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COCHLEAR IMPLANTS AND AUTISM SPECTRUM DISORDER: THE EXPERIENCE OF MOTHERS

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ABSTRACT. Cochlear implant (CI), a device surgically implanted in the ear, may be indicated for people with severe or profound hearing loss (HI). A significant number of children are affected by HI and other comorbidities, including Autism Spectrum Disorder (ASD). The objective of this study was to understand the experience of mothers of children with CI and diagnosis of ASD. The study had qualitative nature and the method used was phenomenological investigation, which consists in the apprehension of the phenomenon as it manifests itself to the person who experiences it. Six mothers of children with CI and diagnosis of ASD were interviewed. The statements were submitted to the process of phenomenological analysis and were unveiled in seven thematic categories: The impact of multiple disabilities; Exclusive dedication to the children; "Twenty-four hours running after it"; "The cochlear implant was a blessing in the life of both of us"; "It is as if he were speaking"; Need for psychosocial support; How they feel now. The mothers revealed how they are subjectively affected in their relationship with the child with CI and diagnosis of ASD, indicating negative impact on the quality of their life. The CI meant the possibility of the child to participate in the audible world and of they, as mother, to have more access to their world. Hope in the development of their child's speech becomes the inspiration to continue the trajectory. The need for supporting services aimed at parents, the importance of interdisciplinary teamwork and the encouragement of the support network are highlighted in the study.

Keywords: Cochlear implant; autism; mother child relations.

IMPLANTE COCLEAR E TRANSTORNO DO ESPECTRO AUTISTA: VIVÊNCIA DE MÃES

RESUMO. Para pessoas com deficiência auditiva (DA) severa ou profunda pode ser indicado o implante coclear (IC), dispositivo implantado na orelha cirurgicamente. Há um número significativo de crianças com DA e outras comorbidades, entre elas o Transtorno do Espectro Autista (TEA). O objetivo desse estudo foi compreender a vivência de mães de crianças com IC e diagnóstico de TEA. O estudo foi de natureza qualitativa e o método utilizado foi a investigação fenomenológica, que consiste na apreensão do fenômeno tal como ele se manifesta para a pessoa que vivencia. Foram entrevistadas seis mães de crianças usuárias do IC e com diagnóstico de TEA. Os depoimentos foram submetidos ao processo de análise fenomenológica e se desvelou em sete categorias temáticas: O impacto das múltiplas deficiências; Dedicação exclusiva aos filhos; “Vinte e quatro horas correndo atrás”; “Só está faltando ele falar”; “O implante coclear foi uma bênção na minha vida e na dele”; Necessidade de apoio psicossocial; Como se sentem atualmente. As mães revelaram como são afetadas subjetivamente na sua relação com o filho com IC e diagnóstico de TEA, indicando impacto negativo na qualidade de sua vida. O IC significou a possibilidade de seu filho participar do mundo sonoro e elas poderem ter mais acesso ao mundo deles. A esperança no desenvolvimento da fala de seu filho passa a ser o sentido para continuarem a trajetória. Destaca-se a necessidade de serviços de suporte aos pais, a importância do trabalho em equipe interdisciplinar e o estímulo à rede de apoio.

Palavras-chave: Implante coclear; autismo; relações mãe-cria.

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IMPLANTE COCLEAR Y TRASTORNO DE ESPECTRO AUTISTA: VIVENCIA DE MADRES

RESUMEN. Para personas con deficiencia auditiva (DA) severa o profunda puede ser indicado el implante coclear (IC), que es un dispositivo insertado en la oreja quirúrgicamente. Existe un gran número de niños con DA y otras enfermedades asociadas, entre ellas el Trastorno de Espectro Autista (TEA). El objetivo de este estudio fue entender la vivencia de las madres de los niños con IC y diagnóstico de TEA. El estudio fue de naturaleza cualitativa y el método utilizado fue la investigación fenomenológica que consiste en la aprehensión del fenómeno tal como se manifiesta para la persona que lo vive. Se entrevistaron a seis madres de niños que usan el IC y con diagnóstico de TEA. Las declaraciones se sometieron a un proceso de análisis fenomenológicas y se desarrollaron en siete categorías temáticas: El impacto de múltiples deficiencias; Dedicación exclusiva a los hijos; ¨Veinticuatro horas atrás¨;¨Solo está faltando él hablar¨; ¨El implante coclear fue una bendición en mi vida y en la de él¨; Necesidad de apoyo psicosocial; Cómo se sienten actualmente. Las madres revelaron cómo se afecta subjetivamente la relación con su hijo con IC y con diagnóstico de TEA, mostrando un impacto negativo en su cualidad de vida. El IC significó la posibilidad de su hijo de participar en el mundo sonoro y ellas poder tener más acceso al mundo de ellos. La esperanza en el desarrollo del habla de su hijo pasa a ser el sentido para continuar la trayectoria. Se destaca la necesidad de servicios de apoyo a los padres, la importancia del trabajo en equipo interdisciplinario y el estímulo a la red de apoyo.

