

Empowering the family during the first months after identification of permanent hearing impairment in children

Rendere competente la famiglia nei primi mesi successivi all'identificazione di una ipoacusia del figlio

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SUMMARY

The latest international guidelines highlight the importance of involving the family in the diagnostic and rehabilitation process of children affected by permanent hearing impairment. This emphasises how meaningful this approach is for the development of the deaf child. So far, there is very little evidence about this approach in Italy, and there are still some barriers to its practical management. The aim of this paper is to report the results of a strategic analysis, which identifies the strengths, weaknesses, opportunities and threats of the family empowerment process during early auditory diagnosis and rehabilitation. The audiology programme should have the goal to offer information and support to families in order to achieve a conscious decision about the use and type of auditory prosthesis and rehabilitation choice within three months after audiological diagnosis. Within the framework of the Ministry of Health project CCM 2013 "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children", a group of professionals identified three main recommendations that can be useful to foster the natural communicative development of the child by strengthening the therapeutic alliance and empowerment of the family. The recommendations obtained with this analysis can help to develop new Italian guidelines with the aim to foster natural communicative development of the child by strengthening the therapeutic alliance and empowerment of the family.

KEY WORDS: Childhood hearing loss • Early audiological intervention • Interdisciplinary collaboration • Parental empowerment • SWOT analysis

RIASSUNTO

Nelle più recenti linee guida internazionali sull'intervento precoce in audiologia pediatrica emerge l'importanza del coinvolgimento della famiglia nel percorso diagnostico-riabilitativo del bambino con deficit uditivo permanente. Questa modalità di approccio costituisce una ricchezza per lo sviluppo dei bambini con deficit uditivo. Vi sono ad oggi poche evidenze del panorama italiano rispetto a questo ambito e rimangono aperte perplessità e difficoltà di gestione pratica. L'obiettivo di questo articolo è presentare i risultati di un'analisi strategica che prende in considerazione i punti di forza, i punti di debolezza, le opportunità e i rischi di una presa in carico precoce che renda competente la famiglia. Le iniziali fasi della presa in carico devono fornire alle famiglie di bambini con recente diagnosi di ipoacusia permanente le informazioni e/o il sostegno necessario al fine di indurle a compiere la scelta del dispositivo protesico uditivo più idoneo, entro tre mesi dalla diagnosi audiologica. Nell'ambito del progetto del Ministero della Salute CCM 2013 "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" un gruppo di esperti ha identificato tre principali raccomandazioni utili per migliorare lo sviluppo comunicativo del bambino attraverso il coinvolgimento della famiglia e il rafforzamento dell'alleanza terapeutica. Queste considerazioni costituiranno il punto di partenza per riflessioni e analisi più dettagliate che potranno dare luce a linee guida e indicazioni specifiche su come buone prassi di presa in carico di bambino con deficit uditivo e famiglia possano inserirsi e concretizzarsi nel reale panorama italiano.

PAROLE CHIAVE: Ipoacusia infantile • Intervento audiologico precoce • Collaborazione interdisciplinare • Empowerment familiare • Analisi SWOT

Acta Otorhinolaryngol Ital 2016;36:64-70

Introduction

The implementation of the universal newborn hearing screening (UNHS) has allowed for early identification and treatment of permanent hearing impairment (PHI). In the first months after diagnosis, the family of a deaf child

is involved by the audiological team of professionals in making relevant and awkward health choices, i.e. the application of hearing aids or cochlear implantation. Several issues are related with management and emotional issues noticed by professionals and caregivers in the first 3 months after identification of the PHI. Among these are

emotional issues of parents/caregivers after diagnosis; issues related to the communication of diagnosis or related to multiple consultations among referral centres; the role of the rehabilitation professionals or how to communicate with parents/caregivers.

According to the current guidelines of the Joint Committee on Infant Hearing (JCIH), it is essential to coach parents to have a conscious and active role in the auditory, speech and language rehabilitation of the hearing impaired child¹⁻⁶. Empowerment practices are effective in supporting the families of children⁷⁻¹⁰. Moreover, the self-perception of parents to efficiently take part in the rehabilitation programme can improve language outcomes²⁻⁵. High levels of family support can dramatically improve the language development of the impaired child. In this family-centred perspective, the teamwork of a multidisciplinary group of professionals with skills in developmental neuropsychology and family mentoring is of utmost importance. Even if several paediatric audiology services are embracing this model, a systematic approach to the family-centred rehabilitation of the deaf child is not widespread. In the framework of the Italian Ministry of Health project CCM 2013 “Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children”, a multidisciplinary team of professionals carried out a strategic analysis with the specific aim to provide a preliminary set of recommendations to coordinate professional activities that involve and empower families in the first three months after PHI identification in children.

