



The empowerment of individuals with hearing impairment: literature review

O empoderamento de indivíduos com deficiência auditiva: revisão de literatura

El empoderamiento de las personas con pérdida auditiva: revisión de la literatura

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Abstract

Introduction: empowerment is linked to self-advocacy and the learning of both by people with disabilities is essential for them to conquer the personal power to manage their destinies. **Purpose:** to list the intervention strategies used for the empowerment of individuals with hearing impairment. **Methodology:** a search was carried out in the Latin American and Caribbean Literature in Health Sciences (LILACS), Public Medicine Library (PubMed) databases and in the Google Scholar search engine, by crossing previously selected descriptors. Studies that evaluated, proposed strategies or discussed the empowerment of individuals with hearing impairment were included. **Results:** 186 studies were found. Of these, 18 were read in full and 11 were included in this review. The year of publication of the studies ranged from 2011 to 2021. The included studies discuss, at some point, the empowerment of individuals with hearing impairment, but the minority proposes and reports results of intervention strategies to work on this aspect. The studies propose that empowerment start through parents, in early intervention centers. The empowerment of adolescents with hearing impairment is extremely necessary and group intervention strategies can be beneficial for this purpose. Only one Brazilian study proposed an intervention strategy for this population. **Conclusion:** Empowerment must start through the parents, right after the diagnosis

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of hearing loss. Adolescents can become role models for their peers in this regard and adults must be empowered before adapting the listening device.

Keywords: Empowerment; Health Advocacy; Hearing Loss; Speech, Language and Hearing Sciences.

Resumo

Introdução: o empoderamento está atrelado à autoadvocacia e a aprendizagem de ambos por pessoas com deficiência é fundamental para que essas conquistem o poder pessoal de gerir seus destinos. **Objetivo:** elencar as estratégias de intervenção utilizadas para o empoderamento do indivíduo com deficiência auditiva. Metodologia: realizou-se busca nas bases de dados Literatura Latino-americana e do Caribe em Ciências da Saúde (LILACS), *Public Medicine Library* (PubMed) e na ferramenta de buscas *Google Acadêmico*, por meio do cruzamento de descritores previamente selecionados. Foram incluídos estudos que avaliassem, propusessem estratégias ou discutissem sobre o empoderamento do indivíduo com deficiência auditiva. **Resultados:** Foram encontrados 186 estudos. Destes, 18 foram lidos na íntegra e 11 foram incluídos nesta revisão. O ano de publicação dos estudos variou de 2011 a 2021. Os estudos incluídos discutem, em algum momento, sobre o empoderamento de indivíduos com deficiência auditiva, porém a minoria propõe e relata resultados de estratégias de intervenção para trabalhar esse aspecto. Os estudos propõem que o empoderamento inicie por meio dos pais, nos centros de intervenção precoce. O empoderamento dos adolescentes com deficiência auditiva faz-se extremamente necessário e estratégias de intervenção em grupo podem ser benéficas para este fim. Somente um estudo brasileiro propôs uma estratégia de intervenção para essa população. **Conclusão:** O empoderamento deve começar por meio dos pais, logo após o diagnóstico da deficiência auditiva. Adolescentes podem tornar-se modelos para seus pares quanto a esse aspecto e adultos devem ser empoderados antes da adaptação do dispositivo de escuta.

Palavras chave: Empoderamento; Advocacia e saúde; Perda auditiva; Fonoaudiologia.

