

“Suffering in paradise”: the difficulties found by mothers in caring for the child with mental distress**“Padecendo no paraíso”: as dificuldades encontradas pelas mães no cuidado à criança com sofrimento mental**

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ABSTRACT

Our objective was to rescue stories of mothers of children with mental distress, to identify what are the difficulties experienced by them, as well as the relationships experienced while caring for their child. This is an exploratory, descriptive and qualitative research, conducted at a CAPSi in the city of Campina Grande/PB/Brazil. The sample was composed by five mothers of children with mental distress. The material was produced by semi-structured interviews and Thematic Oral History. Results were expressed in four thematic axes: 1) Child's limitation and isolation; 2) Nullification of “being” a woman, to the permanent “being” a mother; 3) “A lonely fight”: the woman as the main care provider for their children; 4) Difficulties of acceptance by the family and prejudice from society. Difficulties from physiological and social nature were identified. It is necessary to build social support networks, more community care and support to these mothers.

Descriptors: Women's Health; Mental Health Services; Stress, Psychological; Psychiatric Nursing.

RESUMO

Objetivou-se resgatar histórias de mães que têm filhos com sofrimento mental, identificando quais são as dificuldades vivenciadas por elas, bem como as relações experimentadas no cuidado para com o filho. Trata-se de uma pesquisa exploratória, descritiva e qualitativa, realizada no CAPSi no município de Campina Grande/PB/Brasil, com cinco mães de crianças com sofrimento mental. A produção do material ocorreu por meio de entrevista semiestruturada e da História Oral Temática. Os resultados foram expressos em quatro eixos temáticos: 1) As limitações e o isolamento da criança; 2) A anulação do “ser” mulher, para a permanência do “ser” mãe; 3) “Uma luta solitária”: a mulher como principal provedora de cuidados aos filhos; 4) Das dificuldades de aceitação na família ao preconceito da sociedade. Identificaram-se dificuldades de natureza fisiológica e outras de cunho social. Faz-se necessária a construção de redes sociais de apoio, maior acolhimento e amparo pela comunidade à essas mães.

Descritores: Saúde da Mulher; Serviços de Saúde Mental; Sofrimento Psíquico; Enfermagem Psiquiátrica.

INTRODUCTION

The Sanitary Reform, the Psychiatric Reform and movements for Human Rights, were some historical events that converged efforts in the trial to make viable the deconstruction of a hospital-centered, stigmatizing and excluding model, and looking for a new proposal to implement community based services, oriented to care for patients with mental disorders within his own social environment, therefore guaranteeing an integral and humanized care⁽¹⁾.

Mental health policies in Brazil still are in construction process, being the infant mental health policies considered one of the main challenges of the Brazilian Psychiatric Reform.

Government regulations recommend mental healthcare of infant-juvenile to be developed in diverse health services, of basic attention to high complexity services, articulated to an attention network to allow social inclusion of its users⁽²⁻³⁾.

Centers of Psychosocial Attention for children and youth (CAPSi) began to operate in 2002, under the same principles of other CAPS in the country. Those are public services of daily attention for children and adolescents with severe psychiatric impairment. Its function is to provide mental healthcare having completeness as their basis. Services are financed with SUS resources and initially planned to meet the demand of cities with 200.000 or more inhabitants⁽³⁾.

A child presenting a health context, in which lifelong continuous care is needed, becomes a big challenge for the family, society and also Public Health. Those children need permanent multidisciplinary services. At the same time, their caregivers also need multidisciplinary attention so that they can sustain their socio-family role⁽⁴⁾.

Many times, the breaking of having a “normal” child idealization can be become a situation that promotes stress to family members. Besides that, the appearance of deviant behaviors which are characteristic of psychiatric disorders, generate conflict situations with the child,

worries regarding to how to deal and overcome the problem, difficulties in the child adaptation in different contexts and losses in quality of domestic interaction⁽⁵⁾.

When assuming the care of a sick child, feelings and emotions can emerge provoking unbalances. Generally, family structure changes, new roles, new rules and situations that often promote suffering to its members. Relationships with the external world also gets shaken, and a family re-adaptation is needed facing the limitations imposed by the disease. It comes the need to acquire stimuli to accept the situation and to help the child, also learning how to live with the disease⁽⁵⁾.