Materials and methods

In the initial phase, positive and negative considerations of current rehabilitation programs were explored with an open-ended questionnaire administered to parents and territorial rehabilitation professionals. Questionnaires were administered prospectively during 10 days in the third level centres of Audiology at Trieste, Pisa and Rome. Inclusion criteria for parents were: a) children affected by non-syndromic PHI, either congenital or acquired, whatever the type and severity; b) Italian native language, to avoid language barrier bias. The results of the questionnaires were discussed by a group of professionals working in tertiary care referral centres for childhood PHI. Professionals reported at least 2 strengths, weaknesses, opportunities, and threats for use in strategic planning. This phase was carried out using the principles of SWOT analysis. The acronym SWOT stands for Strength (S), Weaknesses (W), Opportunities (O) and Threats (T), and corresponds to what the comments of the participants have pointed out. The responses obtained were reviewed by the specialists responsible for this area. To generate recommendations from the

SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organization or programme¹¹⁻¹². The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue. The study and the survey was focused on this specific aim: coordinate professional activities that involve and empower families in the first three months after PHI identification in children.

Results

Twenty-five consecutive families of children affected by PHI were enrolled. All patients had been referred to the tertiary care centre after having completed the PHI identification work-up. On the basis of inclusion criteria, 2 families were excluded, because of foreign mother language ($n = 1$), or because of syndromic habitus ($n = 1$). The severity of PHI in the study population is reported in Table I. The rehabilitation professionals study group was composed of 25 participants (Table II). The 231 open-ended answers ($S = 66$, $W = 62$, $O = 53$, $T = 50$) were reviewed by the authors and grouped in main key points (Table III).

Strength key points analysis

Multidisciplinary working group

In the experts' opinion, the strength of a supportive working group is related to the multidisciplinary competences of its members ($n = 9$). Among them, the presence of a psychologist and/or a counsellor is requested ($n = 9$). Specific skills (e.g. paediatric audiology, children care, family mentoring) are encouraged ($n = 7$), along with effective communication strategies ($n = 6$).

Table I. Severity of PHI in the study population.

Severity of PHI	N
Bilateral severe-to-profound	12
mild-to-moderate	8
Unilateral severe-to-profound	3

Table II. Roles of rehabilitation professionals ($n = 25$) involved in the survey.

Professional role	N
Otolaryngologist/Physician in Audiology	5
Audiologist	
clinical audiometry duties	8
hearing aids/cochlear implant fitting	1
Speech and language therapist	6
Cochlear implant technical specialist	2
Psychologist	1
Primary care paediatrician	2

Table III. Main key points extrapolated from questionnaires.**Table IIIa.** *Strengths.*

Strength key points	N (%)
Multidisciplinary working group	31 (47.5)
Efficient family involvement	16 (23.5)
Strong connection with external networks of care	8 (12)
Tertiary care proficiency and accessibility	5 (8)
Other	6 (9)

Table IIIb. *Weaknesses.*

Weakness key points	n (%)
Inadequate funding opportunities	21 (33)
Inefficient working group	18 (30)
Weak connection with external networks of care	12 (19)
Lack of multidisciplinary continuing education	11 (1)

Table IIIc. *Opportunities.*

Opportunity key points	n (%)
Empowered connection with external networks of care (e.g. web-based technologies)	21 (39)
Strengthen counseling for the caregivers	18 (34)
Multidisciplinary continuing education opportunities	11 (21)
Other	3 (6)

Table III d. *Threats.*

Threats key points	n (%)
Conflicts inside the working group	16 (32)
Increasing multiculturalism	14 (28)
Inadequate funding opportunities	12 (24)
Non-homogeneous competences among professionals with similar roles	6 (12)
Other	2 (4)

Efficient family involvement in the rehabilitation programme

In order to engage the family in the diagnostic and rehabilitation process, valid counseling (n = 7), the enrolment of the whole family in an active care process (n = 5) and the coordination of meetings involving groups of families (n = 4) were deemed to be of utmost importance. A professional can either lead family meetings, or can be self-managed by families.

