Implications of a diagnosis: what the families of disabled subjects feel?

Implicações de um diagnóstico: o que sentem as famílias dos sujeitos com deficiência?

Consecuencias de un diagnóstico: quésientenlasfamilias de las personas condiscapacidad?

Rosana Carla do Nascimento Givigi[*]
Thaís Alves de Souza[**]
Raquel Souza Silva[**]
Solano Sávio Figueiredo Dourado[***]
Juliana Nascimento de Alcântara[****]
Marília Vasconcelos Araújo Lima[*****]

---

[*] *Adjunct Professor, Department of Speech Language Pathology and Audiology –Universidade Federal de Sergipe, Brazil.*

[**] *Speech language pathologist and Audiologist of the Department of Speech Language Pathology and Audiology –Universidade Federal de Sergipe; Brazil.*

[***] *Master degree in Physiological Sciences –Department of Speech Language Pathology and Audiology –Universidade Federal de Sergipe; Brazil.*

[****] *Master in Education –Department of Speech Language Pathology and Audiology –Universidade Federal de Sergipe; Brazil.*

[*****] *Undergraduate student in Speech Language Pathology and Audiology, PIBITI fellow; Department of Speech Language Pathology and Audiology –Universidade Federal de Sergipe; Brazil.*

Conflict of interests: *No*

Authors' Contribuitions:RCNG - Collaborated in the administration of the project, in the conception and study design, interpretation of data and critical review. TAS -Collaborated in the conception and design of the study, the construction of the theoretical reference, in data collection and its analysis, in the writing of manuscript. RSS - Collaborated in the delimitation of the introduction, the delimitation of technical procedures, in data collection and its analysis. SSFD -Collaborated in the methodological delimitation, in data collection and its analysis, manuscript critical review. JNA - Collaborated in data collection and its analysis, in the construction of the study conclusions and writing of the manuscript.MVAL -Collaborated in the delimitation of technical procedures, in data collection and its analysis, in manuscript preparation.

Correspondence Address: Thais Alves.Rua Napoleão Dórea 723, Bairro Atalaia, condomínio Santa Cecília bloco j apto 202, Aracaju - SE. Brasil.
E-mail andress:thaisalves.fono@gmail.com

Received:*11/10/2014*Accepted:*16/06/2015*

Abstract

This study aims to highlight and discuss the feelings, personal impressions and characteristics attributed by the family about having a disabled child. In the case of this study, all presented significant language changes underlying the diagnosis of autism or cerebral palsy.Methodologically, it was characterized as a kind of qualitative study of cases, with numerical description of categories. 10 subjects were surveyed. All families were submitted to initial interviews, which were transcribed and analyzed, resulting in a corpus of 20 reports.As a result, the regularities present in the family discourses about the diagnosis of the disability are pointed, subsequently organized into 10 categories: negative view (rejection, shock, sadness, aggressiveness, prejudice, dependence, different, difficulty and overprotection) and positive view (the potentialities).Through this study, it was possible to contribute to a better understanding of the implications arising from the birth of these children in the family core, as well as to construct a material that gives subsidy and means to professionals who seek to support such suffering in speech therapy clinic and work with these families, facing their anxieties and expectations, giving them the possibility of establishing a new vision about the disabled child..

Keywords:disabled persons; diagnosis; family relations.

Resumo

O presente trabalho objetiva evidenciar e discutir os sentimentos, impressões pessoais e características atribuídas pela família no que se referea ter um filho com deficiência. No caso desta pesquisa, todos apresentaram significativas alterações de linguagem subjacentes ao diagnóstico de autismo ou de paralisia cerebral. Metodologicamente caracterizou-se como uma pesquisa do tipo Estudo qualitativo de casos, com descrição numérica de categorias. Ao todo foram pesquisados 10 sujeitos. Todas as famílias foram submetidas a entrevistas iniciais, que foram transcritas e analisadas resultando num corpus de 20 relatórios. Como resultados, apontam-se as regularidades presentes nos discursos familiares em relação ao diagnóstico da deficiência, organizados posteriormente em 10 categorias: visão negativa (a rejeição, o susto, a tristeza, a agressividade, o preconceito, a dependência, o diferente, a dificuldade e a superproteção) e visão positiva (as potencialidades). Por meio deste estudo, foi possível contribuir para um melhor entendimento das implicações advindas do nascimento dessas crianças no seio familiar, bem como construir um material que dê subsídio e meios aos profissionais que buscam amparar tais sofrimentos na clínica fonoaudiológica e colaborar com essas famílias no enfrentamento de suas angústias e expectativas, conferindo-lhes a possibilidade de instituir uma nova visão sobre a criança com deficiência.

