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Early care in children with permanent hearing impairment

Presa in carico precoce del bambino ipoacusico

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SUMMARY

The implementation of regional protocols for newborn hearing screening and early audiologic diagnosis represent the first step of the entire diagnostic, rehabilitative and prosthetic programme for children with permanent hearing impairment. The maximum benefit of early diagnosis can indeed be obtained only by prompt rehabilitation aimed at fostering the child's communicative, linguistic and cognitive development. Within the framework of the CMM 2013 project of the Ministry of Health entitled "Preventing Communication Disorders: a Regional Program for Early Identification, Intervention and Care of Hearing Impaired Children", the problems concerning the promotion of the global development of children with PHI throughan early rehabilitation project based on shared knowledge and scientific evidence. In this project, our specific aim was to define the features and modes of access to a precise and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis. Three main recommendations relative to assessment and rehabilitation aspects of early care emerged from the study.

KEY WORDS: Early care • Childhood permanent hearing impairment • Auditory rehabilitation • SWOT analysis

RIASSUNTO

La messa a punto di protocolli regionali di screening audiologico neonatale e la diagnosi audiologica precoce rappresentano il primo passo dell'intero percorso diagnostico, protesico e riabilitativo a cui deve sottoporsi un bambino ipoacusico. Il massimo beneficio di una diagnosi precoce può essere ottenuto solo con una presa in carico riabilitativa tempestiva finalizzata a promuovere lo sviluppo comunicativo-linguistico e cognitivo del bambino. Nell'ambito del progetto del Ministero della Salute CCM 2013 "Programma regionale di identificazione, intervento e presa in carico precoce per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" è stata affrontata l'attuale modalità di presa in carico precoce del bambino ipoacusico in Italia e la promozione del suo sviluppo globale basate su un progetto riabilitativo fondato su evidenze scientifiche. All'interno del progetto il nostro obiettivo specifico è stato quello di definire le caratteristiche e le modalità di accesso ad un progetto riabilitativo specifico e specializzato per il bambino ipoacusico piccolo entro 3 mesi dalla diagnosi audiologica. Dall'analisi effettuata sono emerse tre principali raccomandazioni relative agli aspetti valutativi e riabilitativi della presa in carico precoce.

PAROLE CHIAVE: *Presa in carico precoce • Ipoacusia infantile • Riabilitazione audiologica • Analisi SWOT*

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Introduction

The implementation of regional protocols for newborn hearing screening and early audiologic diagnosis represent the first step of the entire diagnostic, rehabilitative and prosthetic programme for the child with permanent hearing impairment (PHI). The maximum benefit of early diagnosis can be obtained only by prompt rehabilitation care aimed at fostering the child's communicative, linguistic and cognitive development.

According to the guidelines laid down by the Joint Committee on Infant Hearing of 2007 [1] and confirmed in the recent Supplement of 2013 [2], diagnosis of PHI and the activation of an early rehabilitation prosthetic intervention must take place within the first 6 months of life. Prompt intervention is aimed at favouring functional substrate necessary to verbal communication development and at promoting the development of the basic perceptive abilities [3]. A direct relation exists between early care (diagnosis and intervention) and the progress of the disability. The first months of life are decisive for developing the fundamental processes of the child's growth, especially for those children with a sensorial congenital deficit. The specific environmental inputs (sensorial, linguistic, social, emotional) for the development of the various functions (cognitive, motor, linguistic, perceptive, etc.) stimulate

the child's development, especially when there is greater plasticity. Understimulation by the peripheral nervous system may impoverish the cortical areas dedicated to a specific function, resulting in a colonisation of these areas by neuronal tissue devoted to different competences. It has been shown that these effects are strictly correlated both to the duration of sensory deprivation and to the biological age of the subject. In case of congenital neurosensory hearing loss, the temporal areas designed to process auditory stimulation may undergo considerable manipulation due to inappropriate stimulation, with important consequences for both the perceptive and communicative-linguistic development of the child [4].

In the light of these considerations, it is evident that a diagnostic-rehabilitative-prosthetic programme can produce the greatest benefits only when it is performed with extreme precocity. In parallel with prosthetic treatment, it is essential to start an early rehabilitation programme aimed at developing and enhancing the perceptive and communication-linguistic abilities of the impaired child. "Rehabilitation is a problem-solving process and an educational process, during which a person reaches the best quality of life at a physical, functional, social and emotional level". (Guidelines of the Ministry of Health for Rehabilitation Activities, 1998). The features of rehabilitation vary on the basis of the patient's functional profile, and therefore early, multidisciplinary and global care is required.