Strong connection with networks of care

This field focuses on the development of strong connections among caregivers in order to improve the support to families in every step of the diagnostic and rehabilitation process, i.e. logistics, psychological support, opportunity to share experiences. Efficient collaboration with deaf associations (n = 5) and networking among hospitals, schools and family doctors (n = 3) are included.

Tertiary care proficiency and accessibility

This category includes the answers that consider good organisation of services, with adequate facilities for specific kinds of care (n = 3), i.e. medical visits and counseling appointments, short waiting lists, dedicated administrative staff (n = 2) that endorse easy connections with caregivers and make appointments efficiently.

There were 6 unspecified strength key points suggested by the respondents.

Weakness key points analysis

Inadequate funding opportunities

Inadequate funding can have an impact on most of aspects of family support. Long waiting lists and crowded clinics with short time-per-visit (n = 8), poor facilities for adequate counseling (n = 5), reduced staff (n = 4) can be consequences of inadequate resources. Dedicated administrative offices can also be unavailable due to funding restrictions (n = 4).

Inefficient working group

This group includes issues about the efficiency of the working group. Absence of a counsellor/psychologist with competence in the field of audiology and absence of a supportive team were considered of great importance (n = 11). The working group can be affected by organisational issues (n = 7), i.e. ambiguous competence assignment, uneven sharing of information and lack of working meetings, leading to incoherent information given to families.

Weak connection with external networks of care

A strong and efficient network can be compromised by inefficient physical connections between the tertiary referral centre and the other caregivers, schools or families (n = 8). Connections are even weaker with families living far from the audiological referral centre (n = 4).

Lack of multidisciplinary continuing education

Continuing education with a multidisciplinary approach can be a big issue in the field of audiological rehabilitation, with particular reference to efficient communication (among caregivers with different competences and between caregivers and families), and competent care of very young children (n = 11).

Opportunities key points analysis

Empowered connection with external networks of care (e.g. web-based technologies)

Empowerment of connection with external networks of care was reported to be a great opportunity, i.e. through web-based technologies, videoconferences, shared data-

bases, distance mentoring and distance learning (n = 17). Collaboration with associations that offer support to families of deaf children, including logistic management, can be improved (n = 4).

Strengthen counseling for caregivers

This category includes opportunities to strengthen counseling that is systematic and well integrated in the diagnostic and rehabilitative process, for either information or support. Moreover, it is important to sustain and increase the involvement of families in the recovery path, and to organise mutual-help groups (n = 10). The provision of reliable informative material, such as pamphlets and social network sites, with a family-oriented language and readily accessible, can make them more competent and prepared regarding the needs during the first months after diagnosis of PHI in their child (n = 8).

Shared formation for operators.

In this category the answers regarding education for operators was included, especially shared formation for healthcare professionals who deal with paediatric PHI, with sessions combining formation and discussion dedicated to single groups, and advanced courses in counseling techniques (n = 11).

Other answers were uncategorised (n = 3).

Threats key points analysis

Conflicts inside the working group

In this category the themes concerning a group without a counsellor/psychologist, or where the members didn't provide the correct degree of importance to family's support were included (n = 11). In view of the increasing reliance on family support, the absence of a counsellor becomes very problematic. Other issues undermining the group's efficiency arose from poor integration and communication among caregivers, and from disengagement of the family paediatrician (n = 5).

Extraterritoriality and multiculturalism

Difficulties related to management of families whose hometown is far from the audiology referral centre were reported. The answers focused on the difficulties to build a systematic communication network with healthcare services from the patient's hometown, and on management and organisation of control visits necessitating more than one day stay (n = 8). The interaction with users from different cultures was considered even more difficult, where cultural and linguistic barriers are a serious obstacle for family counseling (n = 6).

Lack of funds

This category includes answers concerning the lack of funds and projects aimed at audiology and counseling,

with subsequent reduced staff, long waiting lists and scarcity of funds for research projects (n = 12).

Differences in formation for healthcare operators

This category contains the answers regarding the lack of shared formation and continuing education, for all the operators involved in paediatric audiology, particularly for counsellors and psychologists (n = 3). Many information sources for both operators and parents lack reliability and can cause confusion and false beliefs (n = 3).

Other answers in this area were unspecified (n = 2).