The appearance of mental distress and its consequences can aggravate eventual conflicts in the family's daily life and dynamic, making those people involved with the care of this child specifically, needing help to understand these and other questions; as guilt, the overload, the gloom and the social isolation, which comes after discovering a mental distress in their child.

In this caring process, attention is on the mother figure, who culturally has the role of family caregiver, and after the established diagnosis, in many cases, starts to dedicate almost integrally to the child healthcare.

Studies prove that mothers, when assuming the attention of a mental distress child, socially redefines her familiar and cultural identity trajectory. The most consistent results of these studies show strong presence of social stigma as a factor that promotes introjection of a damaged identity, discredited to this mother, creating on her a heavier psychic overload⁽⁶⁻⁷⁾.

Facing these situations, mothers of children with some mental disorder behave as true heroines, not measuring efforts to best contribute with their child's development, even if an intense sacrifice is needed in her life. It is observed that diverse difficulties faced by mothers generate a strong resilience power to re-write their own life stories in front of the radical adaptation to this new reality⁽⁷⁾.

However, few are the studies developed on this theme, which pay attention to how those characteristics

of infant mental disorders can affect family trajectory. Furthermore, the knowledge of how those difficulties experienced by mothers can interfere in the emotional development of the child in mental distress is incipient⁽⁸⁻⁹⁾.

Thus, it is understood that problems faced by the maternal figure regarding care of a child with mental distress, generate financial, physical, emotional overload and changes in their leisure activities and sociability, therefore, becoming directly dependent of institutional resources, of professional preparation and support⁽⁷⁾.

In this regard, professionals of different sectors should be ready to facilitate the interaction between child and family. They should respect their peculiarities and their sociocultural needs, aiming to improve the way they face mental distress, reducing the family's and in special, the mother's overload⁽⁵⁾.

To hear reports of those mother's trajectories allows a better comprehension of their specificities, difficulties and achievements, enabling interventions to promote quality of life for the child and family who experience mental distress.

In this context, the present study aims to rescue through narratives the stories of mothers with mental distress children, as well as, to identify what are the difficulties and coping experienced by those women in their straight relationship of care with their children.

METHODS

A qualitative exploratory study design using the Oral History as strategy to value and subsidize the qualitative universe⁽¹⁰⁾, configured as a report of personal experiences for individuals with relative common characteristics to significant events and facts, constituting their experience.

The infant-youth CAPS "Campinense Center of Early Intervention" was the research setting, located in the city of Campina Grande-PB. Location choice was based on this health service being presented as a reference institution for infant mental healthcare in the state of Paraíba.

Selection of collaborators was linked to colony formation, that is, a collectivity that has common objectives⁽¹¹⁾. In this study, colony was composed by mothers with children registered at the mental health institution cited above. The network, which is a colony subdivision, was composed by mothers older than 18 years old who accepted to voluntarily participate in the study, and who took part on workshops organized by the service, with their children.

Empirical material was produced by a semi-open interview script. Interviews were scheduled and conducted in accordance with participants' availability, respecting desired time and place. Authorization to use a recorder was previously asked, and the Free and Informed Consent was signed.

The material analysis was guided by the vital tone, which are the strong expressions that came up in the stories. To identify narratives, super-heroes pseudonyms were used, chosen by collaborators.

The study was developed based on ethical aspects of research involving human beings and recommended by the resolution 466/2012 of the Brazilian National Council of Health of the Health Ministry, which addresses duties and rights of researchers and subjects. Thus, this study was submitted for appreciation of the Ethics in Research Committee of the University Hospital Alcides Carneiro, under the protocol number CAAE: 11276113.6.0000.5182.

After empirical material collection, interviews were submitted to these phases, following the Oral History method: Transcription – interviews were listened and transcribed in their literal sense, removing only repetitive words, without losing characteristics of each narrative; Textualization – in this phase, questions were removed and the text ended as narrative form; Transcreation – the text was recreated through paragraph ordination, in which some words and phrases were removed/added in accordance with observations and notes, without changing the text meaning⁽¹¹⁾.

