

Hearing Impairment: An Initial Exploration of Information Sharing Practices

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Abstract. Hearing impairment is becoming increasingly prevalent. Even though hearing aids can contribute to increased quality of life, actual usage has proven to be problematic and limited. This preliminary explorative study has been carried out in order to get an initial understanding about sharing of hearing-loss-related information, both in terms of how information is shared as well as what kind of information is shared. We conducted four sub-studies with peer members of an interest group and people visiting relevant online resources, and combined the use of questionnaire, semi-structured interview, online observation and short survey. While our results are preliminary, they suggest that current information sharing practices are fragmented regarding both the content that is shared as well as which actors and media are involved, and the Internet as a multifunctional arena is underutilized. Finally, some possible directions for further research are outlined.

1 Introduction

Very many of the cues we are surrounded by in our daily lives are auditory signs. Being unable to perceive these sounds has a significant impact on how we are able to navigate and how we interact with tools, products, services, and each other. The number of people with hearing impairment is increasing [1]. For elderly people, degeneration of hair cells in the cochlea is a normal physiological process. Thus, in a population with a growing number of elderly people, hearing impairment is common. In addition to the physiology of aging, noise, trauma, medical side effects and genetic disposition may all contribute to increase the problem.

Much equipment and many tools have been developed for bridging the problem of hearing impairment. There is widespread work on improving hearing aids and speech processing [2]; courseware for various disabilities [3-5]; approaches for improving websites for special needs [6, 7]; as well as the use of the web for cooperative

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learning [8]. Additionally, there are mandatory (but poorly adhered-to) international rules for Universal Design, which allow technology-assisted transformation of webpage information for the disabled.

When used successfully, hearing aids have been proven effective in providing increased quality of life [1]. However, many international studies show that actual use of hearing aids is problematic. Many hearing impaired do not, for various reasons, acquire a hearing aid. Among those who have acquired hearing aid have problems using it in the intended way or have stopped using it [9]. One attempt to contribute to this issue is the development of a service that supports patients' participation in the tuning and fitting of their own hearing aid through the use of an interactive tabletop [10].

The support for individuals with hearing impairment has been criticized for being fragmented and not well adapted or scaled to address patients' needs [11]. The cost and appropriate balancing of service levels within this group will be further challenged since the number of adults suffering from hearing impairment is estimated to increase from 15 % up to 25 % in the year 2020 [1, 12]. In order to meet this challenge, different measures need to be considered to make sure that the delivery of both services and products can be tailored to the patients' needs, and at the same time provide effective management of the hearing loss.

Based on a previous study on internet use by hearing impaired people, the Internet seems to be more intensively used for personal and group communication than by those with normal hearing [13]. In addition, research in the domain of Web accessibility guidelines for hearing impaired people suggests tailoring to improve the interaction and accessibility of the webpage [6]. These two findings suggest that using the Internet is potentially a good strategy for providing information to this group of people. Designing websites that ease access to information as well as accommodating hearing impaired users' needs can improve interaction between people as well as their use of devices.

In order to learn more about the information needs of this group of people, we would like to explore how and where the hearing impaired, their next of kin, and health care personnel share information outside the clinical setting. We would also like to explore which information the hearing impaired are most interested in.

2 Methods

Without a predetermined notion of how hearing impaired people in Norway currently gather information relevant for their life situation, we decided on an explorative, largely qualitative approach. This was implemented as four sub-studies with different methods. We allowed ourselves to pursue ideas as they emerged, rather than follow a predetermined protocol. This approach was expected to lead to a comprehensive view of the study topic. The methods we used together with the related sub-studies are described in the following.

2.1 Questionnaire

First, we contacted Hørselshemmedes Landsforbund (HLF), the patient organization for hearing impaired in Norway. They have local chapters in most municipalities, and each chapter has a group of specially trained members who assist local members with information. In this context we have called them peer members.

We identified ten peer members on the official HLF website who we requested by email to fill out a questionnaire. We asked about which communication channels patients would mostly use to contact them, frequent topics and questions they were being asked, and which sources of information they would typically suggest to members. The peer members are responsible for different age groups and selected topics.