Palabras-clave: Implantación coclear; autismo; relaciones madre-niño.

Introduction

Hearing impairment (HI) is defined as total or partial loss of hearing ability and may be congenital or acquired. It is classified according to type (sensorineural, conductive or mixed) and severity (mild, moderate, severe or profound). Bevilacqua, Moret and Costa Filho (2011) explain that cochlear implants (CI) can be indicated for people with severe or profound HI. A CI is a surgically implanted device capable of directly stimulating the auditory nerve, allowing access to the audible world and the development of oral language.

About 40% of HI children present other deficiencies as comorbidities, of which 1.1 to 2.2% correspond to Autistic Spectrum Disorder (ASD) (Fitzpatrick, Lambert, Whittingham & Leblanc, 2014). Research has shown that the diagnosis of one condition often leads to a delay in the diagnosis of the other (Jure, Rapin & Tuchman, 1991; Roper, Arnold & Monteiro, 2003). According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), ASD children have significant deficits in three main areas: communication/language, behavior and socialization.

The studies by Donaldson, Heavner and Zowlan (2004) and Daneshi and Hassanzadeh (2007) indicate that the use of individual sound amplification device (ISAD) or CI for children with hearing loss diagnosed with ASD is not contraindicated, but Tharpe et al. (2006) argument that the success of adaptation is variable, since hyperresponsiveness to auditory stimuli can be happen in these children.

According to Lachowska, Pastuszka, Lukaszewicz-Moszyńska, Mikolajewska and Niemczyk (2016), ASD children may develop communication skills after the CI, in some cases even speech understanding, which is very important for the sensation safety, and facilitating the interaction with parents. However, the authors note that oral communication is not a likely realistic goal.

Vernon and Rhodes (2009) emphasize the difficulty caused by the lack of access to specialized rehabilitation and by the preparation of professionals to deal with the two associated conditions. Research also shows that caring for a child with multiple disabilities is more challenging than caring for a child with one single disability, which can lead to more stress and impact on the quality of life of mothers (Cho & Hong, 2012; Hwang, 2008). In addition, according to Perold (2001), the mothers are the persons who accompany patients on most of the treatment and spend more time with the children.

In a literature review conducted by Beers, McBoyle, Kakande and Dar Santos (2014), it has been demonstrated that most studies describing the relationship between HI and ASD address audiological assessment and auditory habilitation and rehabilitation and few describe the psychological aspects involved these two associated conditions. Yamada and Valle (2014) sought to address these aspects in relation to the use of CI, while Favero (2005) focused on family issues related to ASD. In turn, Donaldson et al. (2004) and Wiley, Gustafson and Rozniak (2014) sought to address the psychological aspects incurred by the two conditions in comorbidity.

Yamada and Valle (2014) performed a study with the mothers of the first children who underwent CI surgery in the Cochlear Implant Section of the Audiological Research Center of the Hospital for Rehabilitation of Craniofacial Anomalies of the University of São Paulo (CPA-HRAC-USP). Participants reported on the impact of the diagnosis of HI, on how they saw the CI as the cure of deafness, the rejection of their children, fear of surgery, anguish caused by the choice and emotion during activation of the device.

The mothers also reported how they gave themselves up to dedicate their all to the rehabilitation of their children, with negative effects on the conjugal relationship, the professional, social and financial life and even on their own health. As a positive aspect, the mothers reported on the struggle for overcoming the situation, developing the ability to cope with problems, the support they received, the value of teamwork and the importance of psychological support throughout the process.

Favero (2005) investigated the emotional overload (stress and depression) and the quality of life in order to know the main difficulties arising from the care given by mothers to their ASD children and their coping strategies. The results indicated that most of the mothers were stressed, two were depressed and one presented dysphoria.

