Studies on Stigma regarding Hearing Impairment and Hearing Aid Use among Adults of Working Age: A Scoping Review

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Abstract (198 words)

Purpose: Research on stigma has been criticized for centering on the perceptions of individuals and their effect on social interactions rather than studying stigma as a dynamic and relational phenomenon as originally defined by Goffman. This review investigates whether and how stigma has been evaluated as a social process in the context of hearing impairment and hearing aid use.

Materials and methods: Systematic literature searches were conducted within four major databases for peer-reviewed journal articles on hearing impairment and hearing aid rehabilitation. In these, 18 studies with stigma, shame or mental wellbeing as the primary research interest were identified. The reports were examined for their methodology, focus and results.

Results: The reviewed studies used both quantitative and qualitative methodologies, questionnaires and interviews being the most common methods. All studies concentrated on the participants’ experiences or views concerning stigma. Studies examining the social process of stigmatization were lacking. Most studies pointed out the negative effect of stigma on the use of hearing aids.

Conclusions: In order to understand the process of stigmatization, more studies using observational methods are needed. Moreover, additional research should also focus on how stigma as a social and relational phenomenon can be alleviated.
Keywords: hearing impairment, hearing aid, stigma, working-aged adults

Implications for rehabilitation

- Low adherence in hearing aid use is connected to fear of stigma related to hearing impairment and hearing aids.
- Hearing health services should include counseling to deal with individual’s experiences and fear of stigma.
- Stigmatization is a social process that concerns individuals with hearing impairment in contact with their social environment.
- Hearing health professionals should consider including close relatives and/or partners of hearing impaired individuals in discussions of starting hearing aid rehabilitation.
- In consulting patients with hearing impairment professionals should give advice about how to deal with questions of hearing aid, hearing impairment and fear of stigma at work.

Introduction

Stigma is a frequent explanation for problems experienced during social interactions by people with various disabilities. By stigma, we refer to Erving Goffman’s idea of a process whereby individuals who become associated with a stigmatized condition, such as mental illness or AIDS, experience a lowering of their social status: they are perceived (by others and/or themselves) to bear a sign of spoilt identity [1, 2]. Stigma may appear at societal, interpersonal, and individual levels [3]. Further, it may manifest itself as the institutional legitimization of a stigmatized status, it may be observable in the perceptions and actions towards those who possess the stigmatized condition, or it may appear as an individual’s anticipation of being exposed to stigmatization and to the internalization of the negative beliefs and feelings associated with the stigmatized condition [3]. This fear of being exposed
to stigmatization is one recurrent explanation for the low adherence rate in seeking treatment for various disabling conditions, such as mental illness and physical disabilities [4–10].

Among the various stigmatizing ailments, there are those where the diagnosis itself may cause fear of stigma (such as mental illness or AIDS) and others where the treatment for the ailment is the possible source of stigmatization (such as physical disabilities requiring a specific aid) as the treatment represents a visible sign of disability. Thus, the concealability of the ailment may have impact on stigma management and rehabilitation outcomes [cf. 11]. In hearing aid rehabilitation, these two characteristics - fear of diagnosis and visibility of the remedy - are combined. Hearing aids offer a means to alleviate problems of hearing, which in social interactions are often treated as problems of understanding, implying that the cognitive competence of the person with hearing impairment may be diminished [12, 13]. Furthermore, problems in hearing may result in hearing impaired people being perceived as unfriendly as they may not reply when addressed or may ask their co-participants to speak more clearly [14]. In this way, hearing impairment, as such, could lead to stigma. To avoid such a stigma, hearing aids offer a solution. Yet, according to various studies [13, 15, 16], individuals with hearing impairment are concerned about the visibility of the hearing aid and how it may change their appearance. Furthermore, the use of a hearing aid is often culturally connected with old age and weakening of cognitive competence [17, 18]. Thus, hearing impaired people face a dilemma: avoiding being seen as old and with weakened cognitive competence through not using hearing aid, potentially resulting in categorization as a person with limited social or cognitive skills through hearing impairment.

Drawing upon different estimates, only 20-50% of those who would benefit from the use of hearing aids actually use them [13, 19]. Yet, hearing impairment concerns about every third adult over the age of 40 in Western societies [20, 21]. In a Swedish survey with more than 11 000 respondents, 31% of the working population and 36% of the non-
working population reported hearing loss or tinnitus [22]. Particularly within the working population, hearing impairment is also burden to the economy as it is associated with high frequency of sick leave [23] and early retirement [24]. With respect to the low adherence rate for acquiring and/or using a hearing aid, although it would provide an easy and efficient treatment for the problem, there are consequences for the national economy by increasing the sustainability gap. The reasons for this low adherence include financial reasons, such as the cost of hearing aids, technical reasons, like the fit and comfort of using a hearing aid, as well as psycho-social and situational factors, including stigma [25], which is our concern herein.