2.2 Semi-structured Interview

Secondly, we conducted an in-person semi-structured interview with one of the peer member who responded to our questionnaire. Three researchers were present for this recorded interview. We aimed to get a more in depth understanding of their experiences from advising about hearing loss. What do HLF members ask about, and what kind of information or understanding do they seek, and need?

Guided by some predefined topics, the interview can be characterized as a semi-structured and open-ended conversation which lasted for 90 minutes. Our questions covered the existing services and community networks related to hearing loss, the type of communication channels that people use to reach the peer members, what kinds of information people were typically seeking and the challenges faced in providing this information.

We did a rough content analysis of the transcribed interview to identify important themes.

2.3 Observation and analysis of web forums

We wanted to observe some of the hearing loss-related community networks suggested to us in order to analyse posts and identify, first hand, the types of information members were seeking. We asked the administrators for permission to participate as invited observers in two closed Norwegian Facebook groups aimed for people with hearing impairment. Facebook Group 1 (FBG1) targeted people associated with hearing impairment. Facebook Group 2 (FBG2) targeted people having a hearing impairment.

FBG1 was not clearly defined but the pinned introduction emphasized that the group was a closed group for the deaf, people with hearing impairment, or of normal

hearing. The postings might contain personal issues and good conduct toward members of the group was to be expected.

While FBG1 had no details in its description, FBG2 was meant for hearing impaired in employment, and wanting to remain working despite their hearing impairment.

Unfortunately, due to privacy concerns on behalf of the members, we were denied access as observers in both Facebook groups, but we did get permission to post a survey on FBG1, as described in the next section.

To broaden our perspective we also observed and analysed a public US discussion room webpage in English (MyHearingloss.org). We looked at what kinds of questions were asked and how these were responded to both in terms of content and style.

2.4 Survey

The final study is the survey distributed via FBG1. The survey was Internet-based and anonymous, using surveymonkey.org. The survey had two main parts with 5 questions in total.

The first section addressed our main research objective with pre-selected answers on a scale from 1-5 (1 = low agreement / 5 = high agreement). In the second section, to be answered in free text, we asked the participants to state how they valued the feedback from fellow members in the Facebook group compared with the feedback from the peer members representing the patient organization HLF. Privacy was ensured by not identifying the IP address of respondents. The sampling method can be characterized as purposive and based on members' own interest to participate.

3 Results

We present the results in accordance to the four sub-studies as delineated above.

3.1 Questionnaire results answered by peer members

We got two responses. According to these two respondents, members use different communication channels to get in touch such as e-mail, cell phone and face-to-face meetings during seminars or other arrangements. Frequent topics and questions concern case handling for acquiring hearing aids, communication with audiologist and labour rights. The respondents' suggested sources of information were grounded in personal experiences, dedicated websites and social media, leaflets and centres of expertise.

3.2 Semi-structured Interview with peer member

The results from the interview are structured around two categories: 1) Information connected to patient networks and 2) Information connected to understanding the consequences of one's own diagnosis. These categories were discussed and constructed in consultation with the informant during the interview. In the following we present the main points of each category.

Information connected to patient networks:

- Information is scattered and there seems to be a lack of coordinating responsibility.
- The treatment pathway appears unclear for patients and professionals.
- The interest group(s) do(es) not actively address GPs and specialists.
- There is a lack of prepared information procedures; it is unclear who has responsibility for providing information. Therefore, access to information from public health services is random - depends on attitude, available time, and knowledge of GP and specialist (consequences, rights, practical arrangements etc.).
- The interest group does not appear to be visible enough, much because they operate on voluntary basis.
- Peer members from patient organizations get few direct inquiries.
- Internet and social media are important for information and networking among peers. However, many of the hearing impaired are probably rarely (if ever) on Facebook.

Information connected to understanding the consequences of one's own diagnosis:

- Hearing loss often occurs gradually, and it is an invisible handicap. This makes it challenging to understand and acknowledge for the patients as well as for the people around them.
- Energy loss, stigma and embarrassment is commonly experienced, but information about how to deal with this is not readily available.
- It takes a long time to get used to hearing aids, information about how to deal with this is often not clear from a user perspective.
- The grieving process that comes with sensory loss, and how to deal with it is not an emphasized topic.