Resúmen

Introducción: el empoderamiento está vinculado a la autogestión y el aprendizaje de ambos por parte de las personas con discapacidad es fundamental para que adquieran el poder personal para gestionar sus destinos. **Objetivo:** enumerar las estrategias de intervención utilizadas para el empoderamiento de las personas con discapacidad auditiva. Metodología: se realizó una búsqueda en las bases de datos de Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS), *Public Medicine Library* (PubMed) y en el buscador *Google Scholar*, cruzando descriptores previamente seleccionados. Se incluyeron estudios que evaluaron, propusieron estrategias o discutieron el empoderamiento de las personas con discapacidad auditiva. **Resultados:** Se encontraron 186 estudios. De estos, 18 se leyeron en su totalidad y 11 se incluyeron en esta revisión. El año de publicación de los estudios osciló entre 2011 y 2021. Los estudios incluidos discuten, en algún momento, el empoderamiento de las personas con discapacidad auditiva, pero la minoría propone e informa resultados de estrategias de intervención para trabajar en este aspecto. Los estudios proponen que el empoderamiento comience a través de los padres, en los centros de intervención temprana. El empoderamiento de los adolescentes con discapacidad auditiva es extremadamente necesario y las estrategias de intervención grupal pueden ser beneficiosas para este propósito. Solo un estudio brasileño propuso una estrategia de intervención para esta población. **Conclusión:** El empoderamiento debe comenzar con los padres, inmediatamente después del diagnóstico de pérdida auditiva. Los adolescentes pueden convertirse en modelos a seguir para sus compañeros en este sentido y los adultos deben empoderarse antes de adaptar el dispositivo de escucha.

Palabras clave: Empoderamiento; Defensa de la Salud; Pérdida Auditiva; Fonoaudiología.



Introduction

Health promotion strategies have been modified along the years from the moment that there was a disruption from a bio-ethical to a biopsychosocial model¹. Recently, the need that a subject become autonomous and socially responsible has been standing out in terms of health promotion².

Empowerment is a complex concept with its roots linked to social movements from the second half of the 20th century, followed by self-help and Psychology movements¹. It means to provide someone with power. However, another adopted concept of empowerment follows the reasoning that:

“The empowered person, group or institution is the one that performs the necessary changes and actions by themselves, leading them to evolve and strengthen themselves”³.

Not all health promotion strategy is an empowerment strategy. Nevertheless, every empowerment strategy is also a health promotion⁴. Therefore, the use of empowerment strategies in health care aims that subjects get more control over their decisions and actions affecting their health³.

Empowerment is connected to self-advocacy, and learning both is fundamental for disabled individuals so that they can achieve personal power to manage their destinies. Self-advocacy can be seen as a philosophy, aiming to rescue the value that impaired people as human beings, and also makes them authors of their own story⁵.

Hearing impairment (HI) is a condition that requires individuals to make use of electronic devices applied to deafness, such as hearing devices and/or cochlear implants so that they can develop their hearing skills as well as oral language. Such individuals may become fragile and vulnerable due to the stigma of their condition, their difficulty in communication and the fact of wearing an electronic device by itself, often making them speechless and withdrawn in certain situations^{6,7}.

Thus, empowerment strategies for hearing-impaired subjects are essential to promote their awareness about themselves and their rights, apart from doing away with their stigma and disability paradigm⁷.

Given the aforementioned, this study aimed to survey intervention strategies reported by literature and used for the empowerment of hearing-impaired individuals.

Methods

“An integrated literature review was conducted. The guiding question considered was as follows: “What strategies have been used for the empowerment of hearing-impaired individuals?””.

Search was carried out in the databases of Latin America and Caribbean Center on Health Sciences Information (LILACS in Brazilian Portuguese), Public Medicine Library (PubMed), and in the Google Scholar public search engine in June 2021. The following descriptors were selected in the Health Sciences Descriptors (DeCS in Brazilian Portuguese): “empoderamento para saúde” (“empowerment for health”), *advocacia em saúde* (“*health advocacy*”) e perda auditiva (“*hearing loss*”).

The adopted inclusion criteria were as follows: studies that assessed proposed strategies or discussed about disabled individuals’ empowerment in Portuguese or English in full version, with free access and/or by means of the Virtual Private Network (VPN). Excluded studies were the ones which only addressed or comprised individuals with other disabilities rather than hearing impairment. A pre-defined time span was not established for study inclusion. The selection phase was conducted independently by two reviewers. Disagreement between them on study inclusion was settled by a third reviewer with experience in the area of hearing re(habilitation).