Global intervention consists in getting involved not only the child but also the family, starting from the very first phases. Many authors have confirmed that the quantity and quality of maternal stimulations influence considerably the linguistic abilities reached by small children with cochlear implants [5-9]. Tobey et al. (2012) have recently demonstrated that hearing impaired children for whom care started immediately (before 12 months of age) and whose parents integrally participate in the rehabilitation process at 5 years, reach better linguistic performance than those involved later [10]. When the child is taken into rehabilitative care, the family must be appropriately informed and trained with regards to the different therapeutic proposals and possible objectives that can be attained. After defining the features of the intervention, the team members will need to share the specific treatment programme with the family using clear and transparent communication.

One of the main objectives of early speech therapy treatment addressed to hearing impaired children is to stimulate the development of their perceptive abilities. Within the rehabilitation project the therapist must plan and realise customised perceptive training targeted to the enhancement of auditory attention and to the development of complex perceptive abilities [11]. Within the rehabilitation project, information counseling will allow the therapist to inform the parents on the child's difficulties caused by sensory deficits; the activity will also foster the emergence of types of behaviour that can help the child enhance auditory attention and achieve increasingly complex perceptive abilities. Another important objective of rehabilitation is to favour communicative-linguistic development. The communication aims will be different according to the age of the child.

Early care is therefore essential for the good success of an audiologic and rehabilitation protocol whose aim is to achieve optimal global development. From the very early phases of the diagnostic program the child faces different specialists who coordinate their efforts to achieve common objectives. The multidisciplinary team rotates around the needs of the child and the family; therefore, the professionals of the team can change according to the specific requirements (e.g. patients with multiple disabilities). The multidisciplinary team is generally formed of physicians (neonatologists, otolaryngologists, audiologists, family paediatricians, neuropsychiatrists), technicians and therapists (audiometrists, hearing aids specialist, psychologists, speech therapists), school operators (curricular teacher, assistant teacher, communication assistant) and social workers. In order to guarantee optimal care, all team members need to possess a basic background of knowledge concerning physiological and pathological development [1 2]. The implementation of guidelines could represent a valid solution to standardise this knowledge and to structure a control system ensuring quality of treatment to patients.

To date, numerous studies and systematic reviews are available in the literature concerning the perceptive and communicative-linguistic outcomes in hearing-impaired children [4]. These allowed to outline the probable evolutionary lines, but unfortunately only a few systematic reviews exist on the treatment approaches and their efficacy. One of the general objectives of the project of the Italian Ministry of Health is to favour the global development of children with hearing loss through an early rehabilitation project and the activation of assessment and rehabilitation protocols based on scientific evidence and shared knowledge. In this respect, a preliminary strategic analysis has been established. To investigate positive and negative issues in early rehabilitation care for PHI children, the study was carried out by a multidisciplinary group and specifically aimed at defining the features and modes of access to a tailored and specialised rehabilitation project for the small hearing-impaired child within three months from audiologic diagnosis.

Materials and methods

In order to facilitate the collection of information for strategic analysis of early care, a questionnaire was developed to assess the positive and negative aspects of the protocols and programmes of diagnosis and early treatment of pre-lingual child hearing impairment currently available at our Unit. The questionnaire was then distributed among the

families whose children are being treated at the Operative Unit of Otorhinolaryngology, Audiology and Phoniatrics, University of Pisa, and a group of operators belonging to or collaborating with our Unit (otolaryngologist, audiologist, speech therapists, audiometrist, hearing aid specialist, neuropsychiatrist, paediatrician). The families and operators were informed on the objectives and modes of the research, and gave their consent to participate in the project.

Twenty families of children with different types of permanent impaired hearing were involved in the study, and in particular 13 with profound bilateral sensorineural PHI, 7 with severe bilateral sensorineural PHI, along with 12 healthcare workers (3 otolaryngologists, 3 audiometrists, 3 speech therapists, 1 paediatrician, 1 neuropsychiatrist and 1 hearing aids specialist).

The questionnaire was structured in two specular versions: one for the operators and the other for the families. Both versions included 31 multiple-choice questions concerning multidisciplinary rehabilitation care after audiologic diagnosis. More precisely, the questions concerned the management of the child by the several involved professionals (audiologist, neuropsychiatrist/psychologist, speech therapists, and other therapists belonging to the team). In the final part of the questionnaire, parents and operators were also asked to list what they considered as the strong and weak points of the programme.