Participants used coping strategies that focused on religious practices, fanciful thoughts, and problem-focused thinking. The analysis of the interviews originated the themes: the trajectory of the family in the search to understand the problem of the child in the search of hospitals and health professionals; the mourning faced by the family and the difficulties of dealing with the child's condition; the changes in family dynamics and the emotional overload with rationalization of suffering; and the sense of helplessness about the child's future.

A study by Donaldson et al. (2004) with fathers and mothers of children diagnosed with ASD sought to evaluate the subjective impressions of the CI in the quality of life before and after the implant. Most participants indicated that they would recommend the CI to other families in a similar situation. Parents also reported benefits of the CI, including: changes in behavior, communication, and increased awareness of environmental stimuli. In addition, they reported increased reaction to music and other sounds, vocalizations, eye contact, use of gestures for communication, and answers to questions.

The families of the children diagnosed with ASD reported little or no change after the CI in relation to interaction with siblings and other children or in relation to the family routine. Therefore, the authors emphasize the importance of discussing these aspects with parents of ASD children who consider the possibility of CI, and exhort that parents should understand that the surgical intervention may have little or no direct effect on ASD-related behaviors.

The families of ASD children reported that their children did not develop as much as they expected after the CI. Thus, the authors emphasize the importance of preoperative preparation by an interdisciplinary team that should include information about the possible impact of individual differences or even deficiencies not yet diagnosed in the development of the child, so that parents may have more realistic expectations.

Wiley et al. (2014) also raised questions to a group of fathers and mothers about the impact of dual diagnosis and rehabilitation resources. Families described various communication strategies (oral, signs, writing) and prioritized day-to-day behavior rather than academic performance. Special educational environments were perceived as useful in the treatment, but parents highlighted the difficulty to find professionals specialized in the care of HI/ASD children and reported that they have found the internet as a resource to obtain information and exchange experiences with families with similar needs.

Therefore, it is necessary to understand in greater depth the experiences of the families of children with the two associated conditions. Thus, the objective of this study was to understand the experience of mothers of children diagnosed with ASD who use CI, seeking to describe the significant aspects of their experience.

Method

The project was initially submitted to the Human Research Ethics Committee of the HRAC-USP, where the data were collected, and it was approved in its entirety (CAAE 49065915.4.0000.5441). Mothers of children using CI and with confirmed diagnosis of ASD were included in the study, and mothers of children with suspected ASD and mothers of children with other comorbidities were excluded.

Mothers were invited to participate in the research on the scheduled return days to the service. All participants were informed about the purpose of the research and signed the Informed Consent Term.

Six mothers of children with CI and diagnosis of ASD participated in the study, who attended the scheduled return consultation in the service, and thus dispensing the need for inclusion of new participants, as the meanings expressed in the statements were sufficient to understand the phenomenon investigated. We used the criterion of "repeatability" that expresses the manifestation of the phenomenon in its essence, indicating the termination of data collection (Boemer, 1994). Participants were between 24 and 43 years old and their level of education varied from Complete Elementary School to Complete Higher Education.

According to Holland (2006), the phenomenological interview is an appropriate methodological resource to explore the experience of a certain phenomenon. This method allows the possibility of exploring the experience from the perspective of the research participant. In this way, the interviewer seeks to develop a climate in which the interviewee feels free to express what was requested. The first seeks to hear the testimony of the interviewee, without giving judgments of value, capturing the testimony as it is being described (Valle, 1997).

In the present research, individual interviews were conducted without limit of time, seeking to understand the mothers participating in the study. The following guiding question was adopted: "How has been your experience with your child, with the cochlear implant and with autism?".

Three interviews were conducted in the presence of the children of the participants, at their request, since they did not use to be under the care of unknown people, a common behavior of ASD children. However, according to Paula, Padoin, Terra, Souza and Cabral (2014), during the development of the interview, intercurrences such as noise, environmental movements and interferences of other people may happen, and this may reduce or interrupt the relational attitude established. However, these events do not make interviews impossible, provided the necessary adjustments are made, which requires attention, availability, involvement and effort to reach the phenomenological attitude.

The interviews were recorded and transcribed verbatim for analysis of the statements, using the qualitative method in the phenomenological perspective suggested by Martins and Bicudo (2005). The verbalization of the mothers were the basis to apprehend the meanings attributed to their experience, seeking the understanding of the phenomenon as it presents itself, based on the feelings and thoughts of the lived reality.

