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Teleaudiology: efficacy assessment of an online social network as a support tool for parents of children candidates for cochlear implant

Telessaúde em Audiologia: avaliação da eficácia de uma rede social on-line como apoio aos pais de crianças candidatas ao implante coclear

ABSTRACT

Purpose: To assess the efficacy of an online social network as a support for parents of children with hearing impairment. **Methods:** Twenty-two mothers, randomly divided into experimental (n=11) and control (n=11) groups, filled in an online form containing the Parental Stress Index – Short Form (PSI-SF). Only the experimental group had access to the “Babies’ Portal” social network. Both groups filled in the online form once again 3 months after the first assessment, for evaluating the use and participation in the social network. The posts on the social network were rated by two independent raters regarding themes and mechanisms of self-help. **Results:** No difference was observed in mean PSI-SF scores between the groups for both assessments. Intragroup analysis showed no difference for total and subscale results of PSI-SF between the two data collected for both groups except for the “Defensive Response” subscale, in which a decrease was observed in the score for the control group. The most frequent posting themes were related to personal information and expressions of religious beliefs. Regarding self-help mechanisms, a higher frequency of exchanging experiences and gratitude expressions was observed. Participants in the experimental group stated they would have liked to participate more frequently in the social network as they considered this tool important because of the exchange of information and experience with other mothers and hearing health-care professionals. **Conclusion:** The posts and the assessment of participants indicated the potential of this network to support parents of children with hearing impairment.

RESUMO

Objetivo: Avaliar a eficácia de uma rede social *on-line* como apoio aos pais de crianças com deficiência auditiva. **Métodos:** Vinte e duas mães, divididas randomicamente em grupo experimental (n=11) e controle (n=11), preencheram um formulário *on-line* contendo o Índice de Estresse Parental – versão reduzida (PSI-SF). Apenas o grupo experimental teve acesso à rede social “Portal dos Bebês”. Ambos os grupos preencheram novamente o formulário *on-line*, três meses após a primeira aplicação, tendo o grupo experimental também avaliado o uso e a participação na rede social. As postagens na rede social foram classificadas por dois juízes independentes em relação aos temas e mecanismos de autoajuda. **Resultados:** Não houve diferença entre os escores médios do PSI-SF entre os grupos, tanto na primeira como na segunda aplicação. A análise intragrupos mostrou não haver diferença nos resultados totais e das subescalas do PSI-SF entre as duas aplicações, para ambos os grupos, com exceção da subescala “Resposta Defensiva”, em que houve diminuição da pontuação para o grupo controle. Os temas mais frequentes das postagens foram relacionados às informações pessoais e expressões de crença religiosa. Nos mecanismos de autoajuda, observou-se maior frequência de trocas de experiências e expressão de gratidão. Os participantes do grupo experimental relataram que gostariam de ter participado mais da rede social, pois consideraram esse tipo de ferramenta importante pela troca de informações e experiências com outras mães e profissionais. **Conclusão:** As postagens e a avaliação dos participantes indicaram o potencial dessa rede para fornecimento de apoio aos pais de crianças com deficiência auditiva.

Study carried out at the Speech-Language Pathology and Audiology Department, School of Dentistry of Bauru, Universidade de São Paulo – USP – Bauru (SP), Brazil.

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INTRODUCTION

Severe-to-profound hearing loss gravely compromises the acquisition and development of the oral language in children. For this reason, devices such as the cochlear implant (CI) are used to improve the hearing performance and, therefore, oral communication. Nevertheless, only the use of CI will not ensure that the child develops his or her communicative potential adequately. The involvement of the child in a therapeutic process is also necessary, in which the family's participation is essential.

Parents need to deal with new feelings and situations, doubts, and expectations, which generate family stress, common in this situation, so that they can provide the necessary support and make important decisions about the health and communication needs of their child. They also need to learn new skills and adapt to a new perception of the paternity process^(1,2).

Social support plays a crucial role in the ability of hearing parents to deal with the child's hearing impairment, and can be provided by natural and artificial networks. Natural networks comprise spouses, children, parents, relatives, friends, and acquaintances. The artificial networks refer to new contacts with other parents in similar situations, professionals, and other adults with hearing impairment. The availability of personal resources and of these support networks influences the coping process and reduces the stress of families with children with hearing loss⁽³⁾.