In addition, different Internet sources on information about hearing impairment were identified. Two resources for information frequently mentioned by the interviewed peer were HLF and Sansetap. Both websites are open and accessible to everyone. There are also others primarily addressing the deaf community.

The interest group HLF [14] has 58.000 members and is the largest patient organization in Norway. HLF had more than 600.000 hits a year on their website. The website provides general information on hearing and hearing impairment,

announcements, items for sale, options for asking questions and information on what the organization generally does. Sansetap [15] is a public webpage with information about eyesight, hearing impairment and combined loss of senses. The focus of this webpage is on how to cope with the impairment.

3.3 Observation results

Observation was conducted on the US discussion room webpage (MyHearingloss.org), which is an open group for asking questions and reading archived questions about hearing loss. The website is founded by the Hearing loss association of America and uses moderators and administrators to moderate the content and appearance of the posted messages. The questions posted on the forum were categorized into the following groups:

- Technical hearing aid questions
- Is treatment X effective?
- Tinnitus
- Seeking technical aids and/or assistive devices
- Seeking peers with similar experience
- Techniques for coping with hearing loss

Moreover, through further analysis we found that:

- This is a forum where most people have or are experiencing hearing loss and are sharing their experiences with each other. They do not know each other, but they have their hearing loss in common.
- The majority of questions asked are extensive and many users include their personal hearing history in their questions.
- The forum users are friendly and supportive and the responses are mostly positive.
- Most questions are related to how you can cope with hearing loss, and the forum members are posting personal experiences with different treatments and aids.
- Some questions are left unanswered, but there is no clear pattern of which questions are answered and which are not.

3.4 Survey distributed through FBG1

The survey results are presented below, according to the two sections.

3.4.1 Survey section 1

The total number of members in Facebook group 1 was 3175. The group had no formal connection with the patient organization. Forty people completed the survey.

The participants responded a medium high engagement in social media for hearing impaired (mean score 3,6). Details of the respondents' answers to our survey regarding their reason for engaging in social media are presented in Table 1.

Reasons for engagement in social media for hearing impaired patients	
Category	Mean score (1-5)
<i>Objective engagement</i>	
Post questions related to technical issues about settings	3,6
Aid for hearing impaired	2,6
Medical questions	2.3
<i>What they perceived to be the most important reason (personal motivation)</i>	
Asking questions and get good answers	4
To get information about new things (being informed)	2,1
Find people like me	1.7
<i>Actively engaged in giving response</i>	
Response on aid for hearing impaired	3.3
Medical questions	2,7
Technical questions about settings	2,6

Table 1: Survey results – Respondents' engagement in social media

Category of questions they were seeking	
“Questions about any kind of aid for hearing impaired”	60%
Seeking answer for their medical questions	49%
Searching for answer about “technical settings”	45%

Table 2: Classification of respondents' questions

3.4.2 Survey section 2

In section 2 of the survey, the participants were asked to compare the usefulness of the Facebook group “peers” with the trained peer members from HLF.

Some of the participants commented that responses should be carefully considered since the members of the Facebook group might not have the ability to make a qualified response to the problems posted. A few responded that they did not take part in the discussions but used Facebook for getting information and tips and regarded themselves as observers in the group. This comment was also made by a professional using the Facebook group for information about the current “trends” among the people with hearing impairment.

Conformity requirements was commented by some of the participants who explained that posting their opinion could be difficult as they felt it was not accepted “by the group” to post something that was different than the perceived opinion of the group.

Quick access and effective spreading of news and information were considered the most important benefit of Facebook, but some also regarded this a disadvantage since disinformation might be spread just as fast.