The questionnaire examines the following topics in detail: specialist assessment (audiologic, logopedic, neuropsychiatric/neuropsychological); planning of follow-ups and modes of communication concerning clinical test outcomes and observations to the family (interviews and/or written medical reports); subjective perception of the parent in relation to the level of involvement within the rehabilitation project: times of inclusion, frequency and modes of speech therapy treatment (cyclical/continuous therapies, participation/or not of the parent during the session); structures (hospital/territory, healthcare centres, public and private hospital systems); involvement of other professional figures in the rehabilitation project; level of school assistance, parents' enrolment in associations and sharing of opinions among families with impaired-hearing children; qualitative assessment on the general organisation of the service (waiting times, respect of privacy, access to ambiences).

The data were useful to the working groups to form items that drove SWOT analysis and the successive TOWS matrix. For a review of the SWOT methodology, see the work by White and Blaiser (2011) [10 11] or, more specifically, the introductory article of this volume.

Results

This article concerns the topics related to SWOT analysis, the successive study performed by the working group that examined the questionnaire and the final TOWS analysis based on the results obtained by SWOT analysis.

Table I. Main key-points extrapolated from the questionnaires

Table Ia. *Strengths.*

Strength key points	Frequency (%) n = 40
Early rehabilitation prosthetic diagnostic intervention	20 (50%)
Involvement of the family in the rehabilitation treatment project	10 (25%)
Multidisciplinary collaboration	9 (22.5%)
Other	1 (2.5%)

Table Ib. *Weaknesses.*

Weakness key points	Frequency (%) n = 48
Absence of protocols of speech therapy rehabilitation	15 (31.5%)
Difficult communication network between third-level centre and territory	13 (27.08%)
Lack of standardisation in early rehabilitation care	11 (22.91%)
Absence of assessment and follow-up protocols	6 (12.5%)
Other	3 (6.25%)

Table Ic. *Opportunity.*

Opportunity key points	Frequency (%) n = 36
Implementation of shared assessment and rehabilitation protocols	19 (52.7%)
Specific training on early care of the child with PHI	11 (30.55%)
Activation of an efficient communication network among the professionals involved in early care of the hearing impaired child	6 (16.66%)

Table Id. *Threats.*

Threats key points	Frequency (%) n = 40
Variability in the assessment and rehabilitation process	17 (42.5%)
Resources	13 (32.5%)
Inefficient communication among operators	5 (12.5%)
Other	5 (12.5%)

Table I (a b c d) The table shows the frequency of the topics emerged in the categories Strength, Weakness, Opportunity and Threat. (n=164)

From the working group a total of 40 replies were obtained for category S, 48 for category W, 36 for category O and 40 for category T, for a total of 164 replies. These data were then grouped according to type and area of reference. The topics obtained are listed in Table I.

Strength key points analysis

From the overall SWOT analysis, 3 principal topics emerged, which represent the Strengths characterising the area of early care: implementation of early rehabilitation prosthetic intervention (50%), involvement of families in therapeutic rehabilitation (25%) and presence of multidisciplinary collaboration (22.5%) (Table Ia).

The above-mentioned strengths can be analysed in further detail:

Implementation of early prosthetic rehabilitation intervention
This category includes all the replies concerning activation of early intervention including diagnosis, first prosthesis and rehabilitation care. The possibility of starting rehabilitation care at the third-level audiologic centres was seen as a strength to favour early intervention.

Involvement of families in the rehabilitation project
This category includes all the replies concerning the need for family involvement in the therapeutic and rehabilitation project for the child. Transparent sharing of the rehabilitation objectives established by the multidisciplinary group can help the family understand better the methods that will be used, thus fostering the process of generalisation in everyday life. In order to increase the competence and awareness of the parents with regards to the strengths and weaknesses of their child, it is generally better if the caregiver participates in speech therapy sessions (unless contraindicated for any particular reason).

Efficient multidisciplinary collaboration
This category includes all the replies concerning care of the child by the multidisciplinary team. All the members of the team should have specific training in psycho-physical and communicative-linguistic development of the hearing-impaired child. For the multidisciplinary care to be optimal, there needs to be an active collaboration among all the professional figures involved. The possibility of monitoring the development of the child in its entirety by periodical follow-ups allows to determine if the child as a whole is in line with the normal developmental profile and to intervene promptly in case the child is not.