Right after the end of transcreation, the text was brought to collaborators for content checking and choice of pseudonyms, to keep their suitability.

The empirical material analysis was guided by narratives' vital tone, referring to the theme with major expressive strength within the collaborator's report. In this phase, thematic analysis procedure was used, and the 4 (four) thematic axes were found, related to main difficulties experienced by those mothers: the first reflects about child's physical and psychic limitations; the second, explicit abdications done by mothers in their personal and professional lives in detriment to the child's care; the third axis discuss their role as main care provider; and the last axis propose discussions about prejudice, many times present in the family and society.

RESULTS

The study was conducted with a group of mothers who participated with their children in workshops at CAPSi – Campinense Center of Early Intervention. This group had eight mothers in average, but only five collaborators decided to voluntarily participate in the study reporting their stories. Children's age range was five to 14 years.

Although children were accompanied by the CAPSi multidisciplinary team, one of them still did not have a precise diagnosis, making hard the caring process and understanding from the mother about her child's disease. Children's diagnoses of other participants were: autism and mental retardation.

Four thematic axes were created from the fragments of these stories: 1) Child's limitations and isolation; 2) Nullification of "being" a woman, to the permanent "being" a mother; 3) "A lonely fight": the woman as the main care provider for their children; 4) Difficulties of acceptance by the family and prejudice from society.

Child's limitations and isolation

From the following report, it was observed that mothers find difficulties in dealing with the mental

distress of their children, some of physiological and others of social nature, as shown by the fragments of their reports:

[...] he has many limitations! To me, the main are the physiological, I am having a lot of difficulty to go with him to the bathroom to poop [...] this story is really stressing and worrying me! [...] (Mrs. Incredible).

[...] is a child who depends a lot on me. He doesn't shower alone, he doesn't know how to clean himself, I have to help him to get dressed, brush his teeth, wash his hair...I help in everything because he needs to be helped, if not, you know (laughs). But I try to help while teaching because if you don't teach, how is he supposed to learn? [...] (Hawk Woman).

[...] But I also notice limitation in the interaction with other people, he likes isolation, and he is not afraid of things. If I let him free on the street he goes towards the car to see all wheels spinning. He likes everything that spins, and he is also totally dependent of me, not only to eat, but for all other things, I have to be there always helping (Super Woman).

The child's limitation and isolation leave her completely dependent of maternal care, and this generate a major overload for the mother, bringing restrictions to her personal and professional life, which causes her loss of identity in many times, being restricted only to the social role of mother, as it is shown in the reports of the second thematic axis:

Nullification of "being" a woman, to the permanent "being" a mother

[...] sometimes I need to work, I want to work, want to finish my studies, I want everything and I can't anything! In truth I can, but I would have to leave him and this I will never do, I live just for him [...] (Super Woman).

[...] everything is with me! Now that he is studying, I have a little free time in the afternoon, but it is not all afternoon, but I like a lot to read, right?! So then, I enjoy

it. Sometimes the house chores won't let me, because they are many (Mrs. Incredible).

During narratives, it was observed that besides all abdications made, the mother ends up providing care alone. Even when the care is alternated with other family members, the mother in an inevitable manner occupies the space as the central figure for emotional demands of the family and for home maintenance, as observed in the reports of the next axis.

“A lonely fight”: the woman as the main care provider for their children

[...] I'm responsible for caring, really! If she wakes up at midnight, I wake up at midnight, if she sleeps only after sunrise, I only sleep at sunrise. This is my routine; the challenge is big until God's will! (sigh) (Wonder Woman).

[...] And to take care of him, it's only me! I don't trust letting Ivo stay with anybody, because he is really nosey

[...] When I need to leave I let, but only if I'm not taking too long, sometimes with the dad, when he is home, with the sister the brother [...] (Hawk Woman).

In caring for him, I make turns with my husband, but I try to care more, because man does everything anyways, right?! (laughs), I take more care of him because I like everything my way, I don't let him get dirty, I don't let the eating time and medication time pass [...] (Super Woman).

