

# Follow-up of permanent hearing impairment in childhood

## *Il follow up del bambino con ipoacusia permanente*

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### SUMMARY

Programmes for early childhood hearing impairment identification allows to quickly start the appropriate hearing aid fitting and rehabilitation process; nevertheless, a large number of patients do not join the treatment program. The goal of this article is to present the results of a strategic review of the strengths, weaknesses, opportunities and threats connected with the audiologic/prosthetic/language follow-up process of children with bilateral permanent hearing impairment. Involving small children, the follow-up includes the involvement of specialised professionals of a multidisciplinary team and a complex and prolonged multi-faced management. Within 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", the purpose of this analysis was to propose recommendations that can harmonise criteria for outcome evaluation and provide guidance on the most appropriate assessment methods to be used in the follow-up course of children with permanent hearing impairment.

**KEY WORDS:** Childhood hearing loss • Follow-up • Lost to follow-up • Outcome evaluation protocols • SWOT analysis

### RIASSUNTO

*I programmi di identificazione precoce delle ipoacusie infantili permette di intraprendere rapidamente l'iter riabilitativo e protesico appropriato; nonostante ciò appare ancora elevato il numero di pazienti che non aderiscono al programma terapeutico. 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 del processo di follow up audiologico/protesico/linguistico di bambini affetti da ipoacusia bilaterale permanente. Il follow up in questione, coinvolgendo bambini piccoli, implica il coinvolgimento di professionisti specializzati e inseriti in un team multidisciplinare e una gestione plurisettoriale complessa e prolungata. Nell'ambito del progetto finanziato dal Ministero della Salute Italiano CCM 2013 denominato "Programma regionale di identificazione, intervento e presa in carico precoci per la prevenzione dei disturbi comunicativi nei bambini con deficit uditivo" lo scopo di quest'analisi è stata quella di offrire delle raccomandazioni per armonizzare i criteri di valutazione dei risultati terapeutici e trarre spunto da questi per successivamente fornire delle linee guida riguardanti le metodiche più adeguate nella valutazione del bambino con ipoacusia permanente.*

**PAROLE CHIAVE:** Ipoacusia infantile • Follow up • Persi al follow up • Protocolli di valutazione di beneficio • Analisi SWOT

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## Introduction

Early identification of infant permanent hearing impairment (PHI) is one of the primary actions to prevent the occurrence of changes in cortical and subcortical structures caused by the absence of sensory input; these changes will be much more severe and long lasting if the sensory deprivation started early in life and is of longer duration<sup>1</sup>. If the PHI is congenital, it is necessary to provide proper amplification preferably within six months of life to avoid reorganisation of neural networks involved in acoustic processing and eventually offer the opportunity to normally develop auditory perception and verbal comprehension<sup>2,3</sup>. In case of late diagnosis, it will be mainly neces-

sary to correct the PHI and quickly start a rehabilitation program that seeks to compensate for the lack of acoustic inputs. In event of post-verbal PHI, the threshold correction will be followed by careful assessment of the effects caused by the lack of input to plan the most appropriate treatment<sup>4</sup>.

The treatment will be based on an effective cooperation between the multidisciplinary team, family and paediatrician. All are in some way involved in monitoring the outcomes of the treatment program and nurture the relationship with the family.

To determine the benefit of prosthetic intervention/rehabilitation, the tertiary centre team will need to periodically evaluate the young patient in order to assess the aided

auditory response, cognitive and attention development, auditory processing skills and language development<sup>5</sup>.

The follow-up evaluation gives a measure of the rehabilitative treatment efficacy and allows to modulate it according to the needs of the young patient. At present time Italian centres do not share a reference model of follow-up methodology and tools for PHI children.

Within 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”, it was decided to consider the problems relative to the harmonisation of criteria for outcome evaluation. The specific aim is to implement a follow-up protocol that supports effective feedback within tertiary centres and primary care.

## Materials and methods

A group of professionals working in tertiary care referral centres for childhood PHI was asked to complete a survey having as its object the follow up of children with PHI. The survey asked to participants to report at least 2 strengths, weaknesses, opportunities and threats for use in strategic planning. This phase was conducted using the principles of a 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 SWOT analysis, a TOWS matrix was used to match the external threats and opportunities with internal weaknesses and strengths of the organisation or programme<sup>6</sup>. 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: schedule a follow-up protocol that supports an effective feedback within tertiary centres and primary care.

## Results

The study group included 21 professionals. All participants completed the SWOT questionnaire.

