

A global overview on deafness: experiences and perspectives of citizens, patients, caregivers, voluntary associations, and health professionals. Findings from the Varese GOOD surveys.

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Abstract In the last years, important innovations in technologies, diagnostics, and rehabilitative techniques have led to significant improvements in the quality of life of patients affected by hearing loss (HL). While many clinical studies on HL have been performed, less attention has been paid to the organizational and cultural context around it. For this reason, the Audiological Foundation of Varese (Fondazione Audiologica Varese, FAV) decided in 2018 to start collecting information about all 360 degrees of deafness. We share the results of three cross-sectional surveys investigating the experiences and perspectives on HL of citizens, patients, caregivers, voluntary association representatives, and health professionals. In total, 2828 Italian and international respondents were involved. Our findings might provide some valuable practitioner- and policy-oriented suggestions for changes and improvements to address the specific needs and interests of the involved stakeholders. This study was part of the initiative “A Global Overview On Deafness” (GOOD) organized by the FAV, which brought together different actors working toward the common goal of “hearing life”: hearing specialists, technicians, educators, speech and behavioral therapists, researchers, patients, associations, and families. Always looking to a brighter and louder future.

Keywords: hearing loss, Varese GOOD, Fondazione Audiologica Varese (FAV)

Introduction

Hearing loss (HL) is one of the most prevalent chronic conditions and the fourth highest cause of disability globally (Cunningham and Tucci, 2017; World Health Organization, 2015). It affects about 6% of the world's population (466 million people, of which 34 million are children) and this number is expected to increase to over 700 million people by 2050 (World Health Organization, 2018). In Italy, around 7.3 million people require rehabilitation to address their ‘disabling’ HL, corresponding to roughly 12% of the population (Censis, 2019). HL can arise from any portion of the peripheral and central auditory sys-

tems: it is categorized as conductive (caused by impairment of the outer or middle ear), sensorineural (caused by a cochlea or cochlear nerve dysfunction), or mixed (with both conductive and sensorineural attributes). HL may affect all age groups with significant negative impacts on the physical, mental, and social health-related quality of life of patients (Ciorba et al., 2012; Punch et al., 2019). In children, it may adversely affect speech and language development, as well as intellectual and emotional growth (Fitzpatrick et al., 2021). Concerning elderlies, approximately one-third of people aged 65 years and old-

er and 80% of those older than 85 years are affected by significant HL (World Health Organization, 2012). Besides physical and psychological negative outcomes, several studies have found an association between HL and increased loneliness and social isolation in older adults (Shukla et al., 2020). Age-related HL has also been correlated with cognitive decline and risk of dementia in a growing elderly population (Lin et al., 2011; Lin & Albert, 2014). Furthermore, as for other chronic conditions, HL may represent a constant burden not only for hearing-impaired people but also for their families and caregivers (Adib-Hajbarghery & Ahmadi, 2019; Limpawattana et al., 2013).

Fortunately, rehabilitation options exist for all types of HL conditions, regardless of the cause or location within the auditory system. For those who decide to overcome deafness, and choose to do so by hearing and communicating verbally, new and more refined rehabilitative techniques are more and more available. Despite the difficulties in treating the most critical cases, the results of hearing rehabilitation have been systematically shown to be positive, improving significantly patients' quality of life (Brodie et al., 2018). Patients have at their disposal great and constantly improving diagnostics and innovations. Particularly, there is a growing interest in the scientific community in integrating new technologies in the treatment of HL such as digital hearing aids, bone-anchored hearing aids, and cochlear implants (Lachowska et al., 2014; Mosnier et al., 2015; Shin et al., 2007).