Weakness key points analysis
From the analysis of the overall SWOT, 4 main topics emerged, which represent the weaknesses characterising the area of early care: absence of shared rehabilitation protocols (31.5%), inefficient communication between the implantation centre and the territory (27.8%), lack of standardisation in rehabilitation care (22.91%), absence of shared assessment and follow-up protocols (12.5%) and other (6.25%) (Table Ib). All the weaknessess mentioned above can be analysed in further detail:

Absence of shared speech therapy rehabilitation protocols
This category includes all the replies concerning the lack of shared speech therapy rehabilitation protocols. No standardised methods were used for speech therapy rehabilitation adopted within the same type of approach (e.g. oralist approach), nor were any guidelines or official recommendations that could provide uniformity to the various interventions. The presence of different methods may be associated with the lack of shared rehabilitation objectives (e.g. different aims between the audiologic centre and the territory).

Difficult communication network between third-level centre and territory
This category includes all the replies concerning the difficulties in training and maintaining efficient communication networks between the third-level audiologic centre and the rehabilitation structure taking the child into care (territory, structure operating within the national healthcare service/private system). It emerges that communication is often fragmentary, inconstant and unidirectional, which makes it incompatible with the overall programme.

Lack of standardisation in early rehabilitative care
This category includes all the replies concerning the lack of standardisation in early rehabilitative care. No unanimous consensus exists on the categories of patients to be included in a programme of early speech therapy rehabilitation. The weaknesses reported are referred to the scarce lack of systematic protocols when caring for children with mild and moderate PHI and monolateral PHI. Another element included in this category of replies regards the fact that the structures intended for very early care are not being clearly identified (third-level centres? Territory?).

Absence of shared assessment and follow-up protocols
This category includes all the replies concerning the lack of shared assessment and follow-up protocols among the audiologic centres, territorial structures, between the audiologic and different rehabilitation centres (e,g. patients with multiple disabilities who need various therapies). The lack of standardisation concerns several aspects: the areas to investigate during assessment (cognitive, emotional-affective, motor, communicative-linguistic, auditory and perceptive), the assessment tools to be used (variability of test batteries) and follow-up times.

Opportunities key points analysis
From the analysis of the overall SWOT table, three main topics emerged, which represent the opportunities characterising the area of early care: implementation of shared assessment and rehabilitation protocols (52.7%), specific training on early care of the child with PHI (30.55%), activation of a communication network among professionals (16.66%) (Table Ic). These Opportunities can be analysed in further detail:

Implementation of shared assessment and rehabilitation protocols
This category includes all the topics offering a possible solution to the extreme lack of uniformity of assessment and rehabilitation protocols of the child with PHI. The

implementation of assessment protocols shared among various audiologic centres and territorial structures that have taken the child into care could diminish considerably the current variability, with appropriate indications at an international level. To make standardised rehabilitation intervention possible it is necessary to be able to refer to guidelines resulting from a common consensus of professionals, and based on solid theoretical and scientific grounds.

Specific training on early taking into care of the child with impaired hearing
This category includes all the replies offering opportunities to increase training for healthcare operators. In particular, operators involved in early care of the hearing-impaired child should possess basic knowledge about specific physiological and pathological development. The organisation of compulsory training courses and consequent achievement of certificates/qualifications could guarantee the adequacy of competence of the operators involved. In order to encourage all the members of the team, it would be advisable to involve school operators in the training process as well as all those involved the child's everyday life.

Activation of an efficient communication network of professionals involved in child care
This category includes all the topics that offer a possible solution to the problems associated with partial and inefficient communication between a third-level audiologic centre and territory network. The creation of a shared database and telematic systems that can be accessed by all professionals participating in the care programme (or some representatives located in the different structures) may facilitate the exchange of information among the team members, increasing the possibility of controlling the child's overall development. Within the multidisciplinary communication network, the family paediatrician represents an important resource, owing to the constant contact with the child's family.