First, the testimonies of each participant were read for a global understanding of each experience, without seeking any interpretation of what was exposed. After this step, a new reading was made, focusing on the phenomenon under study, discriminating the units of meaning of each testimony. Then the researcher expresses the psychological meaning contained in the testimonies of each unit of meaning, seeking convergences and divergences. Finally, a synthesis of the units of meaning was made, configuring the thematic categories which integrate the meanings contained therein, for the understanding of the data obtained and later discussion with the literature. The excerpts from the mothers' statements were identified by fictitious names of the mother, child and other relatives in order to preserve the personal identity and privacy of the participants and their families.

Results and discussion

Based on the analysis of the testimonies, the phenomenon "experience of mothers of children with cochlear implants and diagnosis of autism spectrum disorder" was unveiled into seven thematic categories, namely: The impact of multiple disabilities; Exclusive dedication to the children; "Twenty-four hours running after it"; "The cochlear implant was a blessing in the life of both of us"; "It is as if he were speaking"; Need for psychosocial support; How they feel now.

The impact of multiple disabilities

When mothers tell about the moment of discovery of ASD, in addition to the HI, they reported feelings were shock and deep sadness with the news of another diagnosis, that is, of the double disability and deconstruction of hope which was full of positive possibilities for the children. For them, this moment meant the "collapse" of their dreams, fears and concerns:

> *It hit me hard; I was sad to learn he had two deficiencies, not just one, let's say. I felt sad, I cried, because with the implant we thought, "Okay, I saved my son's life, he'll start talking, he'll live with the other children, he will not have any trouble." And then, this…What was really hard was that he has both things together. (Bete)*

> *When she was diagnosed with hearing impairment I accepted it very well. [...] And then when I received the diagnosis of autism, everything changed. That mother who was calm, who was peaceful [...] I collapsed! I collapsed because, it was too much, you know? I could not cope with that. (Cristine)*

Favero (2005) in a study with mothers of ASD children with also observed changes in expectations and concerns regarding the future of their children, especially in mothers of children with more severe symptoms, more dependent on care and less likely to have autonomy or mothers with less resources and access to services. From Cristine's account, one can see that the discovery of ASD besides HI meant also a preoccupation and insecurity with the future of her daughter, about what she gets very emotional:

> *What worries me a lot is her future, how it's going to be in adulthood, if she's going to be able to work, if she's going to be self-sufficient, because I'm worried when I'm gone. Who's going to take care of her? [...] How she's going to be treated in the classroom, if she's going to face prejudice, you know, if they're going to leave her in a corner (cries). (Cristine)*

Vernon and Rhodes (2009) already pointed out difficulties related to the process of specialized rehabilitation and the lack of preparation of professionals to deal with the two associated conditions. From Sara's account, we can see that the difficulties faced in dealing with the unpreparedness of professionals generate even more insecurity about how to deal with her daughter and increases the difficulties in visualizing a good prognosis.

> *I had already accepted her hearing problem, but then there was autism and it's complicated, there is almost no specialist available, nobody knows exactly what it is the problem [...] I had already put in my mind that she was going to use the device, I think I thought so, that she was going to talk and everything would be all right. Then after I realized that things were more difficult than that [...] Then I said: "oh God, that’s it, this will never end"! Because you think that someday this will improve and then something worse comes up, something that… only time to see how it will be. (Sara)*

When dealing with HI only, the mother still had positive perspectives about the future of her daughter, but when she learned the diagnosis of ASD, the constructed expectations collapse, and the future is seen as "worse" and "without end".

Exclusive dedication to the children

As reported by Perold (2001), mothers are the persons who accompany the children in most of the treatment and spend more time with them; they are, thus, the main caregivers, responsible for almost all the daily work to supply their needs. The participants in this study also reported the exclusive dedication to children, revealing how they were impacted in their daily lives:

> *My husband was never of the kind that participates in anything that has to do with my son, so I have to be there for everything. Then, when I saw that it was I who had to run after everything I said: "If I get sick too, who's going to take care of him?" (Loreta)*

Beth seems to believe that no one would take better care of her child than herself. She spends so many hours devoting herself to the child that she even feels empty when he is not around. She seems to be experiencing a relationship of dependence in which she feels fused with the child, which may even undermine the process of individuation and the ability to discriminate between the self and the other:

