

Improving regional universal newborn hearing screening programmes in Italy

Raccomandazioni per perfezionare i programmi regionali di screening uditivo neonatale universale in Italia

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SUMMARY

The Universal Newborn Hearing Screening (UNHS) programme aims at achieving early detection of hearing impairment. Subsequent diagnosis and intervention should follow promptly. 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”, the limitations and strengths of current UNHS programs in Italy have been analysed by a group of professionals working in tertiary centres involved in regional UNHS programmes, using SWOT analysis and a subsequent TOWS matrix. Coverage and lost-to-follow up rates are issues related to UNHS programmes. Recommendations to improve the effectiveness of the UNHS programme have been identified. The need for homogeneous policies, high-quality information and dissemination of knowledge for operators and families of hearing-impaired children emerged from the discussion.

KEY WORDS: Newborn hearing screening • Early intervention • SWOT analysis

RIASSUNTO

L’obiettivo dello screening uditivo neonatale universale è di ottenere una diagnosi precoce di ipoacusia congenita. Non appena confermata la perdita uditiva, è necessario intervenire dal punto di vista riabilitativo. 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 professionisti appartenenti a centri di terzo livello con un programma regionale di screening uditivo neonatale, ha analizzato i limiti e i punti di forza dell’attuale impostazione dei programmi regionali di screening uditivo neonatale mediante l’analisi SWOT e la realizzazione di una matrice TOWS. Alcune criticità sono rappresentate dalla copertura dello screening e dal numero di persi allo screening. Sono state sviluppate raccomandazioni volte a migliorare l’efficacia di tali programmi. Sono emerse la necessità di una regolamentazione uniforme dei programmi di screening a livello regionale e nazionale, e il bisogno di ricevere informazioni e formazione aggiornate, di alta qualità, e condivise per familiari e operatori.

PAROLE CHIAVE: Screening uditivo neonatale • Intervento precoce • Analisi SWOT

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Introduction

The Universal Newborn Hearing Screening (UNHS) programme aims at enhancing the child’s communicative, social and academic development through early identification of permanent hearing impairment (PHI). Many regional programs in Italy have improved the detection rate and timing ¹. Before the introduction of UNHS in the Umbria region, mean age at identification of PHI was about 32 months ². Amplification was applied at least 2 months later ². Since 2010, the Umbria region has implemented a UNHS programme with the aim to obtain wide coverage, low re-screening rates, high adherence to follow-up and early intervention ³⁻⁵.

UNHS becomes effective if the diagnosis prompts early and adequate intervention ⁶. It is reported that up to 50% of infants referred from UNHS may not receive a timely diagnosis and intervention, or are not included in the tracking system. Quality services for the child and its family are important to take advantage from UNHS. Actually, parents may become distressed when confirmation of hearing loss is not followed by immediate support, and can consequently impair the therapeutic alliance with professionals ^{7,8}. Considerable efforts are now being employed at a regional and national level to ensure that infants and families receive the best support from UNHS. 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 established a strategic analysis with this specific aim: universal screening and re-screening test to be done within the 1st month of age, preferably before hospital discharge. This study aims to highlight the strengths and weaknesses of current assets in order to achieve preliminary recommendations to optimise UNHS processes.

Materials and methods

Seventeen professionals involved in the field of prevention, diagnosis, treatment and rehabilitation of paediatric PHI (i.e. audiologists, otorhinolaryngologists, audiometry technicians, speech and language pathologists, psychologists, hearing aids professionals, cochlear implant technical specialists) and working in 5 third level centres running UNHS programmes were involved in the strategic analysis. The data obtained were used to complete a SWOT analysis with this specific aim: universal screening and re-screening test to be done within the 1st month of age, preferably before hospital discharge. Next, a reverse process was undertaken, the TOWS matrix, to match the external threats and opportunities with internal weaknesses and strengths of the newborn hearing screening programme. The detailed description of the SWOT and TOWS matrix analysis procedure can be found elsewhere in this issue.

Results

All participants completed the SWOT questionnaire; overall, 201 answers were collected. Fifty-seven answers were obtained for the S category, 51 for the W category, 451 for the O category and 42 for the T category. The answers were grouped according to the field of interest (Table I).

Strength key points analysis

Three fields emerged from the strength points analysis (Table I).

Ease and effectiveness of the procedure

This category includes all the answers about technical specifications of equipment in use, either from the clinical aspects, or from cost point of view. An ideal screening test is inexpensive (n = 6), reliable and easy to use (n = 10), tested and validated (n = 4), straightforward to teach and learn from neophytes (n = 3) and regulated by clear policies at a regional level (n = 8).

