determine the degree of interference of the orienta-

tions based on the results of questionnaires on Quality of Life, this positive interference was evident in the qualitative analysis of intervention processes.

Thus, the hypothesis that “systematic and specific orientations, held for short periods of time and with the possibility of return may not only contribute to the communicative environment of the autistic child but also to the family’s understanding of the abilities and difficulties of each child “ remains open. The need for more adjustments in research procedures that can measure more effectively this degree of interference should not hide the fact that there was a positive impact of a systematic procedure of orientation, conducted parallel to the process of language therapy for children (and not replacing it). These orientations, focused on issues of communication and language, although have a functioning and recording script, allows adjustments to the needs and demands of each group.

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Appendix 1. Summary of topics covered in orientation sessions for parents

Step 1

Theme discussed	Comments/Feedback
<p>Session 1</p> <ul style="list-style-type: none"> -presentation of the proposal, identification of "strengths" and "weaknesses" of each child; - suggestion of identifying pleasant and unpleasant situations. <p>Session 2</p> <ul style="list-style-type: none"> - identification of situations in productive and unproductive interaction between children and therapists; - suggestion of comparison with everyday situations; - Resolution of doubts. <p>Session 3</p> <ul style="list-style-type: none"> - identification of key elements in successful and productive situations and suggestions of possible expansion, multiplication or transfer; - resolution of doubts <p>Session 4</p> <ul style="list-style-type: none"> - identification of key elements in the communication breaks and proposals for alternative procedures; - resolution of doubts. <p>Session 5</p> <ul style="list-style-type: none"> -individual reports on the impact of the guidelines; - resolution of doubts 	

Step 2. Record of sessions

Theme discussed	Intervention/Dynamics
<ul style="list-style-type: none"> - difficulties of the participant with the patient's behaviors - how to handle () - questions about learning / school () - questions about specific activities developed during the therapy () - questions about referrals to other professionals () - questions about the medical management () - independence from the ADL () - news - new achievements () - sexuality () 	<ul style="list-style-type: none"> - the group takes the issue as a collective () - the group operates and interacts on the topic () - the therapist responds directly () - the therapist directs the responses of the group () - the therapist reformulates the question in order to make it more inclusive for the group () - the therapist "returns" the question for the participant to develop better / reflect () - participants bring common themes () - participants are restricted to individual questions () - there was a conclusion of the session ()