Threats key points analysis
From the overall SWOT analysis, 3 principal topics emerged representing the threats characterising the area of early rehabilitative care: variability in the process of assessment and rehabilitation (42.5%), insufficient resources (32.5%), difficulty of communication among operators (12.%) and other (12.5%) (Table Id). The abovementioned Weaknesses can be analysed in further detail:

Variability in the process of assessment and rehabilitation
This category includes the responses relative to the lack of shared assessment protocols specifying the developmental areas to be investigated, follow-up times and assessment tools to be employed. The wide variety of tests available on the market represent a risk for standardisation of the evaluation process.
The same variability can be found in the different rehabilitation approaches that are currently used. Owing to the absence of solid theoretical and scientific grounds, the customisation process adopted by therapists for rehabilitation of the single patient runs the risk of not focusing on general objectives that can be shared by all the colleagues belonging to the same specialisation (e.g. different logopaedic aims between the third-level centre and the territory).
The risks correlated to the lack of standardisation in the processes of evaluation and rehabilitation are increased in the case of deafness-associated disabilities. In multihandicapped patients, the evaluation process presents even greater problems, probably caused by the difficulties of interpretation of the results obtained with structured material.

Resources
This category includes the replies relative to the lack of resources. The lack of resources destined to rehabilitative care induce a chain reaction: the lack of personnel affects the waiting times, with the risk of compromising the "precocity of the intervention".
The risk associated with the lack of resources was also studied in relation to the financial resources of the family. Family units belonging to poorer and more destitute social layers may have difficulty in ensuring complete adhesion to the follow-up calendar or rehabilitation project.

Difficulty of communication among operators
This category includes the responses relative to the difficulties in communication among the different team members who have taken the child into care. The distribution of the interventions in various centres (e.g. third-level audiologic centre/territory) represents a risk for complete and constant exchange of information. Communication exchanges often risk to be unidirectional, so that it is impossible to monitor the developmental growth of the child in optimal manner. The difficult communication among the healthcare operators is linked to communication involving professionals that belong to other fields, e.g. school operators.

Other
This category includes the replies relative to general management problems (medical reports legislation, respect of privacy) and those relative to extraterritorial and multicultural risks. Patients living geographically distant from the audiologic centre of reference might have greater difficulties in structuring a systematic communication network between the audiologic centre and the local rehabilitation centre. Furthermore, the distance from the audiologic centre implies general organisational difficulties concern-

ing various follow-up visits and fosters incomplete adhesion to the programme.
Patients belonging to different cultures are even more complex. In these cases, communication with the team may encounter further problems of a cultural and linguistic type that can make it difficult for the program to be fully efficient.

Discussion

The TOWS matrix was created on the basis of the data of the SWOT analysis. A number of specific recommendations were obtained from the matrix to optimise the process of early (within six months from detection) care of the child. The recommendations can constitute an excellent cause for reflection for third-level audiologic centres, and provide suggestions to optimise resources and produce positive changes. A total of 14 recommendations were obtained from the study and discussion of the current research (Table II).
From the strategic analysis performed, 3 principal themes emerged, representing the greatest Strengths for rehabilitative care, for which external threats are to be minimised and the opportunities implemented:

- implementation of guidelines providing shared indications for assessment and rehabilitative care, also with regards to timing;
- early care by the multidisciplinary team with shared training and creation of a good communication network between the third-level centre and territory;
- involvement of families in the rehabilitation project, starting from the early stages.

In terms of early care, the first recommendation is related to the need to define protocols of well-structured and shared assessment and rehabilitation. Assessment and rehabilitation represent crucial moments in early care, and one of the greatest problems is represented by the different approaches and scarce systematic approach of the procedures.
The definition of a reference point that can guide operators in both the assessment and rehabilitation phases would provide greater consistency of intervention, enabling all children with PHI to have access to the same quality of treatment. Concerning the assessment phase, it will be essential to define which areas of development will have to be evaluated and followed-up (e.g. neuropsychiatrist/neuropsychological assessment, logopaedic assessment, audiologic assessment, etc.) and to indicate follow-up times. It would also be useful to specify the structured tests of reference. The use of the same tests (therefore of a common language) could favour discussion and exchanges of opinion among operators, making it easier to collect data. A systematic collection of data could form a solid base for future research concentrated on the development of the