> *The mother who cares, who shows zeal. Even when my son has a bellyache I already know, just by his eyes. And a strange person does not have that same perception [...] I miss when he is not with me, when he is in school I am like this: "Where is my little appendix?". Because I am always with him, if I'm not with him, I feel empty, he stays with me all the time, and I take care of him. (Bete)*

Yamada and Valle (2014) in their study with mothers of children who use CI and Favero (2005) in the research with mothers of ASD children also reported how these women give themselves up to dedicate their all to the rehabilitation of their children, what can lead to changes in the family dynamics and difficulties in professional, social and financial life. In the present study, the mothers also reported that, because they dedicated themselves exclusively to their children, they left their jobs, which they experience with much regret. For Cristine, her daughter became the priority:

> *Since Joana was born, I totally devoted myself to her. I left everything! I left the job and dedicated myself exclusively to Joana, and I still continue to do so because I haven't come back to work. (Cristine)*

Bete refers to her work as a source of income and personal satisfaction, things that she gave up to be able to dedicate herself to caring for her son:

> *The only time I have to work would be school hours, because even to take the child to therapy, it has to be me. It's because I've always worked, even before colege, I've always tried to work, to have my own income, and I'm not working at the moment, I'm not having any income. That yes, for a woman, it is also difficult! For those who always had an income. (Bete)*

Margarete, in turn, did not want to give up her professional achievement, however she expressed ambiguous feelings, experiencing constant conflicts and much guilt for not dedicating herself exclusively to her son:

> *I try to perform professionally, to pursue my career... Sometimes I still feel very sad, sometimes I blame myself: can I do both perfectly? Because it is a conflict, we are women, when we become mothers, we love our children and want to do everything for our children, but we cannot give up our achievements. (Margarete)*

"Twenty-four hours running after it"

Studies show that caring for a child with multiple disabilities is more challenging than caring for a child with one disability, and may cause more stress and impact on the quality of life of mothers (Cho & Hong, 2012; Hwang, 2008). More specifically on the rehabilitation routine for ASD children with CI, the mothers cited follow up with neuropediatricians, speech therapy sessions, occupational therapy, psychotherapy, physiotherapy, therapeutic horseback riding, among others, as well as frequent returns to the CPA-HRAC-USP for review and evaluation of the CI:

> *I wish that she could get as far as she can. Because you fight for this, we go to speech therapy, we do things for her to get better. So many things, we go in that place, go to that doctor. You go, go, go! [...] It's twenty-four hours running after it (Sara)*

On a day-to-day basis with their children, mothers are constantly on the alert, unable to relax and this can cause much anxiety:

> *I'm going to do the housework, and I get stuck running after him. There are days that I tell you this, it is that day that you go to bed the night and [...] I feel that I am connected in the 220! (Corine)*

> *My mother, for example, comes here, if I need to go to the bathroom and Murilo needs to be with someone, he stays in the room with my mother and I go to the bathroom. Even though the bathroom*

> *is in the suite, but he can do something silly and get hurt there and I'm in the bathroom, taking a shower, or peeing, or something else (Bete)*

Mothers also report "crises" that may be presented by some children related to ASD. Due to the unsteady, agitated and sometimes even aggressive behavior, there may be a need for physical restraint. In these cases, the mothers report physical exhaustion and feel they miss the masculine strength of the father:

> *She has had four or five very difficult crises that she spent more than half an hour crying and kicking and we can do nothing. At these times, the only thing to do is hold her to avoid that she gets hurt and try to calm her down until she gets exhausted. These are the moments that I miss most of my husband [...]. (Cristine)*
>
> *I am no longer strong enough for him [...] People ask me, "My dear, what do you do to lose weight?" And I say, "keep Murilo with you for a month and you'll lose weight", because he does not stop! (Bete)*

In the routine of returns to the CPA-HRAC-USP, mothers also face difficulties due to lack of structure to receive HI children with ASD:

> *It's hard to be coming here ... it's hard to wait down there, there's other kids he's going to bother, so if you do not hold him he'll hurt someone ... [Corine]*
>
> *When I come to Bauru, I get home dead because he does not stop. He's always walking one way, walking down the other [...] (Bete)*

Again, difficulties in the specialized rehabilitation process and the lack of preparation of professionals and of the institution for the care of patients with multiple disabilities or special cases, as mentioned by Vernon and Rhodes (2009), stand out.

"The cochlear implant was a blessing in the life of both of us"

As noted by the study carried out by Donaldson et al. (2004), most participants in this study reported that they would recommend the CI to other families with ASD children. They also cited benefits of the CI, namely: changes in behavior, communication and increased awareness before environmental sounds.