4 Discussion

Our study suggests a lack of coordination and support for providing information to people with hearing impairment. Living with or becoming hearing impaired is a situation that affects both the individual and the person's surroundings. Based on the survey results completed by 40 participants, high engagement in social media (mean score 3.6) indicates that the format is perceived useful for people associated with hearing impairment. A platform which displays the functionalities patients appreciate in this format could represent a benefit for healthcare organizations for sharing information. As participants stated in their response, “asking questions and get good answers” (mean score 4) is one of the most important reasons to use social media. This is considered to be an important finding.

During this study we did not get a clear overview as to how one should proceed and where one should turn to for questions regarding experiencing hearing loss, as patient or as non-patient. Social media is apparently, and not surprisingly, an important source for receiving and sharing information. Therefore, if social media is to be used as official source of information it is necessary that the answers provided are easily accessible and correct.

As respondents stated in their answers, another reason they are involved in social media is networking with people like themselves. Thus, it is important to find out how hearing impaired patients are socially supported, and investigate their difficulties in finding new people/friends to socialize with, and how being in contact with people who have similar problems affects their quality of life.

According to our results, Internet and social media are important sources for different kinds of information about hearing impairment and for networking. For members of HLF and others (hearing impaired or not) seeking information about

hearing impairment, Facebook was recognized as an important arena in Norway. Still, the interviewed peer member pointed out that part of the patient group is probably not using social media. Moreover, the respondent's impression was that peer members from HLF received few direct inquiries in general. Seminars and courses are important arenas for knowledge transfer and social interaction. However, if people are difficult to reach via social media or even email, there is a chance that people miss out on such gatherings and especially if they are not familiar with the organization. For instance, we could not find any page listing up the various Internet-based resources and communities that are relevant in connection to hearing impairment, such as existing web pages and Facebook groups.

We have not been able to identify which basic information is currently being provided to patients, and if there is any kind of procedure to verify how the patients have actually perceived information given. This is nevertheless important in order to facilitate that patients start on the same page, so to speak, after initial consultation with GP and specialist.

A recent European health literacy survey concluded that 47 % of patients do not understand the information given by healthcare providers [16]. It may be reasonable to assume that members of this group might find perceiving information from a verbal source (e.g., from a physician) as even more difficult than in the general population. However, Internet-based information about this seems to be scattered around. Considering that stigma and grief that often accompanies sensory loss, the opportunities for lifting such important and sensitive topics through dedicated Web-based services such as the US discussion room webpage are expected to be highly valuable for both patients and professionals as well as relatives and colleagues.

Regarding different ways of sharing information on the Internet, our comparison between the functionalities offered by Facebook and the US discussion room support shows that:

- Users in the discussion room can log in by anonymous credentials whereas users on Facebook generally use their original Facebook profile.
- The discussion room supports classifying of information on different subjects (i.e., hearing aids, technology tips, families, friends, and parents of children with hearing loss) while in the Facebook groups there are no such categories.
- In the US discussion room, users are able to view the number of posts and topics for each category, when the last post was added to a category and who is the forum moderator. In the Facebook groups however, it is not possible to have such a comprehensive overview on the posts and topics, hence users have to scroll down to see all the posts and the most recent posted topics.
- In the US discussion room, users are able to subscribe to certain forums that they are interested in for receiving a notification email if someone adds comments to the forum, while in the Facebook groups users are not able to do follow up and receive notification emails without commenting on special posts.

Based on these differences between the Facebook groups and the US discussion room, we can emphasize that:

- Users on Facebook may be hesitant to comment or contribute as they are using their real user profile rather than an anonymous user account. This implies that there is a risk of revealing sensitive information or being judged by someone who knows them.
- Tracking of the posts in Facebook on different subjects requires more effort as posts are not classified.
- The person who posts a question on Facebook is the owner of the post, hence she/he is able to delete the post as there is no moderator involved in tracking of the posts and confirming the contents.
- There is a risk of spreading wrong information quickly by the users as a Facebook group does not necessarily have moderator who reviews comments and answers.

5 Concluding Remarks and Further work

Given the rapid technological and medical advances of recent years, along with the prevalence of hearing difficulties within society, we propose that there is a great potential for improvement of services regarding providing efficient information about hearing impairment, service and tools to address the problems.