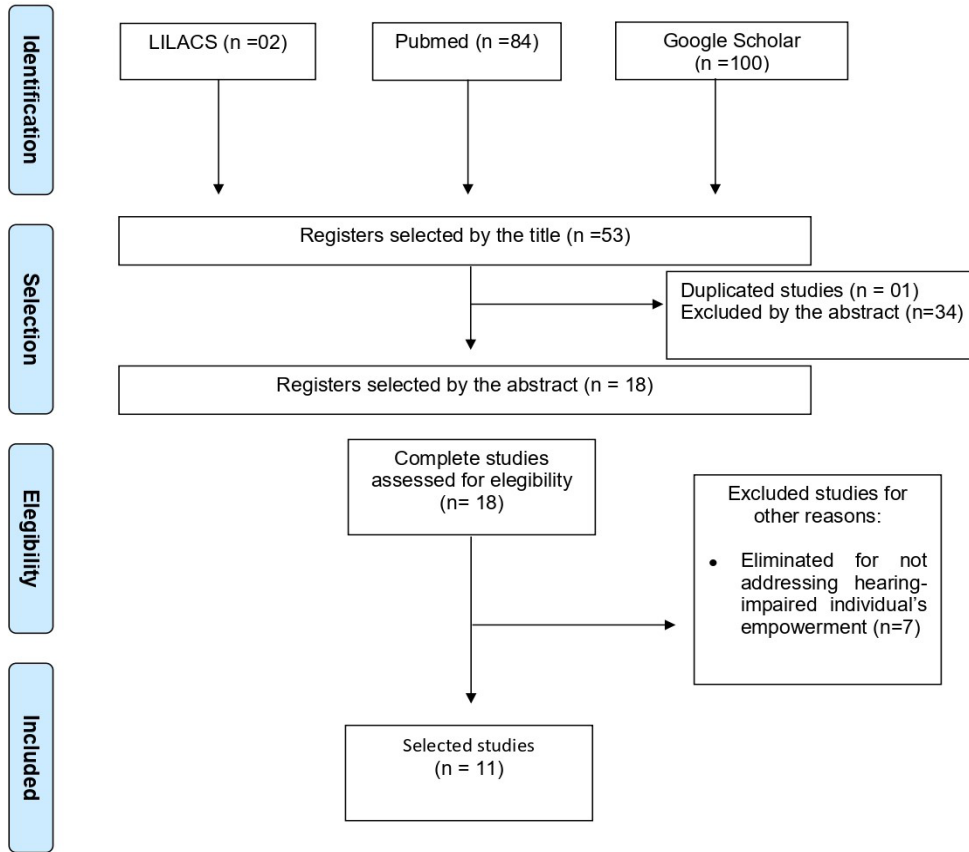
Initially, the studies were pre-selected by the title. Their abstracts were read in order to verify if they met the proposed objective. Subsequently, the full reading of the included studies was carried out.

The included studies were analyzed in view of their objective, studied population, applied methodology, and the obtained results.

Results

Two hundred and eighty-six (286) studies were found in the databases search. From those, 53 were selected by their title. After reading the abstracts, 18 studies were fully read, and 11 met the pre-established criteria, being included in this review (Figure 1).

The main data of the included studies are shown in Table 1.