Research on stigma has been criticized for having had a distinctly individual focus centering around the perceptions of individuals and their effect on social interactions [26]. Critics have noted that with Goffman’s proposed definition, stigma was depicted as a relational phenomenon, a process of becoming stigmatized [1, 2]. Furthermore, in later definitions of stigma, it has been seen to occur within social interactions and reside within the social rather than the individual context [3]. Thus, there has been calls for attention to the importance of social context and environment as characteristics regarded as stigmatizing [27–29]. This review seeks to investigate whether and how this call for research on stigma as a social process may have impacted empirical research within the framework of hearing impairment and hearing aid use.

In this review, we describe and analyze literature concerning stigma and hearing aid rehabilitation with regards to whether the social process of stigmatization, with its relational aspects, are taken into account, and if so, how. We inquire into what kind of knowledge has been produced with respect to the relation of these two phenomena, and what kind of research approaches are used in such studies. We specifically pay attention to the methodological approaches taken. There exists a recent review concerning stigma and hearing
impairment, but the focus there was on the elderly population, whereas this review covers studies including working-age populations [17].

Materials and methods

We conducted a scoping review [30] where earlier research literature was examined in an effort to gain a more profound understanding of the present state of research on stigma and hearing aid use, specifically to identify existing gaps in the available research. Unlike systematic reviews, the method allows for addressing broader topics and integrating various perspectives and methodologies into the review. The review process was carried out in five stages: 1) identifying research questions; 2) identifying relevant studies; 3) study selection; 4) charting data; and 5) collating, summarizing, and reporting the results.

Search strategy

The literature search strategy was developed and conducted together with an expert informant of the university library in Tampere, Finland. The databases used were Ovid, Proquest, Ebsco Academic Premier, and Scopus. In the search strategy, the term, “stigma”, was connected with hearing impairment or hearing aid-related search terms, as well as with search terms that are presented in the literature as social constituents or consequences of stigma. The search strategy and search terms are presented in Figure 1.
Figure 1. The search strategy and the search terms.
**Inclusion and exclusion criteria**

The inclusion criteria were decided by the whole research group. Our focus was on studies on working-aged people with gradually acquired sensorineural hearing impairment. As the definition of working-age differs across various countries, we were not able to define specific age limits. Thus, we excluded studies that focused on children, infants, adolescents, youth, elderly people outside the workforce, and studies where there was no description of age. However, we included studies where working-aged people were not the only participant group, but which also targeted people outside workforce. As we sought to keep the population as homogeneous as possible, we excluded those suffering from traumatic hearing impairment with sudden onset and those born deaf. In these groups, the different circumstances of the onset of hearing problems could have influenced the experience of stigma. For example, people born deaf develop a deaf identity and use sign language (not hearing aids) to communicate effectively, which may intervene positively in the management of stigma [31, 32]. As we were particularly interested in research concerning the social and relational dimension of stigma and the use of hearing aids, we also included studies where the participants were working-aged people with normal hearing, and the focus was on stigma, shame, or mental wellbeing related to hearing aid use. The rationale behind this decision was that with this approach, we could include studies that examined the social contextual aspects attached to hearing impairment and hearing aids.

Our interest in studies examining the social and relational dimension of stigma resulted in three more inclusion criteria: 1) we included studies where concepts describing social and relational aspects of stigma where central. These included concepts, such as social inequality and social identity, as well as social emotions, like shame and embarrassment (see the search strategy in Figure 1); 2) we restricted the scope of the review to peer-reviewed research articles. Our purpose was specifically to address the methodological approaches
employed in research on stigma rather than gaining an all-inclusive mapping of relevant literature. For that purpose, we found it better to concentrate on peer-reviewed articles where a more rigorous utility of methods would be expected; 3) over the course of the search, we specified our research problem, and according to our final research task, decided to include only articles that were published in the year 2000 or later. Our objective was to examine whether the critique presented on the individual bias of studies on stigma had resulted in changes in the research approaches used in investigations of hearing impairment and hearing aid rehabilitation. As these criticisms were published only after the year 2000, we limited the scope of the literature search accordingly, starting January 1st, 2000 and ending December 31st, 2017.

The inclusion criteria are listed in Table 1.