Despite these results and the new possibilities offered by continuing technological innovation, due to an aging population and better and faster diagnosis of hearing impairment conditions, the number of people with HL is expected to continually grow (World Health Organization, 2018). Being a chronic condition, these patients will need to access effective and responsive hearing health services for the rest of their lives. In other words, the growing incidence of HL is likely to put a lot of pressure on health care systems and providers with an increasing bulk of chronic patients to take care of for years. Therefore, great attention should be dedicated to strategic planning determining how future resources will be organized and managed. In this view, it is

fundamental to investigate the organizational and cultural context around HL, where a wide and diverse interrelated network of organizations and stakeholders with different roles, interests, and approaches can be described. While many clinical studies on HL have been performed, less attention has been paid to its organizational and cultural attributes. This is especially true in Italy where, to the best of our knowledge, only scarce evidence currently exists.

The scope of this study is the Italian micro-organizational and cultural background around HL, which comprises patients, caregivers, health professionals, associations, and more broadly the community of citizens. This study aims at providing a first overview of the perspectives and experiences of these stakeholders.

Research Setting

The present study was funded by the Audio-Vestibology Unit of Varese hospital (Unità di Audiovestibologia, ASST Sette Laghi). Its results were presented in December 2020 during the event "A Global Overview On Deafness" (GOOD) organized by the Audiological Foundation of Varese (Fondazione Audiologica Varese, FAV), which brought together hearing specialists, technicians, educators, speech and behavioral therapists, researchers, patients, associations, and families.

Methods

A cross-sectional design was employed consisting of three online self-administered surveys, namely: the Citizens and Patient Survey, the Patients and Caregivers Associations Survey, and the Health Professionals Survey. The Citizens and Patients Survey was addressed to any person aged 18 years and older not suffering from a hearing disorder ("citizens", i.e. normal-hearing people). The questionnaire consisted of 22 items investigating respondents' knowledge about deafness and hearing impairment conditions, as well as their opinions on the expected health and social outcomes. Furthermore, the following socio-demographic variables were also collected from respondents: sex, age, education, employment, and the presence or not of a

hearing impairment diagnosis. In a second moment, it was decided to extend the distribution of the Citizens and Patients Survey to a smaller sample of hearing-impaired participants ("Patients") to provide a benchmark to better discuss the responses provided by normal-hearing respondents.

The Patients and Caregivers Associations Survey consisted of 28 items and was addressed to the representatives and members of associations composed of hearing-impaired patients and their caregivers. Besides collecting master data (such as year of establishment, number of associates, etc.), the questionnaire investigated the mission, main activities, projects, collaborations, issues, and challenges faced by the associations.

The Health Professionals Survey was addressed to three categories of health professionals working in audiology departments: audiologists (27 items), audiometrists (20 items), and speech therapists (23 items). The objective of the questionnaire was to collect different information about respondents' professional experience (such as the characteristics of their patients and the units where they work or the types of treatments and activities covered), besides their opinions about the present and future of their profession.

The surveys were distributed between June and November 2020 through the online platform SurveyLegend®, which guaranteed an automatic de-identification and anonymization of the collected data. To secure an extensive and fast collection of data, a convenience sampling approach was adopted: the distribution of the web links to the surveys was organized by the Audio-Vestibology Unit of Varese hospital through its network of affiliated patients, caregivers, associations, and health professionals. Respondents were also invited to forward the invitation to participate in the research through their networks to further increase distribution ("word of mouth" approach). All three questionnaires were made available both in Italian and English (the Patients and Citizens Survey also in Spanish and Russian) to allow also an international distribution and avoid any possible language barrier for non-Italian speakers.

The data analysis was developed in collaboration with the Department of Management, Economics, and Industrial Engineering (Dipar-

timento di Ingegneria Gestionale) of Politecnico di Milano. First, to increase the reliability of the three surveys, a listwise deletion of missing data was applied. Furthermore, to reduce data noise, responses were carefully checked for possible outliers. Subsequently, descriptive statistics (frequency analysis) was used to report the results obtained from each overall sample of the three surveys. Finally, the differences in the responses among various subgroups of the samples (e.g. between people with hearing impairment and not in the Citizens and Patients Survey) were assessed with a qualitative group comparison analysis.