Caption: n=number of studies

Figure 1. Flowchart of the selection of the studies

Table 1. Main information on the studies included in this literature review

Year	Lead author	Country	Objective	Sample	Methods	Main results
2021	Gotowiec, S	Switzerland	To address how empowerment is manifested from individuals' early awareness of their hearing impairment until the adaptation of the hearing aid	Adults, users of hearing aids for a minimum of 06 and maximum of 36 months (n=18)	Semi-structured interview	Participants reported: to have obtained unclear answers to their doubts by professionals and turned to the Internet after information in the pre-adaptation phase; doubts after the adaptation related to the functioning of the hearing aid and the app for their cellphone; knowledge obtained post-adaptation helped them decide for its use; passive participation in the process.
2020	Silva, RLF	Brazil	To verify the effectiveness of the intervention by means of group activities for the empowerment of hearing-impaired adolescents	Adolescents, users of hearing aids and/or cochlear implants, users of oral language (n=4)	Five face-to-face meetings with recreational activities in line with the Rule at the School; Instruments used: "I can" Self-advocacy Checklist ; CPQ; WASI; IHS-Adolescent	The rapport helped the group strategy. Answers improved in the Self-advocacy Checklist and worsened in some items of the CPQ after the intervention.
2018	Resende, MC	Brazil	To report an event aiming at the visibility of people with disabilities.	Three teams comprising 24 participants each, with 50% of the team participants with some type of disability. (n=72)	Inclusive Gymkhana with the following activities: kayak race, wheelchair race, famous people performance, games with recycling materials and a get-together with artistic performance	The most relevant aspects of the Gymkhana were the representativeness and visibility with the protagonism of the disabled people.
2017	Kulkarni, KA	India	To identify the current empowerment practices of parents who have hearing-impaired children	Parents (n=50) and educators (n=30) from five early intervention centers for hearing-impaired children	Recorded oral interview, subsequently transcribed. Parents' knowledge, engagement and needs on hearing impairment were argued	Parents reported their wish to know about several available resources to their hearing-impaired children, about the hearing aids, needed care and maintenance. Some parents thought that verbal hearing therapy was only applied to children with cochlear implant. Other expressed needs were: information on developmental milestones, "time management", and strategies to prepare them for school attendance



Year	Lead author	Country	Objective	Sample	Methods	Main results
2017	Sexton, J	USA	To address the emotional journey of hearing-impaired adolescents and their families	Not applicable	Review study	Identified empowerment strategies: adolescents' mentoring for hearing-impaired younger children; support groups for hearing-impaired adolescents; use of virtual platforms to facilitate continuing communication between hearing-impaired adolescents.
2016	Ciciriello, E	Italy	To report the results of an analysis which identifies strength, weaknesses, opportunities and threats in the family empowerment process during the early diagnosis and intervention of hearing impairment.	Parents (n=23) of hearing-impaired children and hearing rehabilitation professionals (n=25)	Questionnaire with open questions on the positive and negative points of the intervention program; application of the SWOT strategies.	Parents view as negative points: long waiting lists, poor facilities, understaffing, lack of psychologists. Reported as opportunities: distance training, elaboration of informative, easily accessed materials.
2014	Dantas, TC	Brazil	To analyze individual experiences, laws, policies, guidelines and behaviors related to the empowerment and self-advocacy of people with disabilities in Brazil and in Canada.	Twenty-eight disabled people from Brazil and Canada.	Individual semi-structured interview addressing the following items: (1) Family Life, (2) Schooling, (3) Work, (4) Social life and sexuality and (6) Experiences of self-advocacy and empowerment	Disabled people have changed their reality by means of their life stories and actions, which are decisive to other people's lives.
2013	Vieira, GI	Brazil	To analyze the implementation of the National Hearing Health Care Policy in São Paulo City, São Paulo State	Professionals from High Complexity services (n=47)	Data collection from official documents; from information systems; from observation in regional forums; from semi-structured interview held with professionals.	The discourses evidence a tendency to the biomedical model. Subjects' empowerment was not present in the forums and documents; some discourses address subjects' lack of autonomy.
2012	Bruce, SM	USA	To prepare deaf-blind individuals for self-advocacy.	Deaf-blind young adults (n=6)	One-week course on self-advocacy and engagement, focusing on policy issues that affect the lives of deaf-blind individuals. The course included guidance, interviews, diaries and discussions.	Eight themes emerged from the analysis of the interviews, newspapers and discussion notes in the classroom: (a) definition of defense and advocacy (b) rights and equality, (c) expectations, (d) the role of the education in the change, (e) experience in deaf-blindness, (f) characteristics of effective agents of change, (g) advocacy requires team work and (h) plans for future advocacy.