The support group for parents, composed of professionals and members of other families, has a great value as one of the only places where these individuals are understood, heard without judgment, and the help can be given and received through the sharing of experiences^(1,4). The parents of children with hearing loss seek other individuals in similar situations. That is the result of a process of identification that promotes a sense of group, establishment of alliances, and triggering of transformative actions⁽⁵⁾.

In situations in which geographic, economic, and human resources availability barriers hinder the access to interactive support activities for these parents, the establishment of actions from a distance can be considered.

An online social network aims at connecting individuals, via Internet, providing a basis for maintaining social relationships, gathering users with similar interests, content, location, learning, and mutual aid. Online social networks providing support to individuals with chronic diseases have been studied as a means that enable contact between affected people and professionals⁽⁶⁻⁸⁾, not requiring high financial investments, shortening distances, and maximizing the time.

For these reasons, the objectives of this study were to assess the parental stress of parents of children with hearing impairment that were candidates for CI and to evaluate the efficacy of the online social network "Babies' Portal" as a tool to support these parents.

METHODS

This was a clinical, randomized, and controlled study, carried out in the Speech Language Pathology and Audiology Department

of the School of Dentistry of Bauru at Universidade de São Paulo (FOB-USP) and in the Cochlear Implant Section of the Audiological Research Center of the Hospital for Rehabilitation of Craniofacial Anomalies at Universidade de São Paulo (CPA HRAC-USP), Bauru Campus, approved by the Research Ethics Committee of FOB-USP (process no. 113/2010).

The following inclusion criteria were established for participation in the study: to be literate, to have access to the Internet, not being under psychological or psychiatric treatment, to be the father/mother and/or caregiver of a child aged between 0 and 47 months, regularly enrolled in the CPA HRAC-USP with recommendation for the CI surgery in this service. The child should present severe and profound degree of bilateral sensorineural hearing loss and have no other associated disabilities.

During data gathering, we identified 22 individuals that met the inclusion criteria and agreed to participate voluntarily in the study by signing the online informed consent. Although this invitation was directed to fathers and mothers, only the latter expressed interest in participating. None of the participants had other child or children with hearing loss or other disabilities. The participants were divided into two groups, according to their sociodemographic characteristics by stratified randomization (Table 1):

- Experimental group: 11 women aged between 20 and 36 years (mean of 26.5 years), mothers of children with hearing impairment, 3 single and 8 married or in stable relationships.

Table 1. Sociodemographic data of the participants and demographic and audiological data of the children included in the study

Demographic data	Groups		Total (n=22)
	Control (n=11)	Experimental (n=11)	
	n (%)	n (%)	n (%)
Relationship to the child			
Mother	11 (100)	11 (100)	22 (100)
Educational level of the mother			
High school	6 (27.3)	5 (22.7)	11 (50.0)
Higher education	5 (22.7)	6 (27.3)	11 (50.0)
Socioeconomic classification			
Low	9 (40.9)	8 (36.4)	17 (77.3)
Average	2 (9.1)	3 (13.6)	5 (22.7)
Region of residence			
South	3 (13.6)	2 (9.1)	5 (22.7)
Southeast	4 (18.2)	6 (27.3)	10 (45.5)
Midwest	2 (9.1)	1 (4.5)	3 (13.6)
North	1 (4.5)	1 (4.5)	2 (9.1)
Northeast	1 (4.5)	1 (4.5)	2 (9.1)
Gender of the child			
Female	6 (27.3)	6 (27.3)	12 (54.6)
Male	5 (22.7)	5 (22.7)	10 (45.4)
Age of the child (months) – Mean±SD			
Current	18.6±6.2	22.0±7.5	20.3±6.9
At diagnosis	10.9±7.9	9.5±9.0	10.2±8.3
At the time of PSAP adaptation	15.9±9.1	13.0±7.5	14.4±8.3
At the beginning of Speech Language therapy	15.8±9.3	13.4±7.7	14.6±8.4

Caption: SD = standard deviation; PSAP = Personal Sound Amplification Product

As for the occupation, five participants were housewives and six had workweeks of 20 (n=4) or 40 (n=2) hours.