This study has been performed in accordance with the ethical standards of the institutional research ethics committee of Varese hospital and the 1964 Declaration of Helsinki and its later amendments. All respondents gave informed consent to take part in the study.

Results

Sample characteristics

The sample involved in the Citizens and Patients survey consisted of 2537 respondents: 95.5% normal-hearing and 4.5% with a hearing impairment condition. Women represented around 75% of the sample. Almost 12% of the sample aged 60 years or older, while 18% was 30 or younger. About half of the respondents had a university degree, while 7% had a lower level of education (middle school degree or less). Finally, almost 59% of the sample was employed, students represented 10% of the participants.

The Patients and Caregivers Associations Survey was filled by 28 members/representatives of associations made up of hearing-impaired patients and caregivers. 16 were Italian associations, the remaining international ones (mainly from Western European and Scandinavian countries). 57% operated in more than one country. Besides hearing-impaired people and their caregivers, most of the associations were attended also by hearing health professionals, psychologists, and other external supporters. For half of the sample, the number of associates does not

exceed 100 and the membership is free or its cost does not exceed 20€ annually.

Concerning the Health Professionals Survey, since only a limited number of audiometrists participated in the research, this category of professionals was excluded from further analysis. In total, 263 professionals filled the survey (about 60% audiologists and 40% speech therapists). Around 70% of respondents were 50 years old or younger, almost 60% were working in northern Italy, 11% in the center, and the remaining 29% in the south or the islands. About 95% of the audiologists were employed in a private structure (42,5% of the speech therapists). Finally, almost 61% of the audiologists stated to be in contact with at least one clinical audiology referral center, while 89% of the speech therapists were working in more than one center.

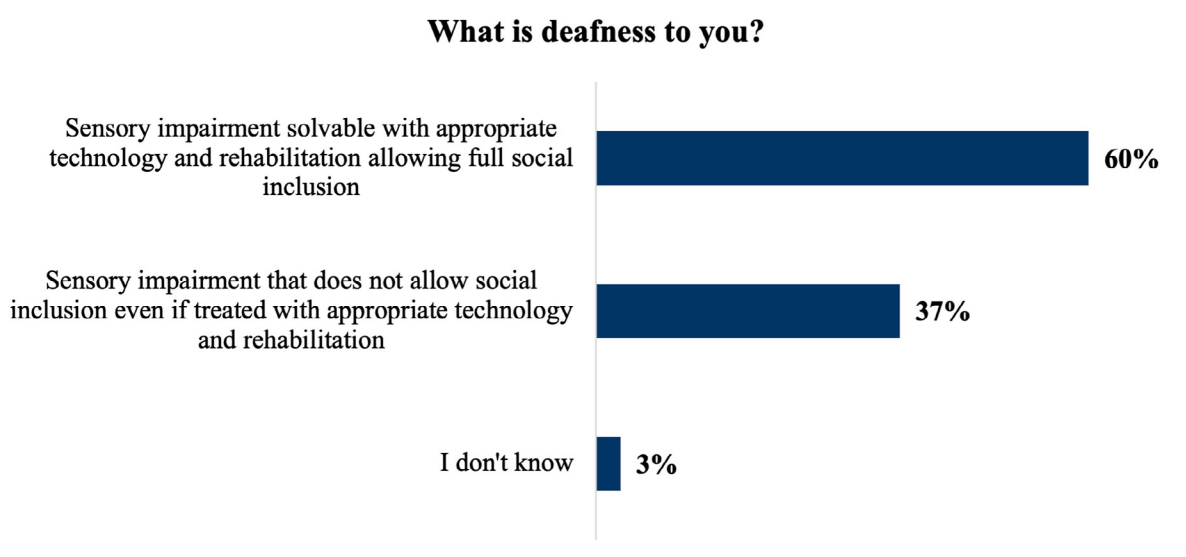
Descriptive statistics and differences across subgroups