Table 1: Inclusion and exclusion criteria of article selection

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Inclusion</th>
<th>Exclusion</th>
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<tbody>
<tr>
<td>Time period</td>
<td>1st January 2000 to 31st December 2017</td>
<td>Not within the time period</td>
</tr>
<tr>
<td>Language</td>
<td>Articles published in English</td>
<td>Not in English</td>
</tr>
<tr>
<td>Type of article</td>
<td>Original research article in peer-reviewed journals</td>
<td>Review, or not peer-reviewed</td>
</tr>
<tr>
<td>Study focus</td>
<td>Stigma, shame or mental wellbeing as the primary focus of the article</td>
<td>Stigma, shame or mental well-being as other than primary focus of the article</td>
</tr>
<tr>
<td>Population</td>
<td>Working-aged people with gradually acquired sensorineural hearing impairment, at least as one part of the participant group, and working-aged normal hearing people</td>
<td>Focus exclusively on children, youth, aged, people with acquired traumatic hearing impairment. Focus exclusively on people with sudden onset of hearing impairment and those born deaf</td>
</tr>
<tr>
<td>Specific focus of review</td>
<td>Addressing social and relational aspects of hearing impairment, hearing aid rehabilitation and stigma</td>
<td>Not addressing social and relational aspects of hearing impairment, hearing aid rehabilitation and stigma</td>
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</table>
Two members of the research group conducted the process of inclusion independently. Unclear cases were brought to the research meetings to be solved. Members of the research group scrutinized the unclear cases independently before the meetings. Consensus was reached within the meetings through discussion. This procedure was considered to add more to the reliability of the choices over procedures where one additional member of the group would solve the cases.

**Data extraction and analysis**

The stages of the literature screening are presented as a Prisma (Preferred Reporting Items to Systematic Reviews and Meta-Analyses) representation [33] in Figure 2.
This left us with 18 articles where hearing impairment and hearing aid rehabilitation were assessed in relation to social, rather than individual aspects, with working-aged adults as a participant group of the research and the research interest clearly involving stigma, shame or
mental wellbeing of people with hearing impairment. The data were augmented by one additional study as a result of a manual search. Two of the resulting 19 articles were reviews and were hence left out of the final collection. The remaining 17 articles were categorized based on their methodology into quantitative (7) and qualitative (10).

Each full-text article was read and analyzed by two members of the research group. Two researchers evaluated the quantitative articles, and two the qualitative articles. The readers made notes on the research question, the data/sample size, the data-gathering methods, the method of analysis, and the main results. Furthermore, they described the role of stigma in each study: whether it was more central, as when used as an interpretative framework for the behavior or perceptions of the participants, or more marginal, as when only certain aspects of stigma emerged in the participant interviews or self-reports. The results of the analyses were merged in a table featuring quantitative articles (Table 3) along with a table with qualitative articles (Table 4). Thereafter, the results were discussed in the research group meetings to draft the outlines of this review.

Results

The results of the analyses are presented in Tables 2 and 3. Here, we describe the methodological approaches used, the role of stigma, and the main results concerning stigma and hearing impairment/hearing aid use in the articles, first focusing on the quantitative articles, then the qualitative ones. Thereafter, we summarize our main findings concerning both types of research methodologies.

Quantitative studies
Table 2 lists the main characteristics of the eight quantitative articles and the role of stigma in the research settings. In the quantitative studies, the sample sizes varied between 24 and 347 participants. The methods used were questionnaires and other measures or scales based upon which quantification was easy to execute. In one study [6], the subjects rated the pictures of hearing aids with different visibilities. Descriptive statistical analyses (e.g., means) and different analyses of variance, multiple regression analyses, or t-tests were used in all studies.

Table 2: Quantitative studies addressing stigma and hearing impairment/hearing aid use (see page 25)

In three of the seven articles utilizing a quantitative approach, stigma was explicitly the main research focus [6, 34, 35]. The participants in these three articles were people with normal hearing from whom the information about stigma related to hearing impairment or hearing aids was gathered. Two of the studies of participants with normal hearing labelled the stigma associated with wearing hearing aid as the Hearing Aid Effect to describe the assignment of negative attributes to individuals who make use of hearing aids [6, 34]. One study, Garstecki and Erler [35], addressed the social conditions of the individual (such as available social support) as a potential background factor influencing the perception of stigma. Their study pointed out that older, more educated female participants with robust social support saw active hearing aid use as a display of competence and control over problems.