Mothers report great satisfaction with the CI and believe that they would face even more difficulties in their daily lives if their HI/ASD children had not had the surgery. The CI means to them the possibility of the child to participate in the audible world and of them, parents, to have access to the child's world:

> *The cochlear implant was a blessing for Luan, in my life and in his life [...] I thank God every day that this diagnosis came after implantation [...] Now, imagine if he has not the implant, it would be difficult for me and a lot harder for him, because he will not have me for life. (Loreta)*
>
> *I would like to make it very clear that the implant made a lot of difference in Joana's life, she may be never able to speak, but she listens to the noise, the sounds of everyday life, she knows how to identify the phone when it's ringing, the bell, she listens to me, [...] And if it were not the implant, she would be in a world of her own and I could not have access, it would be much more difficult. (Cristine)*
>
> *Just to see that she was reacting to my voice, that she began to understand things ... [...] It improved a lot, I think, you know? Because, before that, she did not pay much attention to when we called her ... (Sara)*

"The only thing missing now is him to speak"

As described by Lachowska et al., ASD children may develop communication skills after CI, such as speech comprehension. However, oral communication should not be an expected goal. As noted by Donaldson et al. (2004), even after the diagnosis of ASD, the mothers of the present study also have unrealistic expectations regarding speech development. They have difficulty communicating with their children, and become frustrated and sad about the delay in oral language and report that their children did not develop as much as they expected:

> *That's what I tell everyone, only if he could speak! When he starts talking, the problems will end. (Loreta)*
>
> *So we are having this difficulty, of communicating with him. I've tried to see if he can make Libras and he does not want [...] then he does not have a communication [...] How to communicate with an autistic and deaf child? (Bete)*
>
> *No one knows, neither you, nor I, nor anyone, whether she'll speak it or not. [...] Communication is a great concern because for everything, we have to communicate. (Cristine)*

Margarete and Sara, even though they were advised about the communication difficulties presented by ASD children, seem to experience a process of denial of reality as a way to avoid further emotional suffering.

> *Every time I come here in Centrinho now with Diego after the implant, I leave here a little sad. Because I still had an expectation that after a year he would be already talking some things, that he would develop more, I expected a little more from him. (Margarete)*
>
> *I know she hears everything, she listens super well, but she cannot speak. So, I know there are autistic children who never speak, but then in my case I wonder, if it's an autistic spectrum, an autism caused by what happened to her, it may be different from a child born with autism. (Sara)*

Thus, interdisciplinary care is fundamental, as emphasized by Donaldson et al. (2004) in the pre-surgical phase, which should include information on the individual differences of each child and other associated difficulties that may interfere in the development of oral language, so that parents may have more realistic expectations.

Need for psychosocial support

The CPA-HRAC-USP acts through an interdisciplinary team in the pre and post-surgical care of the CI program. The psychologist, as a member of the team, works at various moments in the group of welcoming new cases, in the psychological evaluation, in the decision process, psychological preparation for surgery, psychological monitoring during hospitalization and during the rehabilitation process, through care for individuals and groups.

Rezende, Yamada and Morettin (2015) conducted a study to understand the experience of the parents of CI children when participating in the psychosocial support group offered by the service. Families stressed the importance of the group to exchange experiences to learn and clarify doubts, for motivation towards rehabilitation, emotional support, feeling of belonging, identification of similar emotions and the reflection process.

In the present study, the mothers also reported the need for exchanging experiences with other parents in the group:

> *So, I find it very rewarding when I come here because we see the experience of a lot of people [...] So, before I joined this group I was a little isolated, I said: "but why, why is it that only Luan is not starting to talk?" But then I see other people telling their story and there are other cases, it is not only Luan, you know? (Loreta)*
>
> *Everyone shares experience [...] It's good when everyone talks because everyone has something to tell. Each one has an experience. (Sara)*

Bete explains that she does not feel well about participating in the group of parents and caregivers of children who use CI at the CPA-HRAC-USP, because she thinks that she has nothing to learn or teach, since her experiences are very different of the other parents of CI children but who do not have ASD in comorbidity. Because of this, she even suggests that a specific group of mothers of HI/ASD children be created, indicating the need to share experiences with similar cases:

> *So I think this exchange is necessary, because they have this exchange for deafness, we need this exchange also for deaf children who have autism. Because sometimes what one has learned, something a person knows how to deal with, the other does not know, but that same thing also happens to the other. (Bete)*

Mothers express the need for professional support to help them cope with the emotional burden they experience in their relationship with their children:

> *I go to the psychologist there. I asked for it myself. I said, "For God's sake, get me a psychologist". (Corine)*

Through psychotherapy, mothers can get in touch with their ideals, frustrations and idealizations related to the conditions of their children (Favero, 2005). The psychologist, through attentive and qualified listening, seeks to understand and welcome the experiences of mothers, clarifying the meaning of their feelings (Yamada and Valle, 2014).