[...] my other son feels that he is very rejected, because I'm always giving too much attention to Vitor, but I call him and talk to him, I tell him that Vitor is special and needs that major attention (Super Woman).

Beyond the obstacles in the caring process and in maternal role performance, prejudice from society and in many times, from the own family, beyond their own difficulty to accept as mother, are configured as other barriers that can affect the care for the mental distress child, as observed in the reports from the following axis.

Difficulties of acceptance by the family and prejudice from society

[...] I've passed through that acceptance difficulty...to me, it was really hard to see my son fine and all the sudden he is that way! It also has the prejudice, people see that his is autistic and don't want to accept it [...] (Bat Girl).

[...] I have the other children, all normal between quotation marks, right?! (sigh). I felt this difficulty of accepting him, I'm assimilating better now, but at the beginning it was really hard (the mother gets emotional and cries) (Mrs. Incredible).

[...] in the family part is hard, because a big part of my family rejects, a big majority laughs (sigh) [...] they turned away so that I don't ask for a favor, don't ask for any type of help (Super Woman).

Sometimes I get in a place, and comes a person saying that my son is beautiful, after seeing that he is special, and then things change, some people try to know how is reality, but others only rejects and leave (Super Woman).

[...] I go out with him, many times he doesn't behave in the corners, I have the biggest trouble, because he gives me lots of work, when those things happen people look sideways, they don't like [...] many people, because he has a normal appearance, say that he is like that because I spoil him, because he is impulsive, that he is misbehaved, that I don't educate him [...] (BatGirl).

Another interesting fact observed was the difficulty of the child's adaptation at school, due to mental distress specificities, and questions related to prejudice, as noticed in the following lines:

[...] Now I have another challenge...school have been the worst place for him to adapt [...] he was always used to stay home, alone, and all the sudden he is in a classroom with other 25 children [...] I have to be there daily, this is when they allow, I think that the biggest difficulty is the school (Super Woman).

[...] he still don't stay quiet in the classroom and he likes to be really isolated, without interacting with other

children in games, sometimes he also gets too agitated, when that happens the school calls for me to go pick him up earlier. Even understanding this attitude, I didn't like it a lot, I got a little sad [...] (Mrs. Incredible)

DISCUSSION

During stories revealed by mothers, we can observe main difficulties experienced by them while caring for a mental distressed child goes, since the child's limitations conditioned by the disorder, as well as the resignations done by those mothers, besides the prejudice existing in society and in their own family against the child's condition.

In the first axis "Child's limitations and isolation", we can notice in the narratives that obstacles cited in the caregiving relationship with this child are characterized by physical limitations, difficulties in social interaction and maternal dependency, that are barriers related to the own clinic of psychic disorders.

Studies⁽¹²⁻¹³⁾ points that main objections presented goes since the discovery of their child having a mental disorder to the strategies used by mothers in how to deal with the child's limitations and dependencies. When the expectations generated by the birth of a child are not met, the family, and specially the mother, does not see herself prepared to face this new condition, which ends up creating conflicts and emotional instability within the family.

Thus, the mother absorbs the child's world and involved in this world intrinsically, she starts to report her routine as a child's routine, sustaining her experience in a zeal and caring way.

Because of the dependence that caring for a mental distress child implicates, the mother began to organize her life around the child's needs, and many times leave her personal and professional needs in a second plan, as it was observed in reports presented in the second axis: "Nullification of "being" a woman, to the permanent "being" a mother.

When experiencing the child's routine and assuming it as hers, the mother slowly loses her own history and give new meaning to her existence, abdicating other social roles to dive into the unconditional task of childcare⁽¹²⁾.

The demand of a constant, specific and routine care towards their children contributes to difficulties of mothers to get separated from them, and vice-versa, so that this binomial suffers with co-dependency. This precludes and restrains them to establish other relationships, as to go on with their professional career. For the mother, her satisfaction stays directly related to the caregiver and home provider role, while the husband stays responsible for physical, emotional and financial support⁽¹⁴⁾.