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

		Internal	
		Strength (S)	**Weakness (W)**
External	Opportunities (O)	**OS strategy** 1. Implementation of guidelines providing shared indications relative to the assessment and rehabilitation aspects 2. Early taking into care by a multidisciplinary team with specific training for early care of the very small child with PHI. Creation of a good network with the territory and in general with all the centres destined to rehabilitation of the child. 3. Involvement of families in the rehabilitation project at the very early phases of intervention	**WO Strategy** 1. Official definition by the institutions on the structures destined to early rehabilitation. Definition of the users who need immediate access to speech therapy rehabilitation and of users whose difficulties were only detected during follow-up 2. Definition of official assessment protocols (areas of development to investigate, timing of follow-up for each area, assessment tools that can be employed) 3. Development of specific guidelines for early rehabilitation care of the child with PHI (theoretically and scientifically based recommendations) 4. Implementation of shared databases for systematic collection of the data achieved during the various stages of assessment for both clinical and research evaluations. 5. Organisation of compulsory training events to standardise the knowledge of team operators with regards to early care
	Threats (T)	**ST strategy** 1. Implementation of shared guidelines for early care (assessment and rehabilitation) allows to standardise care intervention by providing the same learning opportunities to patients from different socio-assistance contexts. 2. Availability of a multidisciplinary team with a good communication network allows to take the patient into care at a global level. Strengthening the communication network with the territory minimises extraterritorial effects. 3. Involvement of the families in the rehabilitation project increases their participation in the project itself.	**WT strategy** 1. Sensitising the healthcare institutions and organisations for the allocation of resources destined to early and overall rehabilitation care of the child with PHI. 2. Sensitising the healthcare institutions for allocation of funds destined to the implementation of systems of communication that can facilitate the collection of clinical data and the exchange of information (e.g. digital databases) 3. Promoting the organisation of compulsory training courses for multidisciplinary team members.

hearing-impaired child. The implementation of ad hoc databases in which the developmental outcomes have been recorded during assessment and rehabilitation could also offer numerous advantages. Access to the database by the professionals involved in early care (audiologist, neuropsychiatrist, family paediatrician) would allow monitoring the development of the child, in order to detect any particular follow-up gaps.

When faced with the variety of rehabilitation approaches in the field of early care, we cannot but refer to evidence-based medicine (EBM). EBM constitutes an approach to clinical practice in which clinical decisions result from integration of clinical practice and the meticulous, clear and sensible employment of the best scientific experience available, and mediated by patient preferences [14].

However, such an approach has long been widely diffused in the medical, but not in the rehabilitation field. There are, in fact, many problems to be faced for the application of these principles to rehabilitation. For example, in order to check the efficiency of a specific therapy, it is necessary to recruit one or more control groups that will not be submitted to any type of intervention. Despite the methodological and procedural difficulties in applying the EBM principles to the rehabilitation process, it is important to promote a culture in which the efficiency of a therapy is evaluated by experimentation based on statistical principles: in fact, the therapist's individual experience alone has limited value in the therapeutic choice [15].

Early care must be as uniform as possible, with guidelines resulting from common consensus and based on solid theoretical and scientific grounds. A positive experience of this type is represented by the Italian Speech Therapists Federation (FLI), which since 2003 has been involved in setting up specific groups of interest aimed at identifying guidelines and recommendations for common models of behaviour by healthcare professionals. It is hoped that common guidelines will also be established for early care of the child with impaired hearing.

A systematic care programme should regard not only the methods of treatment, but also more general management/organisational aspects. In this respect, an important recommendation is the need to define the types of patients to be included in the programme of early care, instead of including patients to rehabilitate only after communicative-linguistic deficits have been detected during follow-up. It is fundamental that all impaired-hearing children requiring logopaedic treatment are included in well-structured rehabilitation programmes specifying times, frequency of treatment and general principles (objectives and methods). The most debatable category, with regard to early care, is represented by children with mild-moderate bilateral hearing loss and children with monolateral deafness.

The process is complex even for two other types of patients: children with PHI belonging to a multicultural/multilingual context and children presenting with PHI associated disabilities. For bilingual children, it will be necessary to consider their multicultural/multilingual context with regard to both the process of assessment (use of standardised tests in their own language associated with semi-structured observations) and the program of rehabilitation. Multi-handicapped children also require complex and global care that takes into account all their areas of development, with particular attention to those more greatly influenced by PHI-associated deficits.

One of the recommendations linked to the organisational aspects is to define at an institutional level the times required for early care; on the basis of the different healthcare structures available in the national territory, it will also be necessary to officially define the structures responsible for care. Since the times of access to rehabilitation do not always correspond to the waiting lists of the territory, it will be important to find alternative solutions for effective care (i.e. within 6 months of life). The external threats related to the first recommendation are basically constituted of the lack of both financial and human resources. The creation and diffusion of a database present several problems associated with implementation costs, personnel assigned to its compilation and preservation of privacy for the users. Considering rehabilitation aspects, the greatest drawbacks derive from the waiting lists of the territorial structures that are not always consistent with the needs of early intervention and are probably linked to insufficient availability of personnel and resources.