Palavras-chave:*pessoas com deficiência;diagnóstico; relação familiar.*

Resumen

Este trabajo tiene como objetivo destacar y discutir los sentimientos, las impresiones personales y lascaracterísticas atribuidas por la familia con respecto a tener un hijo con discapacidad. En el caso de esta investigación, todos mostraron cambios significativos del lenguaje subyacentes al diagnóstico de autismo o deparálisis cerebral. Metodológicamente se caracteriza por ser una investigación del tipo Estudio de Caso Cualitativo, con descripción numérica de las categorías. En total se encuestaron 10 sujetos. Todas las familias se sometieron a entrevistas inicialesque fueron transcritas y analizadas, resultando en un corpus de 20 informes. Como resultado, se señaló las regularidades presentes enlos discursos familiares sobre el diagnóstico de la discapacidad, organizados posteriormente en 10 categorías: visión negativa (el rechazo, el susto, la tristeza, la agresividad, el prejuicio, la dependencia, el diferente, la dificultad y la sobreprotección) y visión positiva (las potencialidades). A través de este estudio, fue posible contribuir para una mejor comprensión de las implicaciones que surgen desde el nacimiento de estos niños en la familia, así como construir un material que proporcione subsidios y medios a los profesionales que pretenden apoyar tales sufrimientos en la clínica fonoaudiológica y colaborar con estas familias en el afrontamiento de sus angustias y expectativas, dándoles la posibilidad de establecer una nueva visión del niño con discapacidad..

Palabras clave:*personas con discapacidad; diagnóstico; relaciones familiares.*

Introduction

The role of the family has suffered a valuable growth as a field of interest in Speech Language Pathology and Audiology. Not only in this science, many areas of knowledge as Psychology, Education and others, have been concerned to discuss it and see it as essential in the work, and as a way of seeing the subjects with disabilities in their entirety. Regardless of the theoretical view and of the place that it occupies for these areas, it is considered the first and one of the most significant children's networks and, therefore, it substantially interferes in the constitution of the subject, in the constitution of language or in the development in general.

The arrival of a new member in the family is permeated by a lot of expectations and emotions for the parents. Therefore, when this subject has a disability or significant language alterations, it is configured a different situation from the one expected. The expectations and dreams built earlier are broken, prompting a series of mixed feelings in the family.As in other studies, the psychic behavior of the family, facing the birth of a disabled child, is the same of loss or death, the "death" of the desired and idealized son, which is necessary and important to make it possible to receive the "real" child, to live the mourning process for that "lost" child.The family dynamics and the individual contingencies will determine the way and the time of preparation of this mourning, besides the necessary reactions against it.[1]

This situation requires parental redefinition of roles, a clear and difficult repositioning, but necessary to the adjustment to the emotional and even physical reception of the disabled child. This son, who was idealized by parents, now presents himself as different and jarring in the family who, often, do not know what to do to deal with this situation.The way that this diagnosis is welcomed by the family will determine its entire future conformation, the way that the family dynamics will constitute itself. As claimed by Batista and França[2], how the family deals with this event will influence decisively in the construction of the family group identity and, as a consequence, the individual identity of their members.There is a search by the family to adapt itself to this new reality and to reorganize itself to face the challenge of living and getting along with the disabled child, to reconstruct this family identity. Along the journey, they show feelings of discouragement, hopelessness, fatigue and, sometimes, its structure is threatened and its ability to react to situations of potentially destabilizing crisis presents itself weakened.[3]

In the same way, studies such as the ones ofBerberianet. al.[4], Momensohn-Santos et. al.[5], Boscolo and Santos[6], Sá and Rabinovich7 bring the discussion about how the diagnoses of different disabilities, whether they are auditory, physical, or more specific diagnoses of Speech Language Pathology and Audiology, such as cleft and lip palate, cause diverse and contradictory feelings in the family of the disabled subject.

Thus, with this work, the objective is to highlight and discuss the feelings, personal impressions and characteristics attributed by the family about having a disabled child, the research subjects. In this study, all of them had significant language changes underlying the medical diagnosis of autism or cerebral palsy.

Through this research, it is aimed to contribute to a better understanding of the implications arising from the birth of these children in the family core, as well as to build a subsidiary material to professionals seeking to support such suffering in speech therapy clinic.

.