A research conducted in United States demonstrates that mothers of children with autism had to restructure their family lives due to their children unpredictable and hard behaviors. Besides, it was observed that child's sensorial experiences, (as the cry, scream and laughs), can affect family occupations, as well as expressions and behaviors of parents can interfere on the emotional development of their children⁽¹⁵⁾.

For mothers, caring is a task to perform alone. Few are the ones who can count with the partner's help, showing evidence of the culturally imposed role to the mother in the family and the overload on her in relation to the mental distressed child, as observed in the reports of the axis: "A lonely fight": the woman as the main care provider for their children.

Although nowadays there is a bigger caring division between family members, it is still centered on the mother, who in addition to caring for family members and home, also needs to be in constant vigil to meet her child's demands and specificities brought by the condition. This accumulation of tasks can initiate and aggravate a physical and emotional instability for her.

Different behaviors of children with mental distress can lead to maternal stress and negativity feelings, which

consequently, will interfere in the binomial mother-child interaction, creating emotional instability to the child⁽¹⁶⁾.

We also noted that many times, the mother's conception about the need of intensive care for the child with mental distress and overload of care provided, makes her neglect attention given to other family members, even if involuntarily.

The heavy load of responsibilities delegated to mothers and to other family members has been becoming an additional problem in the health context. Stress and depression are two of the main factors that lead mother of children with autism to look for social support. In first place, the mother goes to their partner and family to obtain support, and after they search for help groups where they can feel comfortable to discuss their worries about raising a child with mental disorder without being judged⁽¹⁶⁾.

Social support, not only found in closer interpersonal relationships, but also through Non-Governmental Organizations and help groups has been one of the strategies used by families to face barriers imposed by the child's health condition. Besides, professionals of health services need to be prepared to receive maternal and familiar distress, in order to minimize the emotional overload by offering welcoming spaces to exchange experiences that can propitiate family empowerment⁽¹⁷⁾.

Although the problems described above are linked to maternal overload, it can still be observed in the narratives their difficulty to accept it, as well as their families. Which constitute another dimension to be observed by health professionals. In addition, reports still present prejudice experiences from society and in educational services, as addressed in the thematic axis: "Difficulties of acceptance by the family and prejudice from society".

The mental distress of a child intensely affects parents' self-esteem. They feel powerless in most times, fragile and guilty and they can deny the disorder existence⁽¹⁷⁾. Frustration feelings caused by the drop in expectations regarding their child's development,

feelings of guilt and doubt about the child's development are normally present in most parents when they receive a child's psychiatric diagnosis⁽¹⁸⁾.

The child with mental distress hardly will be part of maternal expectations, leading to the symbolic loss of a "normal" child, a feeling that makes difficult the positive affirmation of their personal identity as woman and also as mother⁽⁶⁾.

Rejection from their family is another aggravating factor that can emotionally affect the mother and sometimes can cause upheaval feelings. In a study conducted through narratives of mothers of children with autism, it can also be found the mother feeling pushed away by friends and family. In many times those withdraws are caused by lack of knowledge of people about this types of perturbation and by the fear of confronting the children⁽¹⁸⁾.

Besides prejudice, parents of children with autism tend to limit or avoid specific places or situations due to their children sensibility to fuss, noises, and other sensorial experiences. Those restrictions ends up changing daily routines, searching for knowledge acquisition in books or disorder related events, as a trial to comprehend things from the children's standpoint⁽¹⁵⁾.

Other people's gaze is also an influencing factor in the maternal experience. To see people uncomfortable with the child's presence is felt by mothers as a prejudice act. It is exactly because they perceive child's social fragility that they also feel fragile. To discriminate, have prejudice or even look differently to those children mobilize in the mother a will to protect even more them, that for her perception, it is a helpless child. Thus, due to this major need of protection, mothers dedicate themselves integrally to maternity⁽¹⁹⁾.

Education is established as one more challenge to overcome by mothers of children with mental distress. After the search for understanding the mental disorder condition and treatments, it also arise the need to integrate them to society, and this could be favored by their enrollment at school.