- Control group: 11 women aged between 18 and 39 years (mean of 27 years), mothers of children with hearing impairment, 3 single and 8 married or in stable relationships. As for the occupation, four participants were housewives and seven had workweeks of 20 (n=4) or 40 (n=3) hours.

The link to access the online form (control group) or the online form and the social network (experimental group) was sent via e-mail. The first part of this form, of restricted and protected access, consisted of 13 questions (six open-ended and seven of multiple choice) about the demographics of participants, Internet usage habits, and audiological data of their children.

The second part of the form contained the Parental Stress Index – Short Form (PSI-SF), translated into European Portuguese⁽⁹⁾. The permission from the copyright holders of PSI-SF was obtained to perform adaptations of some expressions to Brazilian Portuguese. An initial study⁽¹⁰⁾ showed that the PSI-SF could be applied electronically.

The PSI-SF consists of 36 statements, divided into three subscales:

- Parental Distress (PD; items 01–12): It evaluates the stress that an individual feels due to the suffering and anguish experienced in the role of father/mother. Example: “I feel restricted because of my responsibilities as a mother/father.”
- Parent–Child Dysfunctional Interaction (P-CDI; items 13–24): It evaluates the perceptions of dissatisfaction of the father/mother, from the interactions with their child. Example: “Sometimes (the child) does things that bother me, just out of spite.”
- Difficult Child (DC; items 25–36): It evaluates the perception of the father/mother of basic behavioral characteristics of the child associated with his or her self-regulatory capacity. Example: “(The child) demands more of me than children usually demand from parents.”
- Optional Subscale — Defensive Response (DR; items 1, 2, 3, 7, 8, 9, and 11): It evaluates the tendency of the father/mother to present the most favorable impression of him or herself and minimize the occurrence of problems or stress in the parent–child relationship.

The score for each subscale is given by the sum of the items that compose it, and the total score is given by the sum of all the items of the instrument. The higher the score, the higher the stress level⁽¹¹⁾. A table available on the test sheet enables us to compare individual data with the percentile of the distribution of the answers of PSI. Results above the 85th percentile are considered high, suggesting the need for intervention.

After filling in the form, only the participants from the experimental group had access to the online social network “Babies’ Portal.” This network, developed in the Ning platform, had access restricted to participants of this study only, using login and password. To receive the login/password, the experimental group completed a specific registration sent via e-mail by the researcher.

In this social network, asynchronous communication tools were used, and it was possible to share text messages, photos, and videos, and to participate in discussion forums. The participants could create the topics of discussion they deemed necessary, with direct communication between them being encouraged.

Two Speech Language Pathologists and a Psychologist, acting as moderators, also participated in this social network, proposing some topics for the discussion forums and answering the questions and comments directed to them. We avoided the interference of the professionals in direct interactions between the participating mothers.

Three months after the first assessment, all the participants were asked to answer the PSI-SF questionnaire a second time. Because of the routine of surgical scheduling and health care of the CPA HRAC-USP, this second assessment was conducted after the child was submitted to the CI surgery (the case of two participants in the control group) or activation of the electrodes (the case of two participants in the control group and one from the experimental group).

The experimental group was also asked to complete a questionnaire containing 14 questions (3 open-ended and 11 of multiple choice) about the evaluation of the use and participation in the social network “Babies’ Portal.”

Two independent Speech Language Pathologists, trained for this purpose, rated the content of posts made on the social network, as follows^(12,13):

- Themes of the messages: dimensions of “experience with hearing disabilities” (six categories), “hearing impairment consequences” (nine categories), and “other comments” (five categories).
- Self-help mechanisms: exchange of experiences; provision of information or advice; request for information or advice, support or empathy; gratitude, friendship, structure, creative expression, negative statements; and computer problems.

Possible disadvantages of using the social network were classified by the researcher as: disadvantage because of the asynchronous online communication, the quality of health information, and negative comments⁽¹³⁾.

The statistical analysis was performed using the software Stata[®]. The PSI-SF scores in the first and second assessments were compared between groups (*t*-test) and intragroup (paired *t*-test). Correlation analyses were performed between the subscales of the PSI-SF and the educational level, socioeconomic status (Spearman), and age (Pearson) of the participants. In all cases, the significance level was 5%.