Methodology

This study was characterized as a type of case study research, with numerical description of qualitative categories. It was developed by a research group at the Universidade Federal de Sergipe (Federal University of Sergipe) - UFS, entitled "The construction of the language, pathologies and clinical practice" starting in 2008.The project was approved by the Ethics Committee of the Federal University of Sergipe, under the number 0133.0.107.000-08. In addition, the guardians of the participants were submitted to sign the free and informed consent term.

1. Selection of the empirical material – Procedures

Initial interviews were conducted with all subjects in the survey, starting in 2008. The interviews lasted about 50 minutes and were recorded with a SanDisk audio recorder (Model: SDMX20R-016GK). After each interview, two reports were made.The first one contained a literal transcription of the interview held, with no impressions or any kind of content analysis. The second was the descriptive-reflective type, being compound by the analysis and impressions of the therapist about that meeting. The two reports of each interview were attached in the database of the research group referred above.

These initial interviews were unstructured8 and conducted by a therapist participant of the research group that, thenceforth, became the responsible for the entire process involving that one patient (interview, evaluation and therapy). In addition, he (or she) was the responsible for the preparation of the reports.Initial interviews took place in the Espaço da Linguagem e ComunicaçãoAlternativa (Alternative Language and Communication Space) of the mentioned university and the information was collected from a conversation with the family responsible for the child. The therapist asked the family to speak what was relevant, and if he found necessary to include some questions to a better understanding of the issues involving the child regarding the communicative aspects and family dynamics. It is noteworthy that these questions were not previously formulated, but happened unpredictably by the dialogical flow.

For this study, 10 subjects were selected. In total, 20 reports were analyzed, being 10 of transcription and 10 of analysis. The criteria for the selection of this group were age (4-14 years old) and the presence of speech therapy diagnosis of language disorder.These diagnoses were established from the evaluation process, in which the children were submitted in their own research group. The exclusion criterion of the subjects of this study was the absence of one of the types of reports (transcription or analysis) in the research database.The variation of age occurred due to the difficulty of selecting subjects in this profile. It is noteworthy that all subjects had some form of disability, physical or behavioral.The therapists were taking notice already in the first meetings, since the subjects had already came to the research with the medical/multidisciplinary diagnosis of Cerebral Palsy or Autism previously closed.

2. Organization of data

For this work, the authors organized the data collected from analyzed reports, showing some regularitiesin the discourses of the families related to the diagnosis of the disability.These regularities were found following the assumptions of the Content Analysis proposed by Bardin9. The transcribed material was read thoroughly and the word sets that mattered for research were identified. The subjects were grouped according to semantic similarity and thus, the categories were created. Such categories characterized the family feelings facing these diagnoses.

3. Profile and presentation of subjects

Altogether, 10 subjects were selected. In the chart 1, the presentation of each subject, age, family configuration and presented diagnosis is present. The age of the subjects varied from 5 to 14 years old, and the sample was composed, mostly, by men, diagnosed with autism or cerebral palsy.

Chart 1. Presentation of the Subjects

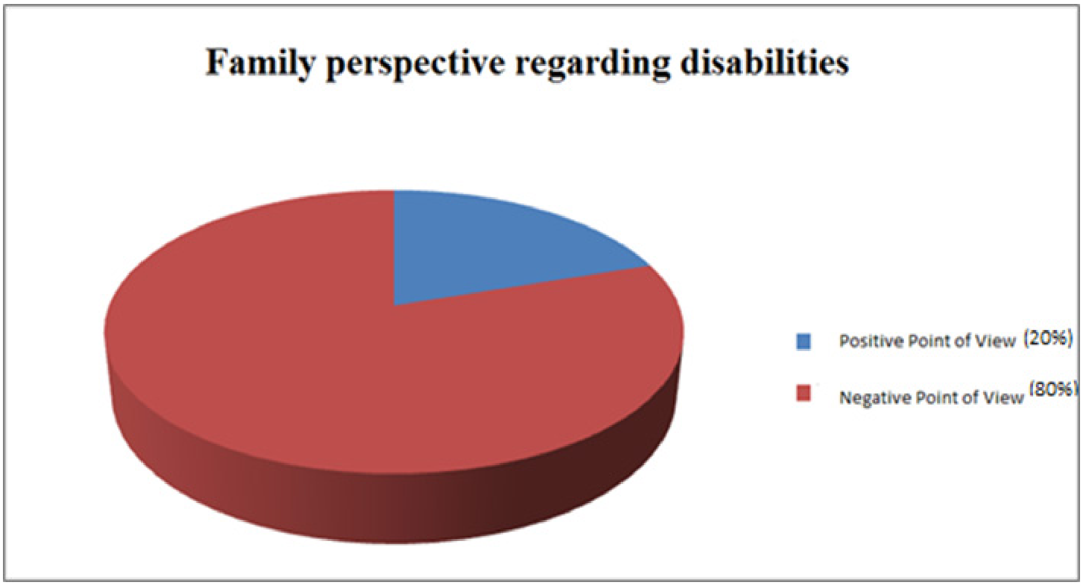
Subject	Age	Sex	Family Configuration	Diagnosis
S1	6 years old	M	Mother and Father	Autism
S2	7 years old	M	Mother	Cerebral Palsy
S3	11 years old	M	Mother, Grandmother and Brother	Cerebral Palsy
S4	8 years old	M	Mother	Autism
S5	8 years old	F	Mother, Father and Sister	Cerebral Palsy
S6	9 years old	M	Mother and 2 Brothers	Autism
S7	5 years old	M	Mother	Autism