The second recommendation concerns the need for early care that is multidisciplinary, integrated and global. The rehabilitation project requires therapeutic polyvalence and a series of competences that vary according to the child's disabilities and developmental stage. Early global care, with integrated and coordinated treatment, is based on different synergies and on the collaboration of all the multidisciplinary team members, even when they belong to services located on different sites (e.g. third-level centre or rehabilitation centre). In order to include the child in a global rehabilitation project, the various professionals need to connect through a solid and efficient communication centre that is able to fully guarantee the multidisciplinary care.

An important aspect of the second recommendation consists in training the members of the multidisciplinary team. Taking a very small (6-9 months) impaired-hearing child into care implies specific training both in terms of developmental features and best communicative and perceptive modes that can stimulate the child. These aspects must be considered during the training process of the operators involved in the project, and an opportunity in this respect is offered by the participation to specific training courses. The need for specific training increases in the case of a medically complex child should also be considered. An external risk might be represented by the insuffi-

cient competence of some operators and the impossibility to check whether the competences of the rehabilitator are actually suitable to the role.
Multidisciplinary care is based on a constant exchange of information among team members. Even in this case, the exploitation of a shared database and telematic systems could be useful. Constant updating of the data available in the database would allow all those who have taken the child into care to check whether the child's growth is in line with the normal developmental stages or whether it presents any peculiarities that are worth investigating. In the absence of a shared database, periodical reports written by all the professionals involved in follow-up and rehabilitation could facilitate the exchange of information among operators, with the inconvenience of the parents having to act as mediators, and burdened with a duty that falls outside their function. An important resource could be represented by the organisation of logopaedic networks over the entire territory. A network of this type, although not yet formalised, has already proven efficient and has for some years now been active in our implantation centre. In the absence of a database, the availability of answering services/direct numbers/e-mail reference addresses for both the audiologic and territorial centres could foster the exchange of information. Even in this case, the major external risk is the impossibility to use the resources that can be assigned to the personnel dedicated to these activities.
The third recommendation concerns the need to involve the parents in the rehabilitation project. By exerting the right of "informed choice", the family must be adequately informed and trained on the various therapeutic proposals and possible rehabilitation objectives to be pursued. This recommendation agrees with the guidelines of the JCIH [2], which underline the importance of the parents' role within the framework of early intervention. According to numerous authors, the child and his/her family must be involved in an intervention that can improve their quality of life, thus fostering the development of auditory and communication abilities [16 17]. The role of parents considerably affects the success of rehabilitation.[18-19] The quality and quantity of maternal stimulation influence the linguistic abilities reached by small children with cochlear implants: for this reason, the parent should know how to relate with the child since the very first years of life, by assuming the role of scaffolder in development [5-9]. An external opportunity favouring the involvement of the caregivers in the rehabilitation project is represented by the possibility to participate in the logopaedic sessions so as to observe directly the perceptive and communicative strategies used by the speech therapist to interact with the child. During sessions, the activities are aimed at achieving communication objectives (enhance non-verbal communication prerequisites; foster all components of verbal communication development; stimulate auditory attention by pursuing the attainment of increasingly complex perceptive abilities). Personal participation in the rehabilitation sessions and observation of the various specific activities will make the parent more conscious of the strengths and weaknesses, both perceptive and comunicative, of the child.
The external risks for this last recommendation concern the difficulties in using clear and exhaustive communication with families. The professionals involved in the rehabilitation process should be sure that the families are fully aware of the rehabilitation objectives and of the methods that will be used for their attainment. The language employed with families will need to be customised to their socio-linguistic features (e.g. foreign parents with scarce competence in Italian), and specialists should be certain that the contents of the message have been clearly understood. In order to facilitate the entire process, it may be useful to give the family periodic medical reports, clarifying the steps of care (short-medium and long-term objectives). According to our clinical experience, in agreement with the recommendations provided by JCIH [1 2], we have observed that for parents of newly diagnosed children the possibility of exchanging ideas with other parents represents an important resource. The activation of a "help-desk" in which professionals and volunteer parents can offer their support to the families represents an important external opportunity to help families in the taking into care process. In our Unit, this activity of family support is carried out by structured medical and technical staff and avails itself of the collaboration of volunteer members of the Association ASIC (Association for Deafness and Cochlear Implants). ASIC is a non-profit volunteer association formed by the parents of hearing-impaired children and by adults with impaired hearing, with the scientific support of audiologic specialists.