The evaluation of the messages posted on the social network “Babies’ Portal” and the impressions of the experimental group regarding participation in this social network were carried out using descriptive statistics. The concordance between the classification of messages of the Speech Language Pathologists was verified by the Kappa coefficient.

RESULTS

It was observed that 72% (n=16) participants used the Internet at least several times a week, with higher frequency

for the experimental group. For most participants, the Internet was accessed at their own homes (68%) and at work (18%), with broadband use (77%).

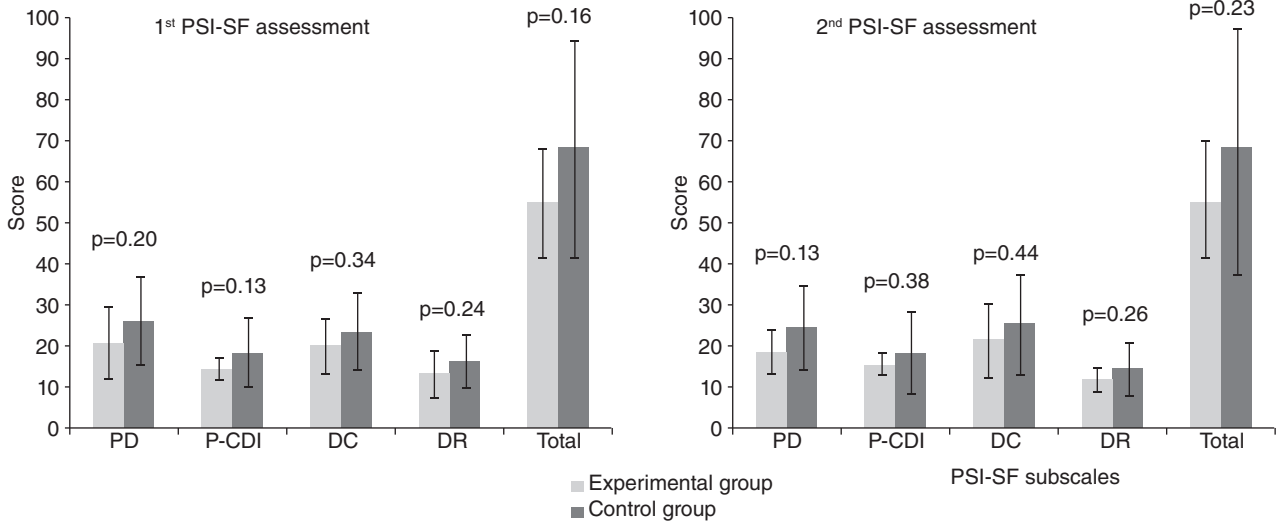
No difference was observed between the PSI-SF results for the experimental and control groups in both the first and second assessments (Figure 1).

The intragroup analysis showed that, for the experimental group, no difference was observed ($p>0.05$) on the total scores and PSI-SF subscales between the first and second assessments (Figure 2). A participant of the experimental group did not participate in the social network and was, therefore, excluded from the analysis. As for the control group, a significant decrease

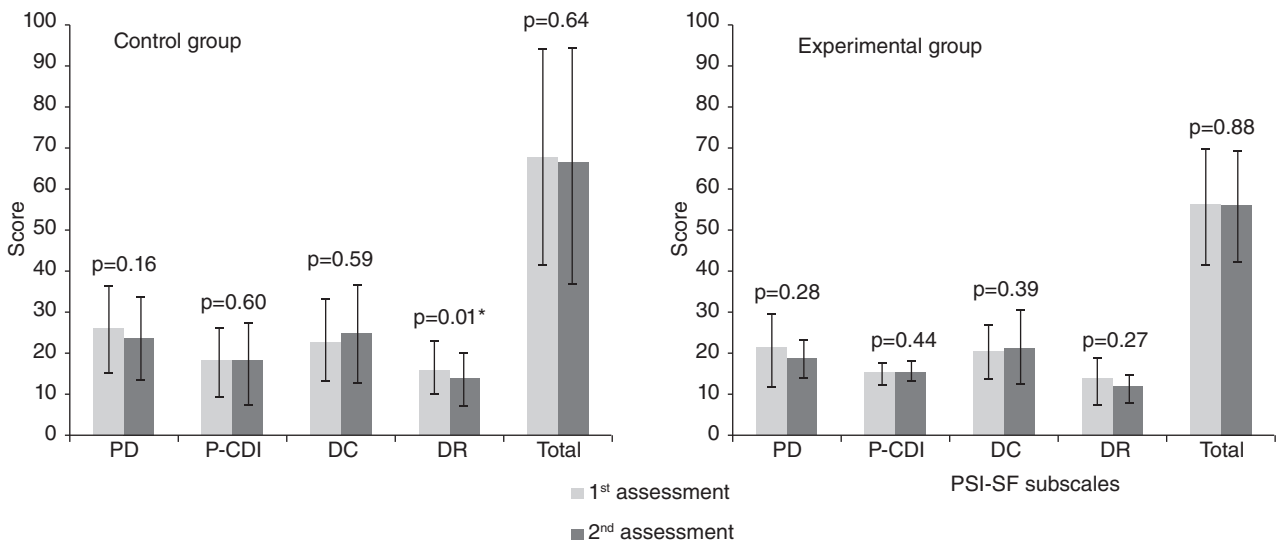
in PSI-SF score was observed only in the subscale “Defensive Response” ($p=0.01$).