The 150 open-ended answers (S = 38, W = 45, O = 38, T = 29) were reviewed by the authors and grouped in main key points (Table I).

### Strength key points analysis

1. The professionals highlighted the presence of a multidisciplinary working group. A dedicated competent/experienced staff (41%), underlining the specific training of all specialists in the field, is needed.
2. Follow-up with standard tests (28%) is considered more competent and reliable feedback of follow-up

**Table I.** Main key points extrapolated from questionnaires.

**Table Ia.** *Strengths.*

Strengths key points	
Multidisciplinary working group	17 (41%)
Follow-up with tests	12 (28%)
Immediate booking appointments	7 (17%)
Accessibility of the centre	5 (12%)

**Table Ib.** *Weaknesses.*

Weakness key points	
Limited personnel	16 (33%)
Weak feedback with paediatricians, speech therapists	14 (28%)
Missed appointments	7 (15%)
Absence of shared protocols	6 (13%)
Multiculturalism and family circumstances	3 (6%)
Miscellaneous	2 (5%)

**Table Ic.** *Opportunities.*

Opportunity key points	
Dedicated secretary	17 (42%)
Paediatric centre	14 (35%)
Follow-up protocols	6 (15%)
Book appointments in advance	2 (4%)
Miscellaneous	2 (4%)

**Table Id.** *Threats.*

Threats key points	
Lack of funding	15 (46%)
Multiculturalism	8 (25%)
Lack of cooperation between specialists	7 (22%)
Miscellaneous	2 (7%)

language when based on the use of standardised tests and accepted nationally and internationally.

3. Immediate booking of appointments and control visits directly by staff (17%), which gives the possibility to scan appointments efficiently and without waiting lists.
4. The hearing impaired child will undergo several medical examinations, therefore, in order to not discourage patients it is appropriate that the reference centre is reachable without great difficulty (12%).

### Weakness key points analysis

1. Limited personnel (33%) related to lack of founding or hiring freezes, with loss of pertinent information.
2. Weak feedback with paediatricians, speech therapists (28%), with loss of effectiveness of the team of the reference centre and difficulties in communicating the results and therapeutic programmes.
3. Missed appointments (15%), are an expression of an unorganised service without a dedicated secretary.

4. Absence of shared protocols (13%) causes poor assessments of information on language development and enables collaboration between specialists.
5. Multiculturalism and family circumstances (6%), in which we also include situations of cultural differences that prevent the family to fully understand the therapeutic program.
6. Other answers were uncategorised (n = 2).

**Opportunities key points analysis**

1. Dedicated secretariary (42%) to manage appointments regularly and enable monitoring them.
2. Paediatric centre (35%) that allows managaing shared programmes with paediatricians and rehabilitation centre within dedicated environments.
3. Follow-up protocols (15%) made of standardised tests that have a rapid and easy execution and low time of administration.
4. Establish appointments in advance (4%) before the patient leaves the centre so as not to create work overload and better manage the timing of follow-up.
5. Other answers were uncategorised (n = 2).

**Threats key points analysis**

1. Lack of funding (31%), resulting in inadequate staff, long waiting lists and time constraints, lack of secretaries and dedicated spaces.
2. Multiculturalism (25%), in which reference is made to the difficulties of managing users geographically distant from the centre audiologic reference and all the family circumstances.
3. Lack of cooperation between the specialists (22%), with sometimes conflicting information, failure of reporting and monitoring, and absence of compliance of the family.
4. Other answers were uncategorised (n = 2).

**Discussion**

The Joint Committee on Infant Hearing<sup>7</sup> stresses the need to increase awareness and knowledge of healthcare personnel about issues related to PHI, coordinate efforts to follow-up allowing for benefit from family collaboration, reduce inequalities in healthcare delivery and ensure that the recommended services are received and reported<sup>7,8</sup>. It is difficult, for this specific clinical area, to divide the external issues from the internal ones because there are variables related both to the compliance of the family and to the territorial professionals (paediatrician, speech therapist) that may affect the work of the referral center. For this reason, it is necessary for the paediatrician and the family to be constantly informed about the treatment plan. Specific educational and training meetings or sessions organised by tertiary centre specialists should be sought. Starting from the SWOT analysis data, a TOWS matrix was created, which compares Strengths-Opportunities, Weaknesses-Threats and Weaknesses-Opportunities. Analysing the data obtained from this research, 8 recommendations were obtained (Table II). Finally, three main themes were recognised, which can contribute to accurate, effective and shared audiologic/prosthetic/language follow-up in children with permanent hearing loss:

- establish the steps of follow-up, defining timing, type and duration of the assessment to be made;
- focus on training of all professionals who are part of the multidisciplinary team, which should also include planning themes such as managing appointments, reporting on databases, etc.;
- build a network with professionals working in the territory with whom to share the follow-up process of the child so that they can be active and aware in the therapeutic programme. This is a particular concern for patients who do not follow the correct follow-up programmes.