S8	14 years old	M	Mother and Sister	Cerebral Palsy
S9	12 years old	M	Mother	Cerebral Palsy
S10	8 years old	M	Mother and Sister	Cerebral Palsy

Results

From the analysis of the 20 initial interview reports with the families, it was observed that among these subjects, 60% had a diagnosis of cerebral palsy and 40% were diagnosed with Autism. The average age was eight years old, also occurring a higher prevalence of men (90%) compared to women (10%).Regarding family dynamics, it was found that, in most cases, families are configured by the mother's presence (central figure) and subsequent father's detachment of the family constitution of the disabled subjects (80%).

When faced with the diagnosis, initially, these families seem to move between two poles and assume different positions in relation to the disability: on one hand, the family that denies, the one that presents what is called here 'the negative view of disability'; on the other hand, the family that welcomes, the one that seems to take a 'positive view of the disability'. These data were organized in Graph 1.



Graph 1.Family Perspective Regarding Disabilities

Among the analyzed discourses of the families of this research, it is clear the prevalence of one over the other. Mostly, the families that have a negative view of the disability attribute to feelings and personal impressions that are regularly present in their discourses. Similarly, those with a positive view towards the disability highlight features about the skills of these subjects, showing as common regularities to the potentiating characteristics (category "Potentialities") assigned to disabled individuals.

Accordingly, such regularities were highlighted and organized into more specific categories. Altogether, 10 categories were found.In chart 2, all categories are presented, followed by excerpts from the reports analyzed that represent the demonstrations of each category.

Chart 2.REGULARITIES FOUND IN THE DISCOURSES

Category	**Demonstrative excerpts**
Rejection	*S4: "I rejected him... did not want to. (...) And the father thought I got pregnant on purpose. Then, I did not want the child anymore... then I went into depression, I rejected him... I did not felt as a mother..."*
Shock	*S6: "Yes... I took that shock... no... At the beginning... when I asked: what is autism, doctor? Then she explained to me, right? I was shocked... my God..."* *S2: "For me, I felt normal because he was the first child, right? And I did not even know correctly what it was to be disabled... but when she spoke, I got scared..."*
Sadness	*S1:"Oh, I cried a lot... Holy Mary... the day I knew, it was a deep sadness... I could not believe it... My husband also could not... until a month ago, he still did not believe in that... no, he is not disabled..."*
Aggressiveness	*S9: "At home, he's a little aggressive, (if it is to talk, I'll tell everything), he is very aggressive with me... when he wants things and I do not give them to him, he yells a lot, he gets mad."* *S9: "When he wants to eat, he shows his belly, right? I know everything... he asks for water, but he's very aggressive with me."* *S1: "... He is aggressive... very aggressive... unusual... even in school ..."*
Prejudice	*S10:"His father is prejudiced, since I lived with him, he avoided going out with him, at the beginning, I thought that it was because he foundhim was strange, there was no way to go out with him, I do not know... but then, I realized that it was prejudice..."*
Dependence	*S4: "I have a responsibility for the rest of my life. I have to be a mother, to take care of him, regardless of what comes (...) I do not leave him with anyone... I do not go anywhere... I am always on his side..."* *S4: "For him, it is like the child does not even exist... but I have that responsibility... I do not go out, I just take care of him... I do not work, I have no fun... I just spend my time with him..."* *S7: "I take him everywhere I go... If I go shopping, I take him(...) no one can do anything for him... just me... my husband cannot give him food... nothing... sometimes I have to solve some problems and I cannot take him with me... and when I get home, he is hungry because he does not eat with my husband..."*
Different	*S4:"I felt that he was not normal... I watched the other children... I realized his ways, right?He seemed kind of slow, strange(...) I thought he had a problem... but we did not want to believe, right?... but I felt that he was not normal..."* *S1: "I thought so... that my son was different... but I did not know what it was... Autism... I had no idea... I thought that my son was different... that he had some unusual thing... but I did not know what it was..."*
Difficulty	*S3: "He has a very serious Cerebral Palsy, it is hard to... everything is harder to him... everything is difficult..."*
Overprotection	*S4: "...The love... the protection... that became exaggerated... everybody calls me neurotic... But I am like this, you know? I do not leave him with anyone (...) I pamper him... I attend all his wishes... we just think about so many things..."* *S6: "We try to take care of him... at home, everyone is very careful... sometimes I think that we exaggerate, you know? He is, already, very spoiled..."* *"*