Because no difference was observed in the results between the experimental and control groups, the correlations of the results of PSI-SF (first assessment) and sociodemographic variables were calculated for the 22 participants in the study (Table 2).

Regarding participation in the social network “Babies’ Portal,” most of the experimental group participants accessed the network less than once per week ($n=6, 54\%$), with a preference for writing about the matter under discussion ($n=7, 44\%$). They also ranked the interaction with the group as being easy ($n=7, 78\%$). All mothers considered the social network an



Caption: PD = Parental Distress; P-CDI = Parent–Child Dysfunctional Interaction; DC = Difficult Child; DR = Defensive Response
Figure 1. Comparison of the scores of the first and second assessments of the Parental Stress Index – Short Form (PSI-SF) for the experimental and control groups ($n=21$)



* $p<0.05$: statistically significant

Caption: PD = Parental Distress; P-CDI = Parent–Child Dysfunctional Interaction; DC = Difficult Child; DR = Defensive Response
Figure 2. Comparison between the first and second assessments of the Parental Stress Index – Short Form (PSI-SF) for the control group ($n=11$)

Table 2. Correlations between the scores of the Parental Stress Index — Short Form and ages and socioeconomic status of the participants and their children (n=22)

Parental Distress	Parental Distress	Parent-Child Dysfunctional Interaction	Difficult Child	Total
Socioeconomic classification	rho=0.03 p=0.90	rho=0.07 p=0.75	rho=0.25 p=0.25	rho=0.06 p=0.80
Age of the mothers	r=-0.27 p=0.20	r=-0.54 p=0.00*	r=-0.20 p=0.35	r=-0.37 p=0.08
Age of the children	r=0.08 p=0.71	r=0.00 p=0.97	r=0.16 p=0.47	r=0.10 p=0.65

*p<0.05: statistically significant

Caption: rho = Spearman correlation coefficient; r = Pearson's correlation coefficient

important tool and would like to have had greater participation; however, the lack of time was an obstacle (67%).

A variation was observed in the number of total responses for each item because in some questions it was possible to choose more than one alternative. In addition, some questions were not answered by all the participants, as the navigation in this part of the form was not linear. The alternative(s) previously selected determined whether someone would be directed or not to a given question.

Among the positive aspects of the participation in the social network, the participants mentioned, in general, the exchange of experiences with mothers that are going through similar situations, receiving, and providing support:

I loved being able to share things from my child with other people! It is very good to know that there are people that support us (E3 participant).

I have been more peaceful when I communicate with members of the network and expose my difficulty (E7 participant).

As to the negative aspects, the lack of time for greater participation and the small number of mothers that sent comments in a more active way were mentioned.

During the data collection, 234 posts were on the social network “Babies’ Portal,” which were classified by two independent Speech Language Pathologists. A high concordance was observed between them (Kappa=0.89) and, for this reason, one of the classifications was randomly chosen for the descriptive analysis of the posts (Tables 3 and 4).

Concerning the potential disadvantages of asynchronous communication (Table 5), the response time was verified to range from 0 to 12 days (mean of 4 days) and six of the mothers’ questions directed to other mothers were left unanswered.