Although nowadays there is a big part of schools with greater openness and comprehension regarding inclusion of children with some special condition, there are still cases in which schools impose restrictions to accept children with mental distress. Hence, the moment of the child's enrollment at school also materializes the question of difference and limits regarding the learning process⁽¹⁹⁾.

Health and education professionals can be support and transformation agents in caring for the child, mother and family. They can propose intervention strategies for the children, but that can also benefit the family and the community, through training programs related to care, which can propitiate ways to deal with children with uneven patterns of cognitive development⁽¹⁶⁾.

CONCLUSION

Even with all changes since the Psychiatric Reform, society moves in slow steps regarding inclusion of people with mental distress. This situation is even more severe when we talk about children with mental distress, in which besides the social stigma related to the child, exists disrespect experienced by the family.

Because of what was mentioned, it was observed that the first challenges experienced by the mother of a child with mental distress, are the confirmation of the psychiatric diagnose and the physical-psyche limitations presented due to the distress itself.

When perceiving the child's special needs, mothers end up abdicating other activities to concede exclusive dedication to their child, many times they have to build new life projects. This peculiar and integral care can lead to mother- child co-dependence situations, favoring maternal emotional attrition and affecting the child's autonomy.

In addition, diagnosis confirmation of infantile mental distress brings serious implications to their family, as difficulty of acceptance by the parents, feelings of guilt on the mother and withdraw of other family members due to lack of understanding about symptoms and obstacles caused by mental distress.

The hardship to find inclusive schools is another factor that emerges in the domestic experience. Many times, due to lack of qualified personnel, school imposes conditions for childcare, generating even more prejudice and exclusion. To avoid discrimination, some mothers prefer to take their child out of school, making even more difficult the reinsertion process of those children in society.

Although this research have addressed the maternal condition in relation to their child with mental distress, more research is necessary to discuss maternal stress as conditioning for the child's emotional development, as how family restrictions and occupations can have a negative impact on this child' life condition.

It is still important to notice the need that society in general, should be better informed regarding mental distress and its consequences to child development. In special, the family institution should be aligned to necessary resources for care, within them, the creation of social support networks, in a way that the mother, as main caregiver figure, feel more welcomed and supported.

In this regard, it is relevant to disseminate knowledge about rights of children with mental limitations, as the right to integral health, since the prevention of diseases until its rehabilitation, and specially, the right to inclusive education, which in many times is violated by regular school, disrespecting diversity and differences.

REFERENCES

1. Oliveira FB, Silva KMD, Silva JCC. Percepção sobre a prática de enfermagem em centros de atenção psicossocial. *Rev. Gaúcha Enferm.* [Internet]. 2009 [cited 2015 sep 30];30(4):692-

9. Available from: <http://dx.doi.org/10.1590/S1983-14472009000400016>.

2. Reis AOA, Delfini PSS, Dombi-Barbosa C, Bertolino Neto MM. Breve história da saúde mental infantojuvenil. In: Lauridsen-Ribeiro, Tanaka E, editors. *Atenção em saúde mental para*