The remaining four quantitative articles [36–39] dealt with stigma more indirectly, addressing the hearing impaired individual’s attitudes, coping strategies, or emotions (such as anxiety, stress, or other negative emotions) and their relation to stigma. In these four articles, the subjects were people with hearing impairment, except in Desjardins &
Doherty [37] which also employed a control group with normal hearing in addition to participants with hearing impairment.

All articles explored the perceptions of stigma and the feelings or attitudes related to it from the perspective of an individual. According to the studies, individuals perceived hearing impairment as a stressor causing anxiety incurring the risk of ridicule while regarding hearing aid use as a negative appearance stigmatizing their identity. However, Desjardins and Doherty [37] found that six-week trial use of hearing aids by potential users who had never worn hearing aids before lessened the stigma related to hearing aid use significantly.

The results of the quantitative studies showed that individuals, whether normally hearing young adults, women of different ages, or participants with hearing impairment, still mainly perceived hearing impairment and wearing hearing aids as stigmatizing, even to the extent that they would not use hearing aids, even if necessary for hearing properly. According to these studies stigma remains an issue that may explain the low adherence to hearing aid use. Consequently, several studies recommended that hearing health services should include, e.g., counseling to deal with individuals’ feelings and experiences of stigma [e.g., 6, 37,]. The study of Desjardins & Doherty [375] also indicated that a short trial use of hearing aids may lessen the fear of stigma by people with hearing impairment who have themselves not sought hearing aid rehabilitation.

**Qualitative studies**

Table 3 features the main characteristics of the qualitative studies and their approach to stigma and shame. The data-gathering method in the qualitative studies was almost exclusively interviews. The sample sizes varied considerably, ranging from four to 91, the smallest sample entailing a biographic narrative interview while the others were semi-
structured qualitative interviews. One study [40] also gathered data by video-recording the encounter of the patient and professional, while another [41] analyzed television episodes about hearing impairment and deafness. The methods of analysis consisted of categorizing the data into themes or categories based on either data or theory-driven approaches. The analytic approaches consisted of grounded theory [42, 43] content or thematic analysis [18, 44–47], interpretive phenomenological analysis [48], textual analysis [41], and theory-driven discursive analysis [40, 49].

Table 3: Qualitative studies addressing stigma and hearing impairment/hearing aid use (see page 28)

Common to the qualitative studies was their strong emphasis on describing and understanding the participants’ views and experiences concerning hearing rehabilitation. Six out of nine studies followed an ethos where the aim was to bring forward the rich plethora of the participants’ experiences in order to increase understanding of the phenomenon studied, while three studies [41–43] also investigated others’, i.e., non-hearing impaired people’s perceptions, or cultural perceptions on the subject. There were investigations [18, 47] where the results contained descriptions of the rehabilitation process, but even there, the results were based on the participants’ descriptions of it rather than observations of the actual activities.

The articles using a qualitative approach can be divided into three categories based on the perspective they revolve around the phenomenon of stigma. In the first category, stigma was analyzed as a phenomenon focusing on the participants’ – that is people with hearing impairment or HA users – understanding of stigma [43, 46]. The second category consisted of four studies in which the effect of stigma on the participants’ conduct was taken as a starting point of the analysis. Out of these, two studies analyzed the effect of stigma on
some aspect of hearing rehabilitation [18, 475] and in two studies, stigma was utilized as a theoretical framework in interpreting the data [40, 49]. The last category included studies where the analysis raised aspects of the participants’ understanding that can be seen as constitutive of stigma [41, 42, 44, 45, 48].

In all articles, stigma was perceived as negatively affecting the process of hearing rehabilitation or the quality of life of participants with hearing impairment.

**Summary of results**

The studies presented concerned mainly individual experiences and views concerning hearing aid rehabilitation and stigma. Similar results were reported in David & Werner’s [17] recent review on stigma and hearing impairment among elderly people. There is thus a major prevalence of research that is based on studying individuals’ self-reports in the form of data drawn from either questionnaires or interviews, rather than focusing on the social process where stigma occurs. In one qualitative study [40], the analysis drew upon video-recordings of patient-professional interactions at the hearing center, but the focus remained on the content of the participant’s conversation rather than on the process of social interaction during the encounter.

There were, however, two studies where structural and cultural factors affecting the experience of stigma were considered. One study [35] gathered information on the social conditions of the individual (such as available social support) as a potential background factor influencing the perception of stigma, while the other [41] took into account the manner by which media representation of hearing impairment and hearing aids may be constitutive of perceptions of stigma. It is known from other studies that structural factors, such as poverty or lack of access to care, increase experiences of stigmatization [50]. However, such structural
and cultural aspects have received less attention in research on stigma in the context of hearing impairment and hearing aid use, and would deserve further attention.