DISCUSSION

Regarding the first implementation of the PSI-SF, the experimental group was observed to have lower scores than the control group; however, these differences were not significant (Figure 1). The scores of this study were similar to those

Table 3. Frequencies of the topics of the posts published on the social network “Babies’ Portal”

Dimension	n (%)	Total n (%)
Experience with hearing impairment		
Diagnosis	3 (0.8)	153 (39.6)
Symptoms	13 (3.4)	
Treatment – local	25 (6.4)	
Treatment – care	22 (5.7)	
Health professionals	37 (9.6)	
Medicines/devices	53 (13.7)	
Consequences of hearing impairment		
Financial matters	2 (0.5)	64 (16.6)
Professional matters	1 (0.3)	
Social network	13 (3.4)	
Restrictions	4 (1.0)	
Emotions	41 (10.6)	
Housing	3 (0.8)	
Legal matters	–	
Use of substances	–	
Social perceptions	–	
Other comments		
Personal	93 (24.1)	169 (43.8)
Background	4 (1.0)	
Resources	3 (0.8)	
Expressions of faith	20 (5.2)	
Other	49 (12.7)	
Total		

Table 4. Frequency of self-help mechanisms identified in posts published on the social network “Babies’ Portal”

Categories	n (%)
Exchange of experiences	33 (29.2)
Provision of information or advice	17 (15.0)
Request for information or advice	19 (16.8)
Empathy or support	6 (5.3)
Gratitude	21 (18.6)
Friendship	14 (12.4)
Structure	–
Creative expression	2 (1.8)
Negative statements	1 (0.9)
Computer problems	–
Total	113 (100)

Table 5. Frequency of messages on the social network “Babies’ Portal” classified as potential disadvantages

Categories	n (%)
Quality of health information	
Conventional information	91 (91)
Negative comments	
Anxiety	2 (2)
Fear	2 (2)
Frustration	5 (5)
Total	100 (100)

found when the PSI-SF was applied to Brazilian parents of children with typical development and no hearing complaints⁽¹⁰⁾.

Initially, the mean stress levels of participants were expected to be higher. However, the stressors do not interfere in parental functioning uniformly, and some parents can continue with their parenting development and skills. Individual and family factors, such as the psychological characteristics of the father/mother and social support, can work as stress relievers⁽¹⁴⁾. In fact, the results of this study are in agreement with those of PSI-SF for hearing parents of children using CI reported by studies⁽¹⁵⁻¹⁷⁾. Also, no differences in PSI-SF results were found among mothers of children with normal hearing and those with hearing impairment, aged 18–26 months⁽¹⁷⁻¹⁹⁾.

The low levels of stress observed in this study may also be the result of an early diagnosis and intervention^(15,17) because, for most children, hearing impairment was diagnosed before 12 months of age, and all of them were already included in an intervention process at the beginning of data collection (Table 1). The existence of acute periods of parental stress in parents of children with hearing impairment, associated with specific events, for example, the time when the parents receive the results of the hearing screening or audiological diagnosis, is reported in the literature. Such stress may decrease when the family receives support during the stages of diagnosis and intervention⁽¹⁸⁾.

Another hypothesis for the results of Figure 1 is that the PSI-SF measures the overall stress level, and parents of children with hearing impairment may have higher levels of stress contextually associated with this condition, such as stressors related to the difficulties of communication, educational concerns, difficulties to maintain electronic devices, and unsatisfactory relationships with health professionals⁽¹⁹⁻²¹⁾.

It should be noted, however, that, when analyzing the individual responses, 22% participants showed scores above the clinical threshold (85th percentile) in at least one subscale of the PSI-SF. Another study also reported that 16% parents of children using CI obtained PSI-SF scores above the clinical threshold⁽¹⁶⁾. We emphasize that this information was subsequently provided to the professionals at CPA HRAC-USP, with the purpose of offering appropriate intervention.

In the second assessment of PSI-SF (Figure 1), the same data pattern as in the first data collection with this instrument was observed. Again, the experimental group had lower average scores than the control group in all subscales and in the total score; these differences, however, were not significant. Contrary to what was presumed, no measurable effect was

observed in reducing parental stress, intergroup or intragroups, from the participation in the social network “Babies’ Portal.”