1. Citizens and Patients Survey

Around 37% of normal-hearing respondents considered deafness as a disease that could prevent the social inclusion of hear-

ing-impaired people, even if treated with appropriate technologies and rehabilitation (Figure 1). Furthermore, while around 94% of them considered hearing impairment not to represent a relevant obstacle to get a university degree, 25% felt hearing-impaired people face limitations in their career advancement. Regarding leisure activities, the percentages of normal-hearing participants who agreed that deaf people can learn new languages, go to the cinema or theater, and play sports without facing great difficulties corresponded respectively to around 78%, 79%, and 87%. 15,5% of them considered the activity of talking on the phone to be very complicated for deaf people. Concerning the technologies and means to cope with hearing impairment, around 88% of normal-hearing respondents reported being familiar with hearing aid devices and 68% with cochlear implants. Specifically, the following were valued as the most relevant: cochlear implants (92% considered them important or very important), hearing aids (94%), and sign language (84%). According to about 30% of normal-hearing participants, hearing-impaired people can still communicate verbally (Figure 2).

Figure 1. Normal-hearing respondents' opinions on deafness



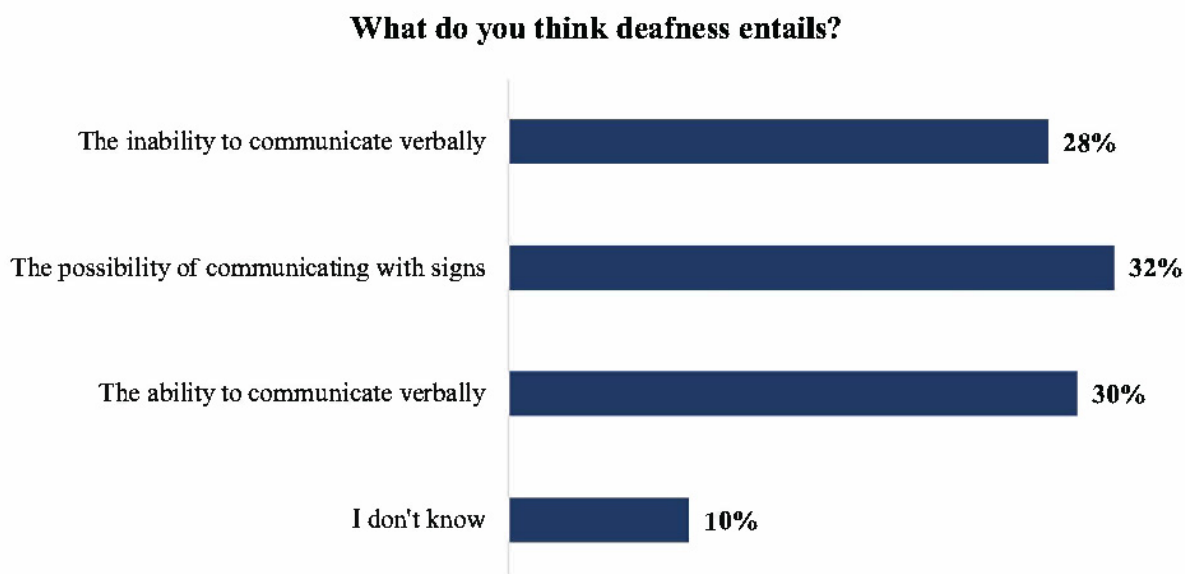
Some relevant differences were observed between normal-hearing respondents and hearing-impaired ones. The latter were less

optimistic about their educational and professional possibilities: around 19% considered hearing impairment to represent a

relevant obstacle to get a high degree of education and 31% in their career advancement (compared respectively to 6% and 25% of normal-hearing respondents). Second, a greater proportion of hearing-impaired participants indicated that, even in presence of their disease, it is possible to communicate verbally

(58% of hearing-impaired respondents VS 30% of normal-hearing ones) rather than with only sign language (5% VS 32%). Finally, sign language was considered very important by only 24% of hearing-impaired respondents (48% of normal-hearing ones).