Third-level centre organisation

In this category, answers regarding organisation in terms of accessibility, facilities and dedicated staff have been

included. Strength derives from competent (n = 9) and collaborative (n = 3) personnel, adequate facilities (n = 2) and staff (n = 1), effective procedures (n = 2), shared databases (n = 2), short waiting lists (n = 2), compelling connection with hospital nurseries (n = 2) and with a nominated person who is responsible for screening (n = 1).

Good family involvement in the diagnostic and rehabilitative process

The chance to involve families of deaf children in the identification process is a strength. This entails, on one hand, that families are informed adequately on the importance of early intervention (n = 1), and on the other, that the staff is skilled (n = 1) and prepared to give adequate and homogeneous answers about the following diagnostic and rehabilitative path (n = 1). The possibility to retrieve “missing” patients is considered important (n = 1).

Weakness key points analysis

Three fields emerged from the weakness points analysis (Table I).

Difficult coverage

The problem of the drop-out from the scheduled re-screening and referral programme is reported (n = 11), especially for non-Italian families. One of the causes can be inadequate staff personnel, either in term of numbers (n = 6) or ineffective communication among referral centres (n = 4). This can be related to excessive personnel turnover (n = 3) and to higher workload resulting in shallow evaluations (n = 1). Unreliable testing devices can cause delays in the screening process (n = 3). Unilateral referral cases can be overlooked in some centres (n = 1).

Local policy problems

In this category, answers regarding policy differences and controversies among regions (n = 6), that prevent homogeneity and promptness of actions (n = 5), as well the opportunity to manage data in a shared database (n = 4), have been included. Lack of funding (n = 1) and uncertainty or controversies on the specificity/sensibility of tests and procedures (n = 3) are also considered.

Communication problems

Weak points have been attributed to communication problems, i.e. insufficient communication with the families about results and importance of the screening procedures (n = 2), or lack of feedback on program implementation (n = 1).

Opportunity key points analysis

Three fields were recognised about opportunities.

Information and formation

This category includes the dissemination of knowledge

about UNHS programmes (n = 12) directed both to families of deaf children and to general population. The opportunity to improve the newborn hearing screening programme also comes from continuing education including distance learning and mentoring (n = 10), efficient organisational support as dedicated administrative office (n = 2) and telematic facilities, e.g. shared online databases (n = 3), online communication of screening results (n = 4).

Policy opportunities

Answers in this category entailed the introduction of homogeneous policies and protocols among regions, centres (n = 12) and areas (n = 1), in order to improve screening and surveillance programmes, extend screening instruments to all hospital nurseries (n = 1), external collaborations with third level centres (n = 1), verification by the paediatrician about completion of screening (n = 1).

Technical and technological aspects

The foundation of a regional network is an opportunity to improve technological homogeneity (n = 1) and mutual advice from a technical point of view (n = 3).

Threats key points analysis

Threats points have been grouped in three categories (Table I).

Table I. Main key points extrapolated from questionnaires.

Table Ia. *Strengths.*

Strength key points	N (%)
Ease and effectiveness of the procedure	31 (54.4)
Third-level centre organization	22 (38.6)
Good family involvement	4 (7)

Table Ib. *Weaknesses.*

Weakness key points	N (%)
Difficult coverage	29 (56.9)
Policy problems	19 (37.2)
Communication problems	3 (5.9)

Table Ic. *Opportunities.*

Opportunity key points	N (%)
Information and formation	31 (60.8)
Policy opportunities	16 (31.4)
Technical and technological aspects	4 (7.8)

Table Id. *Threats.*

Threats key points	N (%)
Cultural, ethnical and territorial differences	25 (59.5)
Lack of information and dissemination of knowledge	11 (26.2)
Resources and equipment	6 (14.3)

Cultural, ethnical and territorial differences

There are issues about the universality of newborn hearing screening, because of cultural, ethnical and territorial differences, leading to misunderstanding or lack of confidence (n = 9), and about the territorial complexity and healthcare organisation weakness (n = 3). Threat points are also attributable to the lack of homogeneity and equity (n = 9), and of national policies about UNHS (n = 2), with overload of a few centres (n = 2)

Lack of information and dissemination of knowledge

This category includes the lack of information (n = 2) and education (n = 1) of professionals regarding the screening/re-screening protocol (n = 2) and about the specific responsibilities of the professionals involved in the programme (n = 1). This can lead to incomplete or erroneous information given to patients (n = 3). The awareness level about hearing problems is low in the general population (n = 1). The problem of mild-to-moderate PHI can remain underrated (n = 1).