Potentialities	*S8: ““My son is very smart, polite, he learns things easily, and he has a good memory (...) he does not even seem to be disabled...”* *S9:”Because he knows everything, this boy is very intelligent, he is smart. If you tell him to go get something, he will...”*

Subtitle: S1: Subject 1, S2: Subject 2, S3: Subject 3, S4: Subject 4, S5: Subject 5, S6: Subject 6, S7: Subject 7, S8: Subject 8, S9: Subject 9 e S10: Subject 10.

Discussion

The first point of analysis of this study refers to the prevalence of the motherly figure in the family constitution of the subjects. From the analysis, it was established that, mostly, the mother was the central figure in the family relations and in taking care of the disabled child. Of the 10 subjects of the research, 8 have only the mother as the central family figure. Socially, the mother seems to assume a place of responsibility for raising, taking care and being affective with these subjects, whatever the circumstances are. Barbosa et al.[10] discourse that the social representations of maternity shows that the mothers perceive the child as a continuation of her own existence and, likewise, as an opportunity to give new meanings to life.Thus, it establishes a relation of affection and patience, surrendering to the child’s care. This act reveals the idea that the child care is her responsibility, considering herself as the leading provider of his needs.It is certainly not a simple, linear process. Formerly, the mother experiences the mourning and denial moments that last for a while, until the roles reconfigure, the emotional responsibility and care providence are retaken.

Accordingly, regarding the negative view of disability, various regularities were found from the unveiled discourses. Feelings and reactions as rejection, shock, sadness, aggressiveness, prejudice, dependence, the different, difficulty and overprotection were highlighted.Altogether, 9 categories were listed and presented terms and peculiar feelings marked by suffering state facing such diagnoses. Accordingly, the authors Barbosa et al.[10] also claim that the emotions and feelings experienced by these families are described by the mothers with great suffering and grief.They live a unique experience, permeated by crying, loneliness, feelings of helplessness and a great desire to get away from the situation experienced. The feeling of anger also arises and manifests toward the child through rejection and disaffection.This rejection is perceived through postures of abandonment, overprotection or denial of the disability, setting a state of fear and anxiety.The abandonment appears as lack of love, dedication or care towards child. The mother reacts to the situation experienced expressing the right to not want the disabled child.

In a more general categorization compared to the present study, Bagarolloet. al.[11] concludes, in his work, that the factor - stigmatization of the subject with disabilities - was present in most of the analyzed material. Accordingly, constant meetings with the families of disabled subjects are suggested, favoring the exchanges of information about the development of their children and allowing the (re) signification - continuous - of the anxieties, sorrows and perceptions regarding the disabled child.

On the positive view, only one category was listed: the potentialities. To consider the family point of view as positive, it was found at the discourse a predominance of words that highlighted the skills of the children, and not their weaknesses, defects or limitations. Accordingly, families with positive view had a prospective discourse, the one of the paradigmatic changes in the view, still prevalent on the disabled subject. In only 20% (2) of the families surveyed, the discourses mainly highlighted the characteristics related to the favorable intellect of these children. Facing this minority, a question could be raised properly. When faced with so many issues, for most of the families, it seems to happen a lack of awareness regarding the potentialities of these children. The negative characteristics overshadow other potential characteristics that are favorable to the subjects that always put them at the expense of the negativistic conceptualizations and positions. Accordingly, Nagy and Passos[10] discourse about the question of the exceeding knowledge about the problem. They claim that the negative characteristics about the condition end up “blinding” the subject/family, to the point of considering only what says the prognosis of that condition.They forget that they are facing a person with wishes, desires, and above all, the ability to break with what is known and surprise with the possibilities of development.