When the full version of the PSI was used to compare the effect of participating in a stress-coping program, lasting 2 months, on parents of children with hearing loss, no differences in the results were seen. The authors thought this time frame may not have been enough to produce changes in the patterns of behavior and parent–child interactions that had existed for a long time already⁽²²⁾.

In this study, it is possible to raise some other hypotheses. Initially, it should be noted that the PSI-SF was developed to assess stress within the family context in a comprehensive manner, focusing on general issues of parental anxiety and child’s difficulties. The average stress levels of the participants already resembled the results of children from mothers without hearing complaints and normal development. Thus, the PSI-SF may not have been sensitive enough to capture the parental stress that is specific to the hearing impairment context^(20,21) and, therefore, the effect of participating in the social network.

It should also be remembered that all the participants of this study were included in intervention programs in their hometowns, and this type of intervention, by itself, can reduce parental stress levels^(15,17). Thus, the effect of participation in the social network may have been diluted in the largest effect caused by early intervention. However, to analyze the role of online social networks in an isolated manner in this group, excluding the intervention would be impossible from an ethical point of view.

It was also not possible to control the effect of other systems of aid and support as a resource available for the participants. The parents of children using CI draw support from a variety of interpersonal relationships, both formal (professional) and informal (family and friends), for problem solving and coping with the situation⁽¹⁶⁾. This greater support in the real world decreases the benefit of participating in online groups for hearing impairment⁽⁷⁾.

Finally, the participation of mothers in the social network was also not active, as it will be discussed later. The virtual communities provide a platform for users to establish social relations that may promote self-help mechanisms. However, not all participants take the same advantage of this possibility. The frequency and duration of access and use of the network are indicators of the development of these relations. The individuals that are active in online groups, posting more messages, develop stronger bonds with the group⁽²³⁾. Thus, the number of participants in the network “Babies’ Portal” and the type of relationship developed between them may not have been sufficient so that an effect in the parental stress could be observed.

The intragroup analysis (Figure 2) showed that, for the control group, a statistically significant decrease was observed in score from 16.27 to 13.91 in the subscale “Defensive Response.” Scores lower or equal to 10 in this subscale are considered extremely low and may suggest the respondent is trying to present a more favorable impression of him or herself⁽¹¹⁾. The individual data showed that three (from first assessment) and five (from second assessment) mothers from the control group had lower scores than 10 in the subscale “Defensive Response”.

The design of this study did not allow us to verify if these participants tried to pass an image of great individual competence or whether they were actually dealing competently with their parental responsibilities⁽¹¹⁾.

Regarding the relationship between sociodemographic data of the participants and the scores of the PSI-SF (Table 2), it was observed that, the higher the mother's age, the lower the stress measured on the scale P-CDI. The literature describes similar results⁽¹⁸⁾, attributing this, in part, to a greater parental experience of the mothers. No correlation was observed between socioeconomic level and chronological age of the child with the parental stress.

The limited availability of time was an important factor (67%) pointed out as an obstacle to participate in the social network "Babies' Portal". The lack of time was mentioned in other studies with parents of children with hearing impairment because of the demand for child care in the first years of life^(16,20).

A heterogeneity of the activities undertaken by the participants was observed, with some mothers not being very active on the network. It is common for individuals to play different roles in an online group. At one extreme, there are those that access and carry out activities (message posts, photo uploads, etc.) daily and, at the other end, there is the majority, the so-called "lurkers" (observers) — a term used in the Internet culture to denote those who read the forum discussions, newsgroups, and chats, but rarely or never actively participate⁽²⁴⁾.

The analysis of the activities of parents in the online group "Babycenter.com" showed that only 8.3% participants published posts and comments very actively, and 21% were not active. The parents were also more involved in commenting on the posts made by others than in the starting posts⁽²⁵⁾.

There are several reasons why a person does not participate in the activities of an online group. Just reading the posts may be sufficient for some individuals to feel a part of the group. The passive observation may occur as a strategy in the early periods of participation, so that the individual can understand the dynamics and operating rules of a group. However, individuals who are just observers can extract fewer benefits from participating in social networks. For these reasons, it may be of interest to encourage the participation of observers, for instance, by making changes and improvements in the communication interface or by providing some sort of "mentoring" for new members of the group⁽²⁴⁾.