Year	Lead author	Country	Objective	Sample	Methods	Main results
2011	Cardozo, PS	Brazil	To analyze the emancipation and empowerment that the Continuous Cash Benefit (Benefício de Prestação Continuada - BPC) provides for the disabled.	Individuals with disabilities (n=52)	Semi-structured interview with the following items: schooling, type of disability, length of time of the concession of the benefit and revisions during the concession, with debate on the autonomy and empowerment of the individual.	The Continuous Cash Benefit is an important acquisition as it is an income-transfer assistance benefit, which has not promoted the autonomy of its recipients yet.
2000	Munoz-Baell, IM	Spain	To discuss the empowerment strategies to hearing-impaired individuals	Not applicable	Review study	Models of empowerment are characterized by a broad context structure. Five strategies can be identified: to improve legislation on communication barriers, to provide the necessary information, to improve patients' coping strategies, to improve the health care settings, and to improve doctor-patient communication.

Caption: CI=Cochlear Implant; n=number of participants.

Discussion

The included studies discuss, at some point, the empowerment of hearing-impaired individuals. However, the minority of such studies proposes and reports results on intervention strategies in order to address that aspect with that population.

Despite a publication time span of the articles had not been defined, those which met the pre-established inclusion criteria were published between 2011 and 2021, with just one study having been published in 2000. Ten-year time gap was verified without any publications with the features searched in this study. The timeliness of the studies included in this review can be justified by the fact that the theme researched here is also a current one.

Empowerment primarily means “giving power and authority to a person”⁸. However, some authors pointed out the need to conceptualize empowerment applied to the journey along hearing health of individuals, thus, they propose the following definition⁹:

“Empowerment along the hearing health journey is the process through which individuals with hearing-related challenges acquire and use knowledge,

skills, and strategies, and increase self-efficacy, participation, and the feeling of control of their hearing health care, hearing solutions, and everyday lives.”

In order to define the general strategies for coping with the diverse issues confronted by the hearing-impaired population, it is fundamental to consider that such population is extremely uneven, comprising, among others, those who feature pre-lingual deafness, post-lingual deafness, individuals who communicate by means of the Sign Language, oral deaf, and users of hearing aids or cochlear implant⁸; each group with their specific needs.

One of the groups comprising such diversity is, for example, the group of parents with hearing-impaired children⁸. Nevertheless, parents' empowerment is not often an objective to be achieved by the centers of early intervention¹⁰.

A study¹⁰ analyzed the result of interviews conducted with that population, addressing four themes: knowledge, engagement in the hearing re(habilitation) process, support and needs. The authors concluded that there are gaps in the empowerment of parents in early intervention centers. Thus, it requires better-structured efforts towards



family empowerment so that parents be heard and engaged in the process of decision making for their children.

Increasingly, the speech therapist who works with hearing re(habilitation) has acted as a supporter, partner and coach. Therefore, there is an international recommendation that the main objective of the early intervention program is to promote family skills to provide an awful lot of language opportunities, jointly engaged routines along the natural daily interactions¹¹.

In that sense, for the international recommendations to be followed¹¹, it is necessary that early intervention programs feature an efficient organization, a trained team and enhancement of the available resources¹².

A path to follow would be the development of a common structure to empower parents. The structure components could be developed by means of several domains, as follows: (1) Impairment-related domain – comprising information on assessments, facilities, concessions, service-rendering; (2) Development domain – entailing the knowledge of the critical period, developmental milestones and biases; (3) Partnership domain - comprising knowledge on linguistic planning, collaborative teaching; and, (4) Advocacy domain – entailing the articulation of the child’s needs, shared decision making, networking and mentoring¹⁰.

As hearing-impaired children grow and reach adolescence, there is a critical need to transfer the hearing loss ownership from parents to adolescents, in order to promote self-advocacy and empowerment¹³. Therefore, empowerment is essential at this age range⁷.