Conclusions

In the working area for early care, three main recommendations were identified that are useful for the planning of a centre for paediatric PHI: implementation of guidelines providing shared indications relative to the assessment and rehabilitation aspects of early care; early taking into care by a multidisciplinary team sharing the same type of appropriate training, and successive realisation of a good communication network between third-level centre and territory; involvement of the families in the rehabilitation project from its very early stages. For the third-level audiologic centres, the recommendations emerging from this process can be valid recommendations to optimise resources and produce positive changes.

References

1 Joint Committee on Infant Hearing. *Year 2007 position statement: principles and guidelines for early hearing detection and intervention programs*. Pediatrics 2007;120:898.

2 Joint Committee on Infant Hearing. *Supplement to the JCIH 2007 position statement: principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing*. Pediatrics 2013;131;e1324.

3 Marciano E, Laria C, Malesci R, et al. *Newborn hearing screening in the Campania region (Italy): early language and perceptual outcomes of infants with permanent hearing loss*. Acta Otorhinolaryngol Ital 2013;33:414-7.

4 Xu Q, Zhai S, Han D, et al. *Meta-analysis on effectiveness of prelingually deaf patients at different ages following cochlear implantation*. Lin Chung Er Bi Yan Hou Tou Jing Wai Ke Za Zhi 2015;29:310-4.

5 Niparko JK, Tobey EA, Thal DJ, et al. *Spoken language development in children following cochlear implantation*. JAMA 2010;303:1498-506.

6 Desjardin JL, Eisenberg LS. *Maternal contributions: supporting language development in young children with cochlear implants*. Ear Hear 2007;28:456-69.

7 Pressman L, Pipp-Siegel S, Yoshinaga-Intano C, et al. *Maternal sensitivity predicts language gain in preschool children who are deaf and hard of hearing*. J Deaf Stud Deaf Educ 1999;4:294-304.

8 Quittner AL, Cruz I, Barker DH, et al. *Childhood development after cochlear implantation investigative team. Effects of maternal sensitivity and cognitive and linguistic stimulation on cochlear implant users' language development over four years.* J Pediatr 2013;162:343-8.e3.

9 Cruz I, Quittner AL, Marker AM, et al. *Identification of effective strategies to promote language in deaf children with cochlear implants*. Child Dev 2013;84:543-59.

10 Tobey EA, Britt L, Geers A, et al. *Cochlear implantation updates: the Dallas cochlear implant program*. J Am Acad Audiol 2012;23:438-45.

11 Erber NP. *Auditory Training*. First Edition. Washington, DC: Alexander Graham Bell Association for the Deaf and Hard of Hearing 1982.

12 White K, Blaiser K. *Strategic planning to improve early hearing detection and intervention programs*. The Volta Review 2011;111:83-108.

13 Bradham TS, Houston KD, Guignard GH, et al. *Strategic analysis of family support*. The Volta Review 2011;111:181-94.

14 Sackett DL, Rosenberg WMC, Gray JAM, et al. *Evidence based medicine: what it is and what it isn't*. BMJ 1996;312:72-3.

15 De Cagno AG, Rossetto T. *Presa in carico e intervento nei disturbi dello sviluppo*. In: *EBM e riabilitazione: il cambiamento culturale per la pratica clinica.* Trento: Erickson, Capitolo 1, 2009.

16 Moeller MP, Carr G, Seave L, et al. *Best practices in family-centered early intervention for children who are deaf or hard of hearing: an international consensus statement*. J Deaf Stud Deaf Educ 2013;18:429-45.

17 Soman UG, Kan D, Tharpe AM. *Rehabilitation and educational considerations for children with cochlear implants*. Otolaryngol Clin 2012;45:141-53.

18 Bradham TS, Houston KD, Guignard GH, et al. *Strategic Analysis of Family Support*. The Volta Review 2011;111:181-94.

19 Ganek H, Robbins AMC, Niparko J. *Language outcomes after coclear implantation*. Otolaryngol Clin 2012;45:173-85.

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