Resources and equipment

Lack of funds (n = 3), unreliable instruments (n = 1), and poor knowledge of their characteristics, maintenance and employment (n = 2) were included.

Discussion

Several issues regarding screening and rescreening newborns have been reported in past years: coverage of the programme, loss to follow-up between first and second screening test, false positive cases, inclusion of unilateral PHI in the detection procedure, homogeneity in procedures between birthing centres within the same region and within the country, 2nd and 3rd level appointments, management of the non-functioning screening instruments, clear roles in the programme, data management^{5 9 10}.

A TOWS matrix has been developed on the bases of the SWOT analysis (S-O, S-T, W-O and W-T strategy). Thanks to the good organisation of services and information, the SO strategy will improve the employment of electronic databases for the collection and share of UNHS data. The W-O strategy will overcome the coverage issues of the UNHS by means of the introduction of regional policies. The S-T strategy will improve UNHS effectiveness thanks to the increased ease of the procedures. The W-T strategy will enrich available funds directed to improve UNHS outcomes, based on a better organisation of the programme. Applying the TOWS matrix to the themes of internal and external factors, as identified by UNHS coordinators with the SWOT analysis, 8 recommendations, or “strategic plans” for hospitals and audiology tertiary care referral centres have been developed (Table II). The 8 items can be summarised in 2 main strategies, which are interconnected and are in accordance with the current international

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

		Internal	
		Strength (S)	Weakness (W)
External	Opportunities (O)	SO strategy 1. Keep updating the UNHS program through a regional network to improve the procedures while developing homogeneous protocols and assistance. 2. Set up an efficient network among centres and territory, in order to improve the involvement of families, education of professionals, involvement of families and sharing of information.	WO strategy 1. Use continuing education to improve the quality of the shared informations, also with the support of new technologies and media. 2. Introduce homogeneous national laws regulating UNHS in order to improve diagnosis and rehabilitation pathways, increasing funds and a common database.
	Threats (T)	ST strategy 1. Demonstrate that thanks to the ease of the procedure and the effectiveness of the organisation, logistic and cultural barriers can be overcome. 2. Use policies to close cultural and information gaps among operators, unaware of the population, and to receive adequate resources.	WT strategy 1. Improve the UNHS and re-screening coverage identifying specific paths and policies to enlarge the staff and the resources. 2. Make aware the institutions that changing the policies about UNHS can improve paediatric population monitoring and assimilate databases in a national registry.

guidelines inspiring UNHS^{4,5}. These strategies are directed to: a) improve policies related to UNHS and b) provide information of high quality to families and professionals. The reorganisation of the policies involved in the UNHS is mandatory. It includes the sensitisation of the institutions and the introduction of adequate job descriptions, with the aim to improve UNHS and surveillance effectiveness, optimise resources, improve continuing education, inform the population and achieve a good and sustainable monitoring of the paediatric population⁹. UNHS should become the object of a nation-wide applied policy in Italy, in order to carry out homogeneous evaluation and ensure uniform levels of care. National policies should be introduced to make the UNHS mandatory, to make plain cultural contrasts and to give adequate resources, including management and supervision offices.

The second strategy entails the dissemination of high quality information through online networks and information exchange for professionals, families and children, in an appropriate language. Information should be given before delivery to parents, highlighting the importance of early identification of hearing impairment, and about the screening path, follow-up process and impact rehabilitation¹⁰. Basic information about anatomy, physiology, pathology, rehabilitation and instrumentation used for hearing assessment and on the specific role of the different professionals will be also provided. Parents will be driven through the rehabilitation path by leaflets, books, videos, distance learning, distance mentoring and other resources. Counseling and communication issues between parents and professionals, or between parents and children professionals and children will be addressed¹¹. Dissemination of information to the general population should be provided at different levels (in the hospital, on the territory). Dedicated secretarial staff will address the needs of families and patients, and receive suggestions by users. High levels of therapeutic alliance must be

achieved. Training of operators should be either theoretical and practical (e.g. nurses should be aware of screening goals, congenital hearing causes, and trained on earbuds positioning), and provided by professionals^{12,13}. Updated protocols need to be periodically discussed, highlighting the pros and cons of the program organisation. A clinical updated is to be included¹⁴. A periodic scientific with all the informative material for parents and professional, and the critical aspects emerged in teaching and training should be collected and published¹⁵.

Conclusions

Two main recommendations have been identified, which are useful to improve UNHS programmes, i.e. the need for homogeneous policies in Italy and for high-quality information and dissemination of knowledge for operators and families of hearing-impaired children. This approach is consistent with current paediatric audiology guidelines^{4,5}.

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