Discussion

Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats, Weaknesses-Opportunities. Analysing and discussing the data obtained from this research, 10 recommendations were obtained (Table IV). These recommendations can represent basis for tertiary care audiology centres to optimise resources and generate positive changes. Finally, three main themes or main recommendation were recognised that contribute to good family support during the first months after PHI diagnosis. These themes are:

- presence of a multidisciplinary team with adequate shared education and training;
- active involvement of families, with adequate informative material;
- building a good interchange net between the tertiary care referral centre and the territory.

American Guidelines for paediatric audiology give great importance to the professional qualifications needed to ensure timely action centred on the family, from birth to three years of age. The formation and continuing education of professionals are also deemed important to ensure a competent working group⁵⁶. The first recommendation is then to ensure the presence of all healthcare professionals, which are important for a timely diagnosis and treatment of the child with PHI, such as the audiologist, oto(rhinolaryngo)logist, speech and language pathologist, counsellor-psychologist expert in PHI and technical specialist (for hearing aids and cochlear implants).

Shared formation and continuing education meetings must be implemented to allow for exchange opinions and integration of knowledge coming from different approaches to the same condition. A team where part of the specific formation is shared permits to favour teamwork and better define roles. This operative method allows giving parents information that is coherent and clear, to grant them a complete understanding of their child's condition, easing trust in the referral centre and reducing the need for consulting other opinions. Allowing the

Table IV. TOWS matrix (see text for explanation).

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	SO strategy 1. To create an efficient and multidisciplinary team with adequate shared formation, inserted in a well-organised service 2. To involve families through systematic counselling and providing adequate informative material 3. Building a network with the territory, with better links with the territory and deaf patient associations	WO strategy 1. Implementing the family counselling to foster a therapeutic alliance that could also form a bridge between tertiary care centre and territory 2. Organising advanced formation and continuing education events where the whole team can take part, so that the family would perceive equity, up to date information and continuity of the cure.
	Threats (T)	ST strategy 1. Having an effective multidisciplinary team, with formative objectives that are clear and to be pursued as a group, where each member has a correct and defined role 2. To involve families and create a network within the territory to minimise problems related to extraterritoriality and multiculturalism 3. Having efficient organisation of the services allows optimising the available funds	WT strategy 1. Reinforcing interactions with national healthcare institutions and structures that support the families, especially with extraterritoriality and different cultures 2. To sensitise healthcare institutions and organisations to assign funds to the team, its projects and continuing education.

team to work in a well-organised structure, with a dedicated administrative staff and adequate personnel, grants the ability to optimise case management. Lack of funds or absence of specific formation courses for the entire team is a major threat for this purpose. It is desirable to create awareness programmes aimed at institutions and healthcare organisations to prompt them to invest in timely and multidisciplinary approach to the child’s condition, to ensure that the team is efficient and constantly up to date ^{2 5 6 13-15}.

The second recommendation is the need to incorporate, especially in the diagnostic phase, counselling for the family to ensure an action of identification, intervention and caretaking of the hearing impaired child centred on the family. The family should be accompanied, supported and informed to be able to make the best choices for their child, in a family-and-child centred manner ¹⁵⁻¹⁷.

Counselling is regarded internationally as a process that, through dialogue and interaction, provides support, guidance and supervision in the diagnosis-rehabilitation route. The fundamental characteristic is that the counselling is focused, in terms of time and work-space, to the current medical condition.

In audiological counselling, the two main aspects are:

- a) support counselling, which is necessary to empower, develop correct coping strategies, overcome critical passages tied to the current medical condition, maximise resources, expectations and issues, explore the impact that PHI has on daily living and develop empathic reactions to emotional stress ¹⁵⁻¹⁸;
- b) informative counselling, which is dedicated to all the information to be provided to the patient and his/her family. All healthcare workers are involved in this step, especially those who have, as a fundamental part of their work, a role in communication of information. Among these professionals: the medical audiologist/

otorhinolaryngologist (to communicate diagnosis, follow-up the patient, coordinate the entire process, etc.), technical audiologist (for explaining to parents the operations and characteristics of the different tests, depending on the age), technical specialists (to give information regarding technical features and maintenance of the hearing aid devices) and speech and language therapist (who explains to parents the hearing and speech development status, the purpose and methods of rehabilitation, etc.) ^{15 17 18}.

Recent studies have demonstrated that it is necessary to make the parents of the deaf child active components in the rehabilitation process, supporting them and helping them understand that their role is crucial in the success of rehabilitation ^{15 16}. Evidence on the efficacy of empowerment practices that can support the hearing impaired children’s families have been shown in several clinical investigations that show how the feeling of self-efficacy in parents during cure and management of the child’s hearing impairment can have a positive effect on the child’s language development ^{15 17 21-24}.