An interesting observation was also that most studies, both qualitative and quantitative, mostly highlighted how stigma negatively affects the use of hearing aids. Only two quantitative studies showed how stigma can be alleviated through social support [35] (Grastecki & Erler) or intervention [37] (free trial for potential HA users). According to our review, more research on how stigma can be positively influenced is necessary.

Discussion

In this review, we asked whether the earlier call for research on stigma as a social process has had an impact on research and research approaches in the context of stigma and hearing impairment or hearing aid use. According to our results, research on stigma as a social process is still scarce, and the main interest in the reviewed studies lies in the views and experiences of the people in question. Considering the original definition of stigma by Goffman [1] as a social process rather than merely an individual experience, this trend may leave some important elements of the phenomenon unexamined. Following Goffman, Yang et al. [29] maintain that stigma is realized during interpersonal communication and lived engagements, so it is relational in nature. Furthermore, they suggest that stigmatization happens between people, embodied in words, gestures, and feelings that are exchanged in interpersonal situations. Thus, according to our review, there is a clear gap in the research addressing stigma and use of hearing aids. In the future, more research should focus on investigating the social interpersonal process of hearing aid use and stigmatization.
Drawing upon the reviewed studies, we know that stigma is perceived as an important factor in people’s attitudes and opinions concerning hearing impairment and hearing aid rehabilitation. What remains unaddressed is the relational process whereby stigma emerges and how stigma is dealt with in actual interactions [see also 3]. Stigmatization may occur in various ways and on different occasions in the encounters between people with hearing impairment and their colleagues, family, friends, or health care professionals. Fear of stigma is connected with fear of the feeling of shame, of losing face [51]. Hence, fear of stigma is not easily topicalized but remains implicit in both every day and institutional interactions. With this, in addition to studying individual experiences, we must garner knowledge on the interaction processes where the phenomenon of stigma may emerge within hearing aid rehabilitation. Specifically, we need to unravel the situational logic in and through which the participants of a social situation manage stigma and stigmatization: if and how these issues are present in conversation. Further, it would be essential to pin down the moments within the longitudinal process of hearing aid rehabilitation involving various encounters with hearing help professionals, members of peer groups, and significant others, where questions of stigma may originate. It has been shown that factors such as prior experience with hearing aids or people who wear them contribute to stigmatization of hearing aid users [52]. Uncovering the logic and dynamics of such processes calls for the use of observational methods, like conversation analysis [e.g., 530] and ethnographic approaches [e.g., 54]. With this kind of scientific knowledge, we can better understand the process of stigmatization in connection with hearing impairment but also other types of stigmatizing ailments. Most importantly, knowledge on how stigma emerges and is managed within social interactions may aid in developing interventions seeking to diminish and overcome the negative consequences of stigma through interactive means.
Limitations of the review

We did not evaluate the quality of the studies included as would be customary for systematic reviews because in scoping reviews such as this one, the goal is rather to examine the range of a research area and identify potential gaps [30]. Instead of assessing the quality of the studies included, our task was to assess the extent to which social and relational aspects of stigma and hearing aid use are addressed in the research approach of the studies. A further limitation of the review is the heterogeneity of the population of interest in the studies. Our focus was on studies on the working-age population, but we also included studies where working-aged individuals were only one part of the population as we considered it most relevant to include studies where the social and relational aspects of stigma were prominent. Furthermore, although our focus was on people with acquired hearing impairment, we also included studies with their communication partners and even with those that have normal hearing as the only participating group - we interpreted these studies specifically depicting a social contextual approach to the problem of stigma and hearing impairment/use of hearing aids. Despite these limitations, the review has shown a clear gap in existing methodological approaches towards the phenomenon of stigma in relation to hearing impairment and hearing aid rehabilitation by pointing out the need to investigate the processual aspects of the stigmatization of hearing impairment.