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

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	<p><b>SO strategy</b></p> <ol style="list-style-type: none"> <li>1. Use standardised tests to make quick and effective follow-up in relation to age and prosthetic trim.</li> <li>2. Competent and motivated multidisciplinary team with specific knowledge of the diagnostic and therapeutic that requires hearing loss.</li> </ol>	<p><b>WO strategy</b></p> <ol style="list-style-type: none"> <li>1. Improve feedback between the referral centre, family paediatricians and local rehabilitative staff by training all professionals and secretarial staff.</li> <li>2. Book the next appointment before leaving, clarifying duration and assessments to be done so that the families can organise themselves better. If a paediatric center optimises all evaluations (also other departments) it can facilitate families who liver far away.</li> </ol>
	Threats (T)	<p><b>ST strategy</b></p> <ol style="list-style-type: none"> <li>1. Give comprehensive and complete information to the family and to the operators of the territory about the goals to be achieved.</li> <li>2. Ensure that the paediatrician and families are an integral part of the multidisciplinary team, establishing regular meetings with them to make the family aware of the importance of regular visits.</li> </ol>	<p><b>WT strategy</b></p> <ol style="list-style-type: none"> <li>1. Improve follow-up rates for families at risk of being lost to follow-up by strengthening the therapeutic alliance with the professionals who deal with family support.</li> <li>2. Build a network with specialists working within the territory; increase awareness so that healthcare institutions and organizations can have increased funding for the team, its projects and continuing education.</li> </ol>

The first recommendation emphasised the need for valid and standardised protocols that can make the evaluation of young patients effective and quick. Correct assessment of language and cognitive development are essential to establish an effective rehabilitation programme, and thus the need to determine which method will allow following as many patients as possible<sup>9</sup>. Speech therapy and follow-up tools require an operative model of reference, updated to the evolution of knowledge and, ensure standard uniform procedures that allow follow up checks to be unambiguous and comparable in data. Most of the tests that are internationally used are in English or standardised in foreign samples, making it difficult to have international shared protocols. The beginning of a national uniformity is foreseen by the authors in the framework of the CCM project shared by the five regions involved.

Clarity regarding the child's rehabilitation programme will facilitate the understanding of the family and make the rehabilitators and paediatrician aware of the rehabilitation project. The second recommendation is that the multi-disciplinary management of the patient should be referred to specialists who are properly trained and aware that the rehabilitation programme is based on the communication between the team members, paediatrician and the family. In fact, a motivated and competent team will be able to encourage the family in a long and demanding follow-up process.

In the management of so many professionals, we need to rely on nurses and administrative employees who are properly trained to manage appointments, to limit the lost to follow-up, and guide families; for this reason, it is necessary to plan training sessions for administrative staff and nurses. In fact, there is still a high percentage of patients lost to follow-up that in part depends on waiting lists, family organisation, and lack of dedicated secretarial staff. The chance to determine the next appointment before leaving seems an opportunity to limit the loss of patients. Equally important will be an updated database with the data of the patient and the telephone numbers of family and paediatrician for better tracking of patients and to improve follow-up rates in families with demographics that place them at risk of being lost to follow-up.

The third recommendation emphasises the importance of a constant exchange of information that allows observing the evolutionary stages of the patient with permanent hearing loss compared to a hearing child, and providing for the creation of a collaborative network between

speech therapists, referral centre, paediatrician and family in order to avoid loss to follow-up. Furthermore, the training of speech therapists and paediatricians in the territory enables collaboration in order to accelerate the execution of tests and improve the clarity of information provided to families.

## Conclusions

Three main recommendations were recognised to have a correct and shared audiologic/prosthetic/language follow-up in children with permanent hearing loss, i.e. establish the steps of follow-up, and define the timing, type and duration of the assessment to be made; focus on training of all professionals who are part of the multidisciplinary team and managing appointments; build a network with specialists working within the territory and following the child so that they can make follow-up faster.

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