The recommendations identified herein are sustained by the indications of JCIH that stress the importance of ensuring that families receive complete and accurate information about the child’s development, play an active role in screening and precocious treatment, and, more broadly, that family and child are involved in treatment that promotes the family’s quality of life, favouring the development of hearing and communicative skills ^{2 5 6 15 17}.

Parents who are competent in managing the child’s PHI and in the therapeutic process aids in minimising extraterritoriality and multiculturalism problems. Good family counselling is establishing a line of direct communication between families and tertiary care referral centres, and building, if necessary, an indirect line of communication with the territory and with different cultures.

In research on the perceived problems of integration of the counselling in the busy activity of an audiology service, English reported that the staff perceives that it is easy to implement counselling activity, without negative consequences on time schedules²⁵.

Many informative pamphlets and brochures exist on paediatric PHI, but sometimes, if given to an unaware parent, they may give rise to confusion (also considering that they may not be in line with current services and practices). It is necessary to have informative material originating from reliable and traceable sources, which can give a valid and exhaustive vision of the problem, from all viewpoints, which is coherent and tailored on the organisation the family will rely on¹⁸.

The third recommendation is to ease the exchange of information among the tertiary care referral centre and territorial centres, using new communication technologies such as videoconferences, distance mentoring, shared databases and informative internet sites with the option to selectively access specific projects, with easy access to early diagnosis and rehabilitation programmes. Another critical facet to obtain a good network of care is the synergic collaboration with deaf associations. To this endpoint, the American guidelines recommend to develop a mechanism that ensures to the family the access to all the resources and informations available, in an accurate, global and impartial way (manuals, websites, associations/national organisations), from the birth to the start of an early treatment programme^{5,6}.

The conclusion is that, to focus on the three main recommendations, it is necessary to have a service with an efficient organisation, a dedicated administrative office, adequate personnel (either staff or skills), this also provides the chance to optimise available funds and invest them to achieve better results, instead of establishing only a minimum standard of quality.

Conclusions

In the field of family support up to three months after identification of paediatric PHI, three main recommendations have been developed, i.e. the presence of a multidisciplinary team with a common basis of knowledge, active involvement of families with adequate information support and strong connections between the tertiary care service and external networks of care. This approach is endorsed by the current international guidelines on paediatric audiology.

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Received: October 26, 2015 - Accepted: November 30, 2015

Acknowledgments

The authors wish to thank all participants in SWOT analysis, i.e. the professional teams of the following Italian tertiary care centres: Audiology and Otolaryngology Unit, Institute for Maternal and Child Health - IRCCS “Burlo Garofolo” – Trieste; Operative Unit of Otorhinolaryngology, Audiology and Phoniatrics, University of Pisa; Department of Head and Neck Surgery, Department of Head and Neck Surgery – Otorhinolaryngology Catholic University of the Sacred Heart “A. Gemelli” Hospital, Rome; Otorhinolaryngology Clinic, University of Perugia, Perugia; Otology and Cochlear Implant Unit, Santobono-Pausilipon Children’s Hospital, Naples. Special thanks must be given for the warm hospitality offered to carry out SWOT analysis at the Gemelli Hospital in Rome.

The group of professionals would like to acknowledge also Mr. Mariottini and Mr. Maggesi, parents and members of FIADDA, Italy; Dr. Paola Bolzonello and all the professionals from the Service of Audiology, Azienda per l’Assistenza Sanitaria n.5 “Friuli Occidentale”, Pordenone, Italy and Dr. Franca Ruta from the Audiology Regional Network of Family Paediatricians, Friuli Venezia Giulia.

Authors are grateful to all the hearing care professionals that participated to the SWOT analysis on early hearing aid fitting Drs: Caregnato, Peri, Capellupo, Comin, De Carlini, Di Donato, Borghi, Pinatti-Pontoni, Vivarelli, Germano.

Finally, authors would like to acknowledge the following cochlear implant technical Ing. specialists: Conni, Terragni, Aragri for helpful advices. Special thanks to Dr. Marco Marcato and Dr. Giovanni Lenzi for helpful advices.

Funding

This research was supported by project CCM 2013 “Preventing Communication Disorders: a Regional Program for early Identification, Intervention and Care of Hearing Impaired Children” by the Italian Ministry of Health.