A study¹³ divided hearing-impaired adolescents into two groups: those who were born with the disability, and those who acquired it during childhood. Regarding the empowerment, the author reported that the adolescents’ parents from the first group went through the different stages of bereavement due to their children’s diagnosis, as well as the doubts on the choice of the communicative approach to be adopted. They often became so over-protective that they did not allow their children’s transition to independence when they reached adolescence. On the other hand, in the second group, there was an issue involving the adolescents themselves, who faced the transition from “listeners” to “hearing-impaired individuals”, featuring several improper behaviors. The authors pointed out that

understanding their own hearing loss, making use of hearing aids, taking care and maintaining these devices are very helpful to develop self-confidence and independence. In addition, this process should get started as early as possible.

The same study¹³ suggested empowerment strategies for hearing-impaired adolescents as follows: to identify other adolescents and children in the community and school that the adolescent can teach what he or she learned on the theme, as a mentor; support groups in face-to-face meetings or online in order to train them and build up their confidence. In addition, the author points that an evidently successful strategy is the concept of family retreat, and refers to the “CARE project”, which provides emotional support from 10 to 12 families, based on a three-day retreat. While parents participate in educational seminars, children and adolescents join activities and tours supervised by a volunteer. Parents join meetings with other parents who are in diverse stages of their emotional journeys and, apart from that, adolescents, who have attended former retreats, have the chance to return to further retreats as team volunteers and mentors.

Other authors⁷ proposed a group intervention to the same population, using activities and games in order to develop self-advocacy. The authors carried out face-to-face weekly meetings, with a planning divided in four units, which contemplated the definition of self-advocacy, knowledge on disabled people’s rights, personal and interpersonal skills, and the use of self-defense strategies. Every meeting, two or three themes were addressed by means of activities and games. The strategy was concluded as efficient to develop self-advocacy skills for hearing-impaired adolescents’ empowerment. Nevertheless, the authors pointed out that among 20 adolescents invited, only four agreed to participate in the study. Therefore, those young people’s motivation to participate in a group like that was questioned.

Trailing the same path of hearing-impaired subjects’ protagonism, formerly reported in the strategy of the family retreat¹³, another study¹⁴ reported the experience account of an “Inclusive Gymkhana”. The event was held to celebrate disabled people’s fight and was organized by representatives of varied disabled individuals’ associations in a city of Minas Gerais State, Brazil. The participants were divided into three teams, 24 participants in each of them, and 50% of those





should be disabled subjects (subjects with physical, hearing, visual, intellectual or mental disability was mandatory), and 50% of the subjects without any disabilities. The authors reported that the strategy of the “Inclusive Gymkhana” aimed at eliminating hurdles that hinder disabled individuals’ socialization and highlighted the representativeness in society, visibility and protagonism of these individuals. The authors did not analyze variables for each type of disability.

One of the rights for impaired individuals is the Continuous Cash Benefit (Benefício de Prestação Continuada – BPC), which provides one minimum salary a month, since the condition is proved to entail physical, mental, intellectual, sensory long-term disabilities, which prevent them from full and active participation in society¹⁵. A study¹⁶ analyzed the use of the BPC as a factor of empowerment for the disabled. In this study, the authors highlighted that 23% of the interviews on the BPC were carried out with family members, and not with the impaired individuals, standing out the idea of their lack of autonomy.

The requirement of impaired individuals being prevented from active participation in society in order to obtain the BPC, changes that benefit into a “disability certificate”, rather than one of their rights. In this context, that is not a leverage for individuals to be empowered with their potentialities and skills, contributing for greater stigmatization of their disabilities. Therefore, in order to use the BPC as an empowerment strategy for impaired individuals, a revision in its concession requirements deems necessary, apart from including application requirements for individuals older than 18 years¹⁶.

Currently, it is predicted the materialization of a world where individuals with disabilities achieve their full potential by means of rehabilitation, education and empowerment¹⁷. Concerning the hearing health services, the National Hearing Health Care Policy (Política Nacional de Atenção à Saúde Auditiva – PNASA)¹⁸ claims the provision of informative, educational actions, as well as family guidance. A study held in 2013¹⁹ analyzed the implementation of the National Hearing Health Care Policy in the city of São Paulo, São Paulo State – Brazil, and verified that great part of the involved health professionals related hearing health to clinical procedures, most of them to the diagnosis and adaptation of hearing aids. In addition, they complained about the need of providing more

information to users. Thus, the author concluded that the empowerment issue was not present in the analyzed documents and in the professionals’ accounts, even evidencing users’ lack of autonomy.