In this study, different topics for messages were posted by the participants (Table 3). The personal information was the most frequent ones, mainly because the participants initially presented themselves to the other members of the network, reporting some aspects about their family, daily life, and a brief background of the child. We also observed a large number of posted photos accompanying descriptions with personal content.

The analysis of an online group for caregivers of people with mental illness showed that 38% of the posts referred to personal information — information about themselves, their relationship with the person with the disease and updates on life events⁽¹²⁾.

In this study, posts related to the "experience with hearing impairment" also stood out (39.6%), especially the ones

about electronic devices used by the child, the interactions with health-care professionals, and aspects of treatment — for example, the CI surgery. The listening and learning about the rehabilitation was part of the experience of mothers, including situations as answering questions regarding the use of personal sound amplification products or CI and learning new activities with the child in the rehabilitation process⁽⁵⁾.

Similar results were found in the literature. In the online group "Beyond Hearing", the messages focused on various issues about hearing and hearing loss, ranging from recommendations about the IC to complaints about comprehension difficulties by individuals who used lip reading⁽⁷⁾.

In a forum for adults with hearing impairment, 31% messages involved topics about electronic devices for deafness, including the adjustment process for these devices and differences between existing models⁽⁸⁾.

Finally, 16.6% topics of the posts in this study were related to the "hearing impairment consequences", especially regarding emotions — thoughts, feelings, and attitudes, directly or indirectly linked to the experience with hearing loss. Parents of children with cancer also reported as the benefits of participating in a self-help group, based on e-mails, expressing emotions (13.7%) and using writing as a means of communication, making the expression of feelings easier (2.7%)⁽²⁶⁾.

Similarly as with face-to-face support groups, participants in the social network "Babies' Portal" used different self-help mechanisms (Table 4). A higher frequency of personal "exchange of experience", linked to the impact of hearing loss and treatment of their children (29.2%), was observed. One of the advantages of the contact with other parents of children with hearing impairment is the relationship with families that have faced or are facing a similar situation, allowing individuals to explore their own feelings and experiences when it comes to hearing loss and discover they are not the only ones going through this⁽¹⁾. The learning through exchange of experiences and the sharing of feelings, doubts, and anxieties alleviate the suffering of these parents⁽⁴⁾. The sharing of experiences was also the support mechanism most commonly found in online groups for adults with chronic diseases^(13,27) and one of the main benefits of the participation of parents of children with cancer in online groups⁽²⁶⁾.

A high frequency of "gratitude" messages, that is, gratitude messages to other participants for their support, was also observed, as well as the request for or provision of information or advice. In a forum for people with hearing loss, the most frequent mechanism of support (87%) was providing information to an issue or problem in particular and the sharing of experiences⁽⁸⁾.

Regarding "potential disadvantages" of participating in the network "Babies' Portal" (Table 5), the most frequent category was quality of the health information (91%). However, although the participants have exchanged health information (diagnosis, symptoms, and treatment of hearing loss), these were mostly reports of results from tests or procedures performed with their children, being classified as "conventional medical information" (information in accordance with the principles of standard Speech Language/Medical Practice and/or scientific evidence). Thus, they cannot be considered as a disadvantage per se.

The divulgation, to lay individuals, of incorrect or fraudulent information about a disorder, prognosis, and/or treatment is one of the ethical concerns of using online groups. However, on many occasions, such misinformation can be corrected by other members and moderators of the group.

Table 5 also shows that negative comments (9%), such as fear and frustration, were verified. It was reported in the literature⁽¹³⁾ that about 9% of messages in online groups contained negative feelings related to the disease, with sadness being the feeling most frequently expressed.

CONCLUSION

The results of the PSI-SF for mothers of children with hearing loss that were candidates for the CI were similar to those of parents of children with normal hearing. The participation in the online social network “Babies’ Portal” did not change the level of parental stress, measured by the PSI-SF instrument. However, the participants reported benefits from participating in this group, highlighting its importance for exchange of experiences and mutual aid similar to those seen in face-to-face support groups. Owing to its potential benefit, it is extremely important to carry out more studies with online social networks that have a larger number of participants.

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