Figure 2. Normal-hearing respondents' opinions on deafness outcomes

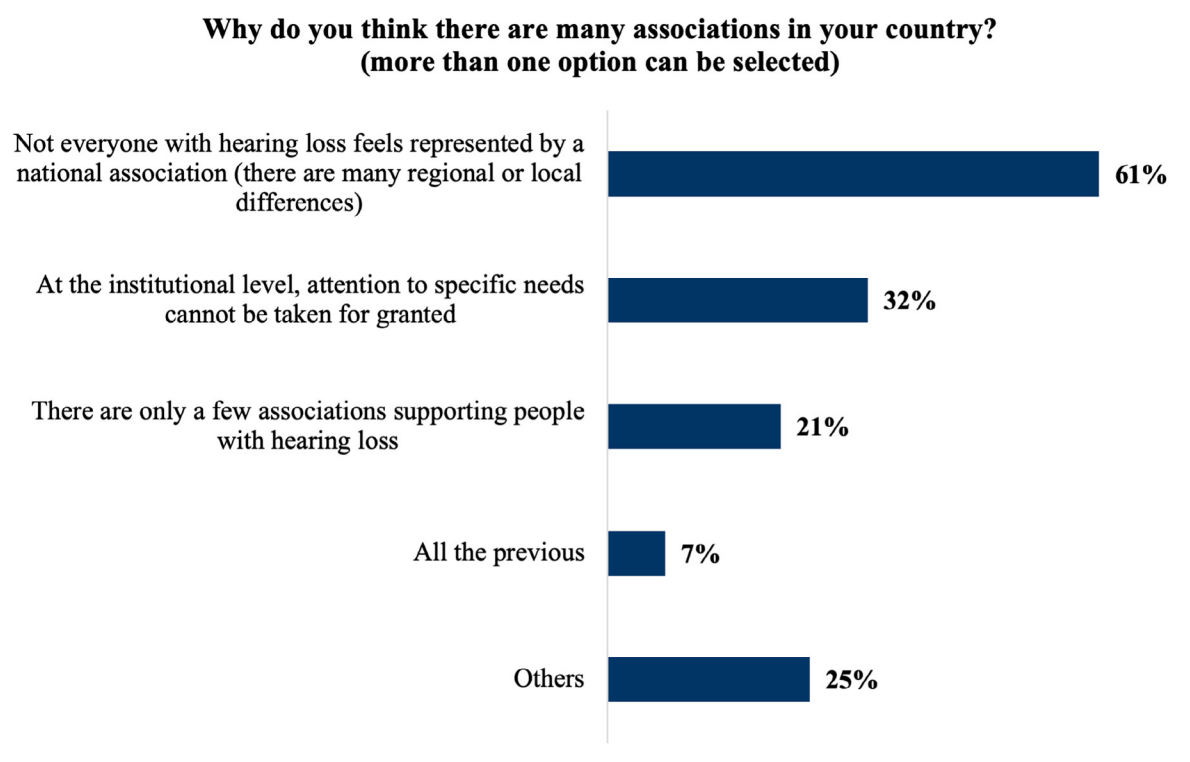


2. Patients and Caregivers Associations Survey

The main reasons why the associations were founded were: exchange information between parents of children with hearing impairment (50% of the respondents), act as an intermediary between hearing-impaired people and politicians/administrative bodies (49%), and promote awareness and information about deafness and its treatments (47%). Other motivations were: exchanging information among parents of children with cochlear implant (43%), supporting research (32%), supporting a specific rehabilitation center (29%), raising funds for specific care projects (14%), and promoting awareness and information about sign language (7%). The main activity covered by the associations was promoting events (such as scientific conferences) to raise awareness about hearing diseases (71.5% of the respondents). Other activities were psychological (39%), legal and administrative support (36%) to the members, and charity

initiatives organization (36%). For 68% of the sample, fundraising is the main problem that associations have to face, followed by institutional relationship management (50%), bureaucracy management (25%), and access to dedicated services for associations (18%). The presence of different regional or local associations was considered necessary by 61% of the respondents: in this way, the peculiar characteristics of each different context can be effectively represented (Figure 3). Furthermore, about 90% of the sample stated that it would be useful to have cooperation between these local associations. Specifically, concerning the Italian associations, the activity on which the cooperation could be more useful was the promotion of events (for example in schools or senior centers) to inform about hearing impairment conditions and their treatment (47% of the Italian respondents). Finally, 80% of them stated that they would be willing to write joint press releases to address policymakers and administrators with common proposals.