- crianças e adolescentes no SUS. São Paulo: Editora Hucitec; 2010. p. 109-30.
3. Ministério da Saúde. Saúde mental no SUS: os centros de atenção psicossocial [Internet]. Brasília: Ministério da Saúde; 2004 [cited 2015 sep 30]. Available from: http://www.ccs.saude.gov.br/saude_mental/pdf/sm_sus.pdf.
4. Borba LO, Schwartz E, Kantorski LP. A sobrecarga da família que convive com a realidade do transtorno mental. *Acta paul. enferm.* [Internet]. 2008 [cited 2015 sep 30];21(4):588-94. Available from: <http://dx.doi.org/10.1590/S0103-21002008000400009>.
5. Navarini V, Hirdes A. A família do portador de transtorno mental: identificando recursos adaptativos. *Texto contexto - enferm.* [Internet]. 2008 [cited 2015 sep 30];17(4):680-8. Available from: <http://dx.doi.org/10.1590/S0104-07072008000400008>.
6. Bastos OM, Deslandes SF. A experiência de ter um filho com deficiência mental: narrativas de mães. *Revista Cad. Saúde Pública* [Internet]. 2008 [cited 2015 sep 30];24(9):2141-50. Available from: <http://dx.doi.org/10.1590/S0102-311X2008000900020>.
7. Semensato MR, Bosa CA. Apego em casais com um filho com Autismo. *Fractal, Rev. Psicol.* [Internet]. 2014 [cited 2015 sep 30];26(2):379-400. Available from: <http://dx.doi.org/10.1590/1984-0292/839>.
8. Fountain C, Winter AS, Bearman PS. Six Developmental Trajectories Characterize Children With Autism. *Pediatrics* [Internet]. 2012 [cited 2015 sep 30];129(5). Available from: <http://dx.doi.org/10.1542/peds.2011-1601>.
9. Gulsrud AC, Jahromi LB, Kasari C. The Co-Regulation of Emotions Between Mothers and their Children with Autism. *J Autism Dev Disord* [Internet]. 2010 [cited 2015 sep 30];40(2):227-37. Available from: <http://dx.doi.org/10.1007/s10803-009-0861-x>.
10. Meihy JCSB, Holanda F. História oral: como fazer, como pensar. São Paulo: Contexto; 2007.
11. Meihy JCSB. Guia prático de história oral: para empresas, universidades, comunidades, famílias. São Paulo: Contexto; 2011.
12. Monteiro CFS, Batista DONM, Moraes EGC, Magalhães TS, Nunes BMVT, Moura MEB. Vivências maternas na realidade de ter um filho autista: uma compreensão pela enfermagem. *Rev. bras. enferm.* [Internet]. 2008 [cited 2015 sep 30];61(03):330-5. Available from: <http://dx.doi.org/10.1590/S0034-71672008000300009>.
13. Barbosa MAM, Baliero MMFG, Pettengill MAM. Family-centered care in the context of children with disabilities and their families: a reflective review. *Texto contexto - enferm.* [Internet]. 2012 [cited 2015 sep 30];21(1):194-9. Available from: <http://dx.doi.org/10.1590/S0104-07072012000100022>.
14. Falavina OP, Cerqueira MB. Saúde mental infanto-juvenil: usuários e suas trajetórias de acesso aos serviços de saúde. *Espaç. saúde (Online)* [Internet]. 2008 [cited 2015 sep 30];10(1):34-46. Available from: <http://www.uel.br/ccs/espacoparasaude/v10n1/Artigo%205%20-%20referente%20ao%2070-2008.pdf>
15. Bagby MS, Dickie VA, Baranek GT. How sensory experiences of children with and without autism affect family occupations. *Am J Occup Ther* [Internet]. 2012 [cited 2015 sep 30];66(1):78-86. Available from: <http://dx.doi.org/10.5014/ajot.2012.000604>.
16. Boyd BA. Examining the Relationship Between Stress and Lack of Social Support in Mothers of Children with Autism. *Focus Autism Other Dev Disabl* [Internet]. 2002 [cited 2015 sep 30];17(4):208-15. Available from: <http://dx.doi.org/10.1177/10883576020170040301>.
17. Borba LO, Paes MR, Guimarães AN, Labronici LM, Maftum MA. A família e o portador de transtorno mental: dinâmica e sua relação familiar. *Rev. esc. enferm. USP* [Internet]. 2011 [cited 2015 sep 30];45(2):442-9. Available from: <http://dx.doi.org/10.1590/S0080-62342011000200020>.
18. Nogueira MAA, Rio SCMM. A Família com Criança Autista: Apoio de Enfermagem. *Revista Portuguesa de Enfermagem de Saúde Mental* [Internet]. 2011 [cited 2015 sep 30];(5):16-21. Available from: http://www.scielo.mec.pt/scielo.php?script=sci_arttext&pid=S1647-21602011000100003&lng=pt.
19. Smeha LN, Cezar PK. A vivência da maternidade de mães de crianças com autismo. *Psicol. estud.* [Internet]. 2014 [cited 2015 sep 30];16(1):43-50. Available from: <http://dx.doi.org/10.1590/S1413-73722011000100006>.

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