> *I'm going to a psychologist in my town [...] and together we worked on some things about Joana, the acceptance [...] emotionally I was shaken [...] I think I have got much better. (Cristine)*

The support of family members, spouses and other professionals is also perceived by mothers with great appreciation.

> *When I was discouraged, giving up the implant [...] he (boyfriend) said: "Let's keep fighting, let's persist" [...] It is with Fábio (boyfriend) that I share my expectations regarding Diego. (Margarete)*

> *I missed my mother, my brother, and my family. It was a very difficult phase for me, because that's when I really realized that she had autism. (Cristine)*

> *I have a very good speech therapist, you know, she always guides me when I lose my way [...]. Wow, she knows everything, everything, everything about Eduarda. [...] she made me run after diagnosis, she made me come to Bauru, in everything, it was she who helped me [...] (Sara)*

Thus, the importance of encouraging the support network and the need for psychological support to mothers to contribute to their well-being and better quality of life stands out.

How they feel now

As observed by Yamada and Valle (2014) with mothers of children with CI and Favero (2005) with mothers of ASD children, the participants of this study also reported on the struggle for overcoming and developing the coping strategies before problems:

> *Today, I am much stronger than in the beginning, when I discovered everything. So we carry on, forget about it and keep seeking his improvement [...]. (Loreta)*

> *So, at first ... not now, now I have already accept it, I've read a lot [...], I try to learn more with the other mothers. [...] (Bete)*

> *Today I've found contentment [...] He does not utter a single word at all, so I'm still sad about it, because I wanted him to be evolving better, but I can see that and be calmer than before, something that I would go into depression back then, I would cry ... and nowadays I try not to do that anymore. (Margarete)*

> *So I think it's just my routine. It's just that I've learned to live like this and it's going to be like this, hoping it gets better! [...] You have to fight, you cannot stop. (Sara)*

Over time, mothers learn to cope with the demands, overcome difficulties and feel more empowered. For some, perceiving the limitations of their children becomes part of the reality that is no longer so painful. However, they cannot quit seeking their internal resources to continue their journey with their ASD child who uses the CI.

Final considerations

This study aimed to understand the experience of mothers of children with CI and diagnosis of ASD, seeking to understand the meanings and senses attributed by them to this experience. Phenomenological investigation was used as methodology, and that allowed grasp the subjective world of the participants.

It can be stated that the objectives of the study were met to the extent that the analysis of the mothers' testimonies helped to broaden the understanding of the theme. The mothers participating in this study revealed how they are subjectively affected in their relationship with the ASD child with CI, indicating high levels of stress and the impact on their quality of life. They showed the importance of the family support network and of the professional team. The CI meant the possibility of their child participating in the audible world and of their increased access to the child’s world. Hope in the development of the child's speech becomes the motivation to continue the trajectory. They feel more empowered and motivated, learning to deal with the demands of the ASD child who is a user of CI.

It is worth emphasizing that novel meanings and senses can be apprehended from new perspectives and readings. It is understood that the present research opens doors to several possibilities of future investigations with other mothers, other relatives, or even the patients themselves.

The results of this study make it possible to reflect on the urgent need for investment in family-centered health policies and support services for parents of HI/ASD children, as well as programs for updating and training health professionals. With regard to the CPA-HRAC-USP CI program, new actions should be considered, taking into account the needs pointed out in this study. Thus, it is necessary to think about how to meet the demands of these mothers, as well as how to develop new research projects geared at provision of full support to families of HI/ASD children.

It is believed that research studies such as this one can help health professionals understand the implications of having a HI/ASD child, which can help the teams in guiding and caring for their families, seeking more humanized actions. Therefore, interdisciplinary teamwork, support network and psychological support to mothers is important to the well-being and better quality of life of families of ASD children who use CI.

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