Figure 3. Reasons why many associations exist in the same country



One significant difference was observed between Italian and international associations: according to 42% of the international respondents, there should be more associations supporting people with hearing impairment (6% of Italian participants).

3. Health professionals Survey

Only around 40% of the audiologists indicated to be currently working with cochlear implants, but 76% of the remaining were interested in this technology. More than 63% of the speech therapists stated that only one out of four of their patients suffer from hearing impairment conditions, mostly children. In this case, while most of the respondents declared to involve parents and/or caregivers during the rehabilitation sessions (almost 77% of the respondents) or at home (65%, through "homework" assignment), just a minority (28%) was using digital solutions (such as telemonitoring and teleconsultation) to implement remote rehabilitation models. In terms of education modes, professional training and updating courses (including online courses and webinars) were indicated as the most

used and suited means (almost 61% of the respondents), followed by national and international conferences (57%). However, the Italian training offer was evaluated poorly adequate by about 54% of the speech therapists. Regarding the future prospects of their profession, 37% of the audiologists foresee their role to evolve into the one of global hearing consultants, while 30% of them expect a sensible increase in the development and implementation of telefitting and remote assistance activities (Figure 4). Greater integration of digital rehabilitation solutions (through telemonitoring and teleconsultation) with traditional ones in their practice was also predicted by almost 66% of the speech therapists (Figure 5). Furthermore, around 27% of the audiologists expect in the future to be more involved in the management of cochlear implants. Finally, the rising sensitivity and awareness about hearing impairment and the subsequent increase in the volume of patients were indicated as the main expected drivers of change for the roles and activities of hearing health professionals.

Few significant differences were observed by segmenting the sample of health professionals through its different descriptive vari-

ables. Concerning cochlear implants, these were managed mainly by older audiologists (63% of 50 years or older audiologists against 33% under 50). Besides, the majority of these professionals were working in northern Italy (51%), while the remaining 36% and 22% respectively in the center and south.