References


<table>
<thead>
<tr>
<th>Study</th>
<th>Research question</th>
<th>Data / sample size</th>
<th>Methods</th>
<th>Analysis</th>
<th>Main results</th>
<th>Connection to stigma</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Andersson G, Hägnebo C. Hearing impairment, coping strategies, and anxiety sensitivity. 2003. <em>J Clin Psychol Med Settings</em> [34]</td>
<td>What is the relationship between coping strategies, anxiety sensitivity and experience of hearing impairment?</td>
<td>94 members of a Hard of Hearing Association</td>
<td>The ways of coping questionnaire (WOCQ), Anxiety sensitivity index (ASI) &amp; Visual rating scale for discomfort</td>
<td>Mean scores and Multiple Regression Analysis</td>
<td>Describes the affective-cognitive-behavioral symptoms of the stigmatized individual and their coping strategies. Hearing impaired individuals do not use escape/avoidance coping more than other coping strategies</td>
<td>Hearing impairment is characterized as a stressor. Anxiety Sensitivity Index reflects also the social dimension of negative appearance, misunderstanding, and risk of ridicule, which relate to stigma and shame. Multiple aspects of stigma arise in the self-reports of the participants.</td>
</tr>
<tr>
<td>2. Desjardins JL, Doherty KA. Changes in psychosocial measures after a 6-week field trial. 2017. <em>Am J Aud</em> [35]</td>
<td>Whether using hearing aids for 6 weeks could alter an individual’s attitudes towards hearing aids?</td>
<td>24 adults with mild to moderate HI and 16 controls</td>
<td>The Hearing Aid Attitude Questionnaire (HARQ) addressing stigma and 2 other questionnaires: HHQ (Hearing Handicap Questionnaire) and IOI-HA (International Outcome Inventory for Hearing Aids)</td>
<td>A repeated measures analysis of variance was performed to measure changes in attitude (and handicap and outcome) over time and across experimental and control groups.</td>
<td>Describes the effects of trial use of hearing aids on hearing handicap (lessened handicap), attitudes on s (lessened HAS, hearing aid stigma), and outcome of HA rehabilitation (successful). Stigma related to hearing aid was significantly (p &lt; .05) lessened after 6 weeks of hearing aid use and remained lessened even after the hearing aid trial ended. (However, stigma related to hearing impairment did not lessen).</td>
<td></td>
</tr>
<tr>
<td>3. Garnefski N, Kraaij V. Cognitive coping and goal adjustment are associated with symptoms of depression and anxiety in people with acquired hearing loss. 2012. <em>Int J Audiol</em> [36]</td>
<td>Do cognitive coping strategies and goal adjustment have joint influence on symptoms of depression and anxiety in people with HI?</td>
<td>119 individuals with moderate or profound HI.</td>
<td>Questionnaires: Hospital anxiety and depression scale (HADS), The goal obstruction questionnaire (GOQ) &amp; The cognitive emotion regulation questionnaire (CERQ)</td>
<td>Summary statistics, Pearson correlation &amp; Multiple regression analyses.</td>
<td>Describes the perspective of the stigmatized individuals, their personal coping strategies and goal adjustment. Anxiety is interpreted to reflect some aspects of being stigmatized. Study results carry important implications for the development of effective services.</td>
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How to measure positive experiences in living with hearing loss?

| How to measure positive experiences in living with hearing loss? | Participants 347 (174 and 173) HI who were HA candidates in hearing clinics. | Two separate questionnaire studies aiming at creating a tool for investigating the positive experiences of hearing loss. | 8 factors (principal component analysis) | Describes changes in self-perception and behavior (e.g. resignation) from the stigmatized individual’s point of view. Six factors are: 1) cognitive changes to self-perception; 2) using hearing impairment to self-advance; 3) successful communication behavior; 4) resignation; 5) effort in communication; 6) technical facilitators. | Negative attitudes and experiences related to stigma are discussed as the other side of the coin. |

Aspects of stigma arise in the self-reports of the participants.

Subjects with normal hearing


What is the degree of stigma associated with hearing loss and HA among three different age-groups of women?

| What is the degree of stigma associated with hearing loss and HA among three different age-groups of women? | Participants 191 women with age-normal hearing from 3 different age-groups recruited by advertisements. | Completion of statements with paired descriptions (positive or negative) | Summary statistics, t-tests and one way analysis of variance, Stepwise multiple regression analyses. | Describes individual’s affective perception of stigma by women of different ages. Younger women perceived greater stigma than older women. Negative perceptions (stigma) are affected by age. | Age is the largest contributor to variance in perceptions of stigma related to hearing loss and hearing aid use. |

Stigma as pre-set potential explanation affecting people’s attitudes towards hearing impairment and hearing aid.