Final Considerations

The family reactions evidenced, mostly, by a state of suffering and anguish, have been checked and discussed in several studies as a problem that needs care. The data collected in this study point to the necessity of a clinical opening for the demand of these families and a sensitive listening, allowing the professional to understand what place the child occupies in this context.

As claimed Dantas et. al.[12], even if there is an initial breakdown by the family, it can, later, develop strategies of confrontation and restructuration of the family routine, adapting it to the birth of this disabled child.In the process, the changes taking place can unleash stress or wake feelings that oscillate between love and fear, what will possibly influence the way the family takes care of the child. In addition, the motor, communicative and behavioral specificities of these children are often a scary situation for parents and family members, making them feel afraid of making mistakes and showing insecurity in care.Therefore, it is crucial the active support of the professionals who assist them, so that, together, they can face the circumstances that the disability evoke in the family dynamic.

The speech therapy clinical interpretation sustains this professional, in order to act in these issues, understanding the symptom beyond the pathological manifestation and acting in it, listening to these families.Thus, the speech language pathologist and audiologist equips himself with the means to work with these families in the confrontation of their anxieties and expectations, giving them the possibility of establishing a new view of the disabled child, based on listening and welcoming, so that, suffering experiences and reactions of the family can be faced, and, if possible, exceeded.

Bibliographic References

1.Vash CL. Enfrentando a deficiência: a manifestação, a psicologia, a reabilitação. São Paulo: Pioneira; 1988.

2.Batista SM, França RM. Família de pessoas com deficiência: desafios e superação. Rev. de divulgação técnico-científica do ICPG. 2007 Jan-Jun; 3(10): 117-21.

3.Barbosa MAM, Balieiro MMFG, Pettengill MAM. Cuidado centrado na família no contexto da criança com deficiência e sua família: uma análise reflexiva. Texto Contexto - Enferm, Florianópolis, 2012 Jan-Mar; 21(1): 194-9.

4.Berberian AP, Tonocchi R, Souza D, Moleta F, Correia-Lagos HN, Zanata IL. Fissuras orofaciais: aspectos relacionados ao diagnóstico. Distúrbios Comun. 2012 Abr; 24(1): 11-20.

5.Momensohn-Santos TM, Paz-Oliveira A, Hayashi NY. Descrição das expectativas e dos sentimentos das famílias de crianças deficientes auditivas usuárias de Implante Coclear. Distúrbios Comun. 2011 Dez; 23(3): 307-15.

6.Boscolo CC, Santos TMM. A deficiência auditiva e a família: sentimentos e expectativas de um grupo de pais de crianças com deficiência da audição. Distúrbios Comun. 2005 Abr; 17(1): 69-75.

7.Sá SMP, Rabinovich EP. Compreendendo a família da criança com deficiência física. Rev. bras.crescimento desenvolv. hum. [periódico na internet]. 2006 Abr [acesso em 10 set 2014]; 16(1): 68-84. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S0104-12822006000100008&lng=pt&nrm=iso.

8.Manzini EJ. Entrevista semi-estruturada: análise de objetivos e de roteiros. In: SEMINÁRIO INTERNACIONAL DE PESQUISA E ESTUDOS QUALITATIVOS, 2, A pesquisa qualitativa em debate, Bauru, 2004. Anais, Bauru: SIPEQ, 2004. 1 CD.

9.Bardin L. Análise de conteúdo. Lisboa: Edições 70, 1995.Barbosa MAM, Chaud MN, Gomes MMF. Vivências de mães com um filho deficiente: um estudo fenomenológico. Acta paul. enferm. [periódico na internet]. 2008 Mar [acesso em 11 set 2014]; 21(1):46-52. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002008000100007&lng=en.

10.Nagy DG, Passos MC. Intervenção fonoaudiológicajunto a mães de crianças com múltiplas deficiências. DistúrbiosComun. 2007 Abr; 19(1): 9-23.

11.Bagarollo MF, Brugnerotto M, Damiani CM, Freitas AP, Camargo EAA, Ribeiro VV, Panhoca I. Sujeitos Deficientes Intelectuais: o papel da linguagem na dinâmica familiar. Distúrbios Comun. 2014 Jun; 26(3): 222-234.

12.Dantas MSA, Collet N, Moura FM, Torquato IMB. Impacto do diagnóstico de paralisia cerebral para a família. Texto contexto - enferm. Florianópolis, 2010 Abr-Jun; 19 (2).