Figure 4. Audiologists' opinions on the future of their profession

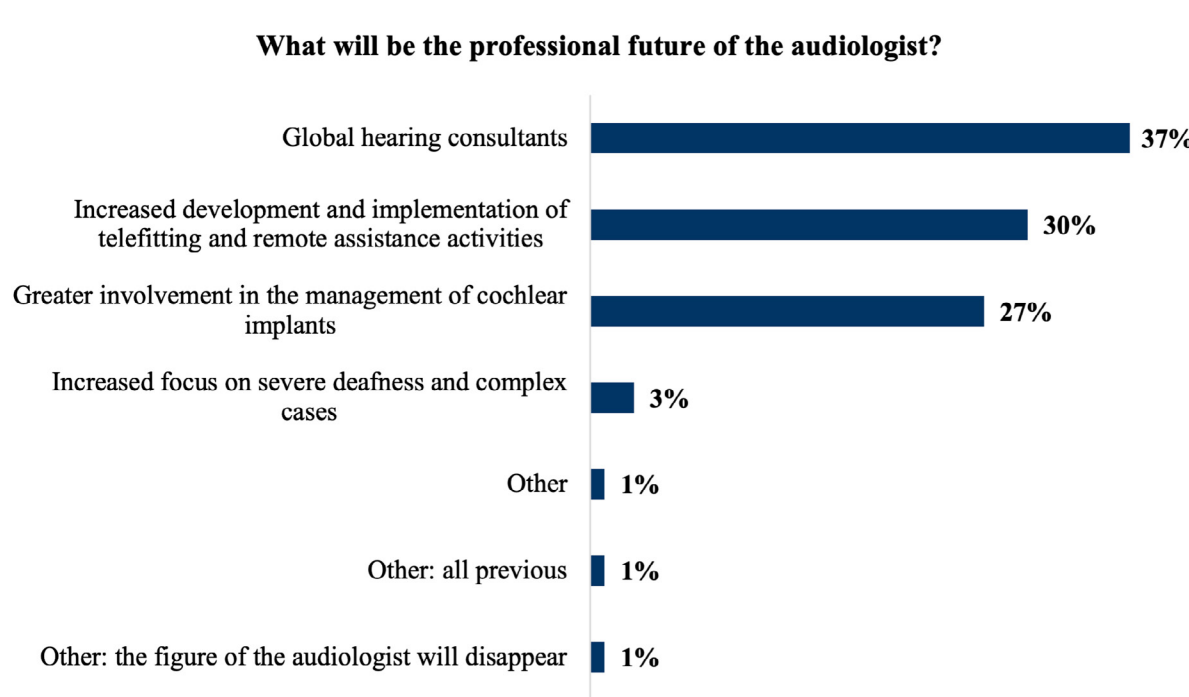
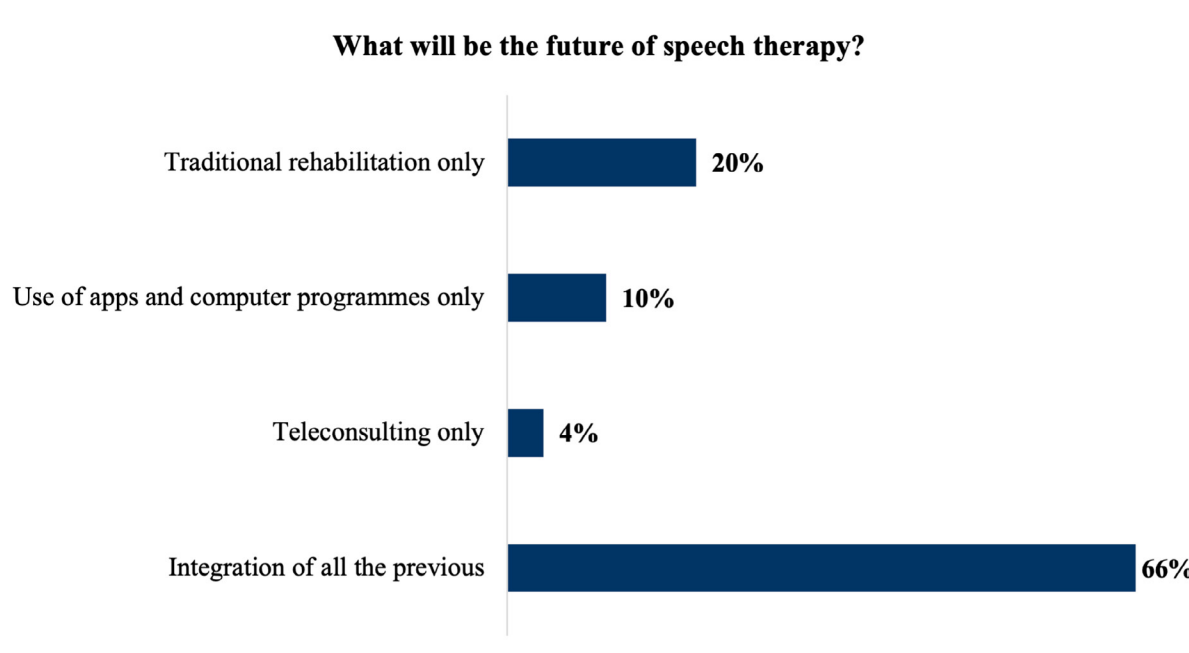


Figure 5. Speech therapists' opinions on the future of their profession



Discussion

The objective of this study was to provide a first overview of the Italian (micro) organizational and cultural context around HL. Through three cross-sectional surveys, the perspectives and experiences of 2423 citizens, 114 patients, 28 members/representatives of associations, and 263 health professionals were collected and analyzed. We also collected data from some participants who were not the primary recipients of our research, such as international associations, which allowed us to have a benchmark to better argue our findings. This extended and diversified sample allowed us to obtain consistent data and draw the first comprehensive considerations about the Italian (micro) organizational and cultural context around HL considering different categories of stakeholders.