Which conditions of adult life course may influence hearing loss management?

| Which conditions of adult life course may influence hearing loss management? | Participants 191 women from 3 different age-groups (between 35 – 85 years) recruited by advertisements. | Measures of hearing knowledge, behaviors and attitudes; health-related locus of control; ego strength; and social support. | Descriptive data & ANOVAs (analysis of variance) | Describes individual’s affective perspective to stigma by women of different ages. HA use is less stigmatizing than hearing loss itself. Some variables deteriorate among subsequent age group (such as ego strength and hearing thresholds) but the reverse is true for others (like social interaction). | Perceptions of stigma or the negative attributes associated with hearing loss and hearing aid use were examined. |

Stigma as pre-set potential explanation affecting people’s attitudes towards hearing impairment and hearing aid.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Year</th>
<th>Objective</th>
<th>Methodology</th>
<th>Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnson CE, Danhauer JL, Gavin RB, et al.</td>
<td>The “Hearing aid effect”</td>
<td>2005</td>
<td>To test the visibility of new hearing aid styles</td>
<td>150 young adults rated photographs of models with 6 hearing aid (HA) styles for visibility with a 7-point equal-interval semantic differential scale.</td>
<td>CIC (completely-in-the-canal) style was rated significantly most “invisible”.</td>
<td>Hearing aid effect (stigma connected to the hearing aids) will continue to be an issue for hearing aid users. The findings have implications for counseling potential users who are reluctant to try hearing aids for cosmetic reasons. Stigma as pre-set potential explanation affecting people’s attitudes towards hearing aids.</td>
</tr>
<tr>
<td>Study</td>
<td>Research question</td>
<td>Data / sample size</td>
<td>Data-gathering methods</td>
<td>Method of analysis</td>
<td>Main results</td>
<td>Connection to stigma and shame</td>
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<td>8. Foss KA. (De)stigmatizing the Silent Epidemic: Representations of Hearing Loss in Entertainment Television. 2014. Health Commun [39]</td>
<td>How and why hearing loss continues to be stigmatized through a study of media messages about hearing loss</td>
<td>276 television episodes involving characters or story lines from 1987 through 2013.</td>
<td>Purposive sample from Direct TV and Internet databases using keywords “deaf” and “hearing loss”</td>
<td>Textual analysis</td>
<td>TV programs convey the message that hearing loss is uncommon, representations are narrow and mostly not equivalent with real life. TV programs depict mostly cases where hearing is restorable, thus, needing no hearing aids as remedy. Programs refer to hearing loss and deafness as embarrassing and threatening to relationships and career.</td>
<td>Stigma as explanation to existing perceptions towards hearing impairment, and how these perceptions are maintained by TV programs.</td>
</tr>
<tr>
<td>9. Hallam P, Ashton P, Sherbourne K, et al. Persons with acquired profound hearing loss (APHL): how do they and their families adapt to the challenge? 2008. Health [40]</td>
<td>What kind of impact does APHL have on the relationship between hearing impaired persons and their close family members? What sort of adjustments are made?</td>
<td>25 persons with APHL and 25 family members</td>
<td>Interviews</td>
<td>Grounded theory, N-Vivo</td>
<td>APHL places considerable strain on relationships and increases their vulnerability for failure. The adjustment strategies can either maintain or deteriorate the relationship between the persons with APHL and their close family members. Perceived stigma from social environment is clearly an issue for both family members and persons with APHL.</td>
<td>The adjustments found included stigma-related aspects such as negative public perceptions and negatively perceived adjustments on relationships as a sign of personal inadequacy of negative social evaluation. Aspects of stigma emerged in the interviews.</td>
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<td>10. Hindhede, AL. Everyday trajectories of hearing correction. 2010. Health Sociol Rev [38]</td>
<td>Why a person seeks treatment?</td>
<td>41 individuals with mild to severe hearing impairment aged 20–70</td>
<td>Video recordings of the fitting process with interviews before and after the fitting</td>
<td>Theory driven discourse analysis</td>
<td>HI as a problem is not localized in the body only (as in the medical model) but it has links with individual’s everyday life, social expectations and human judgements. Need can be a result of social pressure or derive from a situational sense of need. The patient’s agenda or stance is not revealed in the consultation data, but is revealed in the interviews</td>
<td>Attitudes towards hearing aids influence people’s tendency to seek help for hearing impairment. Individuals had negative beliefs and attitudes against HI and HAs. Yet, some of them had an interest in normalizing their hearing impairment with HA. Stigma as an interpretative framework for people’s behavior</td>
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<td>11. Hindhede, AL. Negotiating hearing disabled identities. 2012. Health [47]</td>
<td>How working-age adults confront the medical diagnosis of hearing impairment?</td>