While our results are preliminary, they suggest that current information sharing practices connected to hearing impairment are fragmented both regarding content as well as across a variety of actors and media, and the Internet as a multifunctional arena is underutilized. The issue of information sharing needs to be addressed more closely.

First, we have to investigate different practices for providing information during the first consultation: What kind of information is given by the GP, specialist and the audiologist, how is information provided and how do the patients and relatives perceive this information? To investigate this, studies at different clinics and among different practitioners in audiology should be conducted.

Secondly, we need to explore the basic knowledge about hearing loss that healthcare professionals have and how this knowledge best can be shared between various actors. This includes exploring how different media can be utilized. We also need to investigate why “asking questions and getting good answers” has such a high mean score. We will investigate who people can turn to in order to ask questions, and who are responsible for replying, and within which timeframe one can expect this to happen.

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References

1. DACEHTA, F., SBU, SMM in collaboration with MRC, Hearing impairment among adults (HIA) – Report of a joint (Nordic-British) project. <http://www.julkari.fi/bitstream/handle/10024/77618/HIA2001.pdf?sequence=1>, M. Sorri, Editor. 2001: Printed in Helsinki Finland, Edita Oyj.
2. Magotra, N., et al. Quantization analysis for fixed-point implementation of speech processing for the hearing impaired. in *Circuits and Systems, 1999. 42nd Midwest Symposium on*. 1999.
3. Chaisanit, S., S. Suksakulchai, and R. Nimnual. Interactive multimedia courseware of vowel training for the hearing impaired. in *Control Automation and Systems (ICCAS), 2010 International Conference on*. 2010.
4. Mohid, S.Z. and N.A.M. Zin. Courseware accessibility for hearing impaired. in *Information Technology (ITSim), 2010 International Symposium in*. 2010.
5. Mohid, S.Z. and N.A.M. Zin. Accessible courseware for kids with hearing impaired (‘MudahKiu’): A preliminary analysis. in *Pattern Analysis and Intelligent Robotics (ICPAIR), 2011 International Conference on*. 2011.
6. Namatame, M., M. Kobayashi, and A. Harada, A Case Study for Reaching Web Accessibility Guidelines for the Hearing-Impaired. *PsychNology Journal*, 2003. 1(4): p. 400-409.
7. Lynch, K.R., D.J. Schwerha, and G.A. Johanson, Development of a Weighted Heuristic for Website Evaluation for Older Adults. *International Journal of Human-Computer Interaction*, 2012. 29(6): p. 404-418.
8. Li-Hua, S. and X. Jia cheng. A research on web-based cooperative learning of hearing impaired university learner. in *Computer Science & Education, 2009. ICCSE '09. 4th International Conference on*. 2009.
9. Smith, J.L., et al., A health policy for hearing impairment in older Australians: what should it include? *Australia and New Zealand Health Policy*, 2005. 2: p. 31-31.
10. Dahl, Y., H. Linander, and G.K. Hanssen, Co-designing interactive tabletop solutions for active patient involvement in audiological consultations, in *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational*. 2014, ACM: Helsinki, Finland. p. 207-216.
11. Donahue, A., J.R. Dubno, and L. Beck, Accessible and Affordable Hearing Health Care for Adults with Mild to Moderate Hearing Loss. *Ear and Hearing*, 2010. 31(1): p. 2-6.
12. HLF, HLFs innspill til Akuttutvalget. 2015, HLF Hørselshemmedes Landsforbund (National Organization of Hearing Impaired Norway): <https://www.hlf.no/hva-vi-jobber-med/horingsuttalelser/akuttutvalget/>.
13. Barak, A. and Y. Sadovsky, Internet use and personal empowerment of hearing-impaired adolescents. *Computers in Human Behaviour*, 2008. 24: p. 1802-1815.
14. HLF. Hørselshemmedes Landsforbund (National patient organization for hearing disabled). Available from: <https://www.hlf.no/>.
15. Sansetap. (“Sensory Loss”). Statped. Available from: www.sansetap.no.
16. HLS-EU-Consortium, *Final_report_-_Executive_summary_of_HLS-EU*. The European Health Literacy Project. 2012: Maastricht University.