Regarding the Citizens and Patients Survey, normal-hearing respondents had a pessimistic, if not negative, view about some of the outcomes and possibilities of people with hearing impairment, especially regarding social integration and career advancement opportunities. Part of this result might be due to the respondents' lack of appropriate knowledge and information about hearing impairing conditions and the benefits of effective treatments and rehabilitation. However, some of these issues and difficulties were also confirmed by the patients who filled in the same survey. Therefore, from our data, two distinctive needs and possible indications for practitioners and policymakers emerge. First, the need to increase the awareness and knowledge of citizens about HL and its treatments. Second, to ensure that people with hearing impairment are always put in the best possible conditions from the point of view of social integration and equal opportunities.

Concerning the Patients and Caregivers Associations Survey, associations resulted to be important points of reference for their members in different areas ranging from bureaucratic/organizational issues assistance to psychological and/or social support. Further research should be done to verify if and how these associations are filling some of the gaps in the support of patients and caregivers left at the institutional level, as some of our data seem to suggest. Interestingly, a significant

proportion of international respondents argued that there is a shortage of associations in their countries, unlike Italian respondents. The vast ecosystem of Italian associations instead seems to be capable of expressing the various local needs and demands. However, a will for aggregation and collaboration at a broader (national) level was also expressed. This would allow taking charge of the requests and issues of greater scope.

Finally, in the Health Professionals Surveys, the most relevant finding emerged from the perspectives about the digital solutions enabling remote activities such as telemonitoring, telefitting, and teleconsultation. Both audiologists and speech therapists are confident of the growing importance and the need for the integration of these solutions into their practices. However, despite these claims and the still ongoing pandemic period, the use of digital solutions seems to be quite limited from what emerges from our data. Yet, telemedicine could be a key instrument for effectively managing the increasing number of chronic patients that will need treatments and rehabilitation for the rest of their lives, such as hearing-impaired ones (Cristofari et al., 2021; Meli et al., 2021).

Our study was subjected to some limitations. First, while easy and fast to obtain, our convenience sample might not be fully generalizable to the overall population since the sample has been drawn from that part of the population that was close to hand (i.e., around the network of the Audio-Vestibology Unit of Varese hospital). Second, in the Citizens and Patients survey, the sample of patients was quite restricted compared to normal-hearing respondents (4.5% patients, 95.5% citizens). However, this proportion is roughly consistent with the proportion in the global population (World Health Organization, 2018). Finally, because of the limited number of responses provided in the Health Professionals Survey, it was not possible to analyze the perspectives and experiences of the audiometrists who joined the research.

Since, to the best of our knowledge, this was the first research of this kind in the Italian context, the findings of our study should be further investigated with future research. Our study could also be replicated over different periods of time, adopting a longitudinal ap-

proach (e.g., analyzing the experiences of patients in different phases of the rehabilitation process). Finally, the methodology followed in

our study could also be refined starting from the limitations mentioned above.

Conclusions

In this study, we provided a first overview of the Italian organizational and cultural context around HL considering the perspectives and experiences of several different stakeholders. These actors have different roles, interests, and approaches. In a world with an increasing need for hearing assistance, only considering all these different facets will it be possible to reach the common goal of “hearing life”.

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Declaration of conflict of interest

The authors declare that there are no relationships/conditions/circumstances presenting a potential conflict of interest.

Supplementary materials

The English version of the three surveys presented in this study and the frequency tables of each survey question are available upon request to the authors.

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