<td>41 individuals with mild to severe hearing impairment aged 20–70</td>
<td>Interviews before and after the HA fitting</td>
<td>Theory driven discourse analysis. Disability theory and social science</td>
<td>Three categories of identity negotiations and ways of discussing identity. They were related to issues of: 1) emotion management; 2) rehabilitation technologies; and 3) aging body, normality and the hearing disabled identity.</td>
<td>The issue of stigma arises through identity negotiation when facing a dilemma of normal vs. disabled self. HAs are perceived as stigma. Stigma as an interpretative framework for people’s behavior</td>
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<td>12. Laplante-Lévesque A, Knudsen LV, Preminger JE, et al.</td>
<td>What are the perspectives of adults with hearing impairment regarding hearing help-seeking and rehabilitation as a process?</td>
<td>34 adults with hearing impairment from 4 countries (Canada, Denmark, USA, UK)</td>
<td>Interviews</td>
<td>Inductive content analysis</td>
<td>Examples of the ways in which hearing impaired adults experience the help-seeking process and rehabilitation are given.</td>
<td>Specific aspects of stigma, such as concern for appearances with HA, and uncomfortable feelings by oneself or other when discussing hearing impairment, are described. Aspects of stigma emerged in the interviews.</td>
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<td>13. Preminger JE, Laplante-Levesque A.</td>
<td>What are the views of a diverse sample of adults with hearing impairment on Age and Brain and how these relate to their hearing help-seeking and rehabilitation?</td>
<td>34 participants with hearing impairment from 4 countries (Canada, Denmark, USA, UK)</td>
<td>Interviews</td>
<td>Content analysis &amp; interpretive phenomenological analysis</td>
<td>Age and Brain were seen as factors contributing to hearing impairment, disability, help-seeking, and rehabilitation. Stigma and ageism were depicted as closely related, however not all perceptions of aging and hearing impairment were negative. Perceptions of stigma are modulated in the course of getting older, e.g. wearing HA was described as more acceptable</td>
<td>Self-image was discussed mainly in terms of stigma and ageism, which were depicted as closely related.</td>
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<td>14. Sankar P, Cho M, Wolpe P, et al.</td>
<td>Does genetic testing or genetic cause of a disease have a stigmatizing effect? Does heritance as such entail a stigmatizing experience?</td>
<td>86 individuals with 1 of 4 conditions: deafness or hearing loss; breast cancer; sickle cell disease or cystic fibrosis.</td>
<td>Interviews</td>
<td>Thematic analysis with software program QSR NUD*IST V.6</td>
<td>A genetic cause did not automatically impart to respondents a sense of being stigmatized. Stigma emerges from a variety of sources in the context of the lived experience of a particular condition. Non-genetic hearing loss was perceived as more negative than genetic hearing loss.</td>
<td>Knowledge about dimensions of stigma as experienced by hearing impaired</td>
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<td>15. Southall K, Gagné J-P, Jennings M.</td>
<td>How stigma impacted upon the help-seeking activities of adults</td>
<td>10 people with hearing loss, all members of peer-support groups.</td>
<td>Audio-recorded semi-structured interviews.</td>
<td>Inductive thematic analysis</td>
<td>Most respondents experienced a heightened propensity to seek help, when negative stress and positive energy were out of balance.</td>
<td>Stigma is in the focus of the research.</td>
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<td>Study</td>
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<td>Research Questions</td>
<td>Methodology</td>
<td>Findings</td>
<td>Stigma Relevance</td>
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<td>16. Southall K, Jennings M, Gagné J-P. Factors that influence disclosure of hearing loss in the workplace. 2011. Int J Audiol [45]</td>
<td>What factors lead individuals to conceal or disclose their hearing loss in the workplace?</td>
<td>12 people; aged 43-73; purposeful sampling to get as diverse a sample as possible</td>
<td>Audio-recorded semi-structured interviews. Photo elicitation interview technique was employed.</td>
<td>Denial and concealing problems was preferred over explaining them to others. Help seeking was also hindered by lack of knowledge.</td>
<td>Congruent findings with both stigma-theory, and social-cognitive theory.</td>
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<td>17. Wallhagen M. The stigma of hearing loss. 2010. Gerontologist [41]</td>
<td>What are the dimensions of stigma experiences by older adults with hearing loss and their communication partners?</td>
<td>Dyads of HI people and their communication partners: 91 at baseline, 87 at 3 months, and 84 at 12 months</td>
<td>Longitudinal study: 3 x interviews of hearing impaired and their communication partner.</td>
<td>Perceived stigma influences the experiential continuum of hearing loss. Stigma was related with 1) alteration in self-perception; 2) ageism; and 3) vanity.</td>
<td>Stigma as a theme of the whole article. Professionals, partners and marketing were seen as reinforcing the stigma. Knowledge about dimensions of stigma as experienced by hearing impaired and their partners.</td>
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