The use of tools to measure the empowerment dimensions may allow further intervention studies on that aspect⁹. Aiming at coordinating the professional activities entailing family empowerment in the first three months after the hearing loss diagnosis in children, researchers¹² used a tool based on the SWOT analysis principles, that is, Strength (S), Weaknesses (W), Opportunities (O) and Threats (T).

In another study⁸ included in this review, semi-structured interviews were conducted with adults who make use of hearing aids for a minimum of 6 months and a maximum of 36 months. The guiding questions used in the interview were designed to ask about each of the empowerment dimensions: (1) knowledge, (2) participation, (3) control, (4) skills and (5) self-efficacy in each of the points of interest along the timeline (pre-adaptation, post-adaptation and post-adaptation of the hearing aid). Lack of knowledge on hearing impairment and device used along the timeline were observed. Thus, the participants answered that they only knew where to get more information on the theme in the post-adaptation period. Regarding the skills and strategies, the reports evidenced strategy development during the pre-adaptation and adaptation, with the use of skills only during the post-adaptation phase. Lack of social participation was observed between pre-adaptation and adaptation. Participation regarding hearing health self-care was verified during adaptation and social participation after the adaptation. Reports still evidenced that the use of hearing aids was associated to greater feeling of control. Thus, the authors concluded that the empowerment dimensions are important along the self-knowledge trajectory regarding hearing health. Additionally, the creation of strategies, which support hearing-impaired individuals’ empowerment before the adaptation of hearing aids is utterly necessary.

A study held in 2012²⁰ applied an empowerment strategy to deaf-blind young subjects from 18 to 24 years old. The participants attended a one-week course on engagement and self-advocacy. Discussions, interviews and diaries were carried out on the following themes: (a) defining advocacy and advocate, (b) rights and equality, (c) expecta-



tions, (d) the role of education in the change, (e) expertise for the deaf-blind, (f) characteristics of effective agents of change, (g) advocacy and team work, (h) future advocacy.

Apart from refining their communication skills and self-advocacy, some of the young subjects took on the mentoring role on the theme to a new group of “Deaf-blind Young in Action”. These young subjects became role models to others who wanted to take roles of leadership in defense of their rights.

In 2017, a study⁴ aimed to discuss policy issues, social as well as legal ones on the empowerment of the disabled individual, also by means of a semi-structured interview. The sample comprised subjects who lived in Brazil and Canada. The author pointed out that the empowerment of an impaired person is hindered by socioeconomic inequalities of a country, as in developing countries, such as Brazil, this aspect generates fewer opportunities for independent life, work and study.

In Brazil as well as in Canada, the participants highlighted the social discrimination that they suffer due to their feeling of being “pulled off” their family interaction in order to attend specialized institutions⁴. This feeling stresses even more the need to follow the recommendations of international guidelines¹¹, strengthening family participation in the process of (re)habilitation, and making the health professional take the role of a “coach” for that family. Additionally, in general, the institutions, the State and the schools are the voice of the impaired subjects, silencing them. Therefore, the empowerment of this population is the main tool to be used for them to become protagonists of their own stories⁴.

Despite the importance of empowering hearing-impaired individuals, it was observed the scarcity of studies in literature that report strategies to be used in order to achieve that objective. Thus, it is important that further studies on this theme be carried out.

Final considerations

The empowerment of hearing-impaired individuals must start in early childhood by empowering parents in early intervention centers, soon after their children’s diagnosis.

To adolescents, group empowerment strategies have been beneficial, and these individuals may

become knowledge multipliers and role models to hearing-impaired children and adolescents.

Hearing-impaired adults and older adults must be empowered on their condition before the adaptation of their hearing aids.

Disregarding the age range, the diversity of hearing impairment must be considered during the moment of the elaboration and application of strategies.

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