

Introduction

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Hearing loss is a prevalent communication disability, yet to date there is almost no research on naturally occurring interaction which examines how participants handle hearing loss and the use of hearing aids in communication. In contrast, research focussing on the medical and technological dimensions has advanced tremendously. Still, the social reaction to hearing loss is frequently stress, withdrawal and isolation. Despite the enormous technological development, most people who could benefit from a hearing aid do not use it. The goal of this edited volume is to present a theoretically founded, interdisciplinary research approach geared at understanding and improving social interaction impacted by hearing loss and (non-)use of hearing technologies. Towards this end, we are integrating Conversation Analysis, audiology and User Centered Design.

The World Health Organization (“WHO”) identifies hearing loss as a “global burden” with a heavy social and economic toll. Adult-onset hearing loss is estimated as “the second largest cause of Years Lost to Disease” (WHO 2009). As a physical disability, hearing loss is experienced first and foremost in social interaction. For this reason, the United Nations 2006 draft on the “Convention on the Rights of Persons with Disabilities” is particularly influential. It replaces the concept of disability as a condition of an individual, who needs to be treated, by a holistic concept of disability as a participatory socio-cultural phenomenon, which a multi-cultural society needs to address by integrating all members as full participants. This shift widens the focus from an individual with hearing loss to participation in socio-cultural interaction and opens up new perspectives to understanding and solving the enormous problems associated with hearing disability.

Although hearing loss is a condition experienced foremost in communication, the research area of social interaction has not focussed much on interaction with hearing loss, and likewise, it is not recognized as a possible contributing field by the fields of medicine and technology. A representative of the hearing aid company GN Resound (Bisgaard 2009) lists as “Hearing Industry Specific” the following research areas:

- *Auditory research*
 - *Basic psychoacoustics*
 - *Hearing impairment*
 - *Audiology/diagnostics*
 - *Linguistics*
- *Acoustics*
 - *Electro-acoustics*
 - *Transducers*
- *Signal Processing*
 - *Audibility restoration*
 - *SpeechNR improvement*

Hearing loss

- is the second most frequent disability globally
- is mostly incurable
- is experienced in communication
- affects all participants

The UN views disability as a participatory socio-cultural phenomenon.

Social interaction is a research field that needs to be included in the scope of disciplines.

- *Environmental adaption*
- *User profiling*
 - *Psychology*

In this edited volume we are exemplifying how the research field of social interaction can contribute towards understanding communication with hearing loss and the social dimensions of hearing technologies by integrating three disciplines: Conversation Analysis, audiology and User Centered Design.

The most frequent type of hearing disability, sensorineural hearing loss, develops due to ageing, exposure to noise and infections, affecting about every third adult above the age of 40 in western societies. Although sensorineural hearing loss is permanent and can only be treated by hearing aids, less than 20% of affected persons use hearing technologies (for a more detailed description of types of hearing loss and its prevalence, cf. Mourtu/Meis, ch.2, this volume). Compliance rates around the world are low and correlate with national wealth, e.g., India and China less than 5% compared to Europe with less than 20% (Bisgaard 2009). Still, national economies are clearly not the only factor, because across western national health care systems, compliance rates also differ, e.g., Finland less than 15%, Germany and the USA less than 20%, with the highest compliance rate world-wide reported for Australia and Denmark at about 40% (Bisgaard 2009). The reasons for the discrepancies in western countries do not seem to lie in technology. Today's hearing aids are highly advanced, and a large variety of technological and design features is available. This indicates that the low compliance rate of this assistive technology needs to be understood in terms of its social and psychological dimensions (cf. Mourtu/Meis, ch.2, this volume).

Communication during medical and audiological encounters is highly relevant to successful coping with the disability and using the hearing aid, both in terms of information transfer and sociality, as shown by a large interview study (ProMatura 2007a/b). Research on medical encounters has established that communication is the key to whether or not patients follow the doctor's advice and prescriptions, yet little is known about what actually happens interactionally in audiological encounters. As these findings indicate, an important reason for the low compliance rate in hearing aid use seems to lie in the health care interactions, and likewise, a reason for the significant national differences in hearing aid use seems to lie in the ways in which the services and availability of assistive technologies are organized. The researchers in this edited volume are the first to study naturally occurring audiological interactions.

The problems associated with hearing loss are mainly social and psychological. Stigmatization, taboo, interactional cover-up and stressful emotional experiences lead to withdrawal and isolation (WHO 2001). Even in the initial stage of hearing loss, communication is impeded (Christensen 2006a/b; Kramer et al. 2006: 504), and related problems such as fatigue and mental distress affect private and work relationships. Lower quality of work, a significantly higher frequency of sick leave, and early retirement are among the consequences. The economical loss is estimated at 200,000 US Dollars to society for each person dropping out of the workplace early due to hearing loss (WHO 2001).

Both problems, the communication difficulties associated with hearing loss and the reluctance to use the help that is available, include interrelated aspects, which can be described at the micro level of social interaction, with respect to the meso level of institutions, organizations and companies providing care, and at the macro level of a country's policy on disability, health

The goal of this edited volume is to exemplify a new interdisciplinary collaboration.

- About 80% of the persons affected by hearing loss do not use hearing aids.
- The rate differs across countries depending on income, health care system and unknown factors.

Health care encounters:

- Communication problems seem to be significant.
- Little is known how these problems arise.
- We study authentic video-taped medical and audiological encounters.

Results of not coping well with hearing loss and noncompliance:

- Stress
- Isolation
- Problems at work
- Early retirement

care system, culture and language. Beyond the macro level of nations, there are overarching global trends, in particular the wide-spread non-usage of hearing aids, stigmatization of hearing loss, and lack of research on social interaction with hearing loss in private settings, at the workplace and in health care encounters. In the network of researchers who present their initial work in this edited volume, we are integrating the micro, meso, macro and global perspectives by studying how the different dimensions of hearing loss emerge in real-life encounters. Research based on surveys, questionnaires and interviews has identified problems of communication and barriers against seeking help. Yet, to date we have almost no knowledge about how hearing impaired persons and their communication partners handle these problems in actual social interaction. While communication problems are reported routinely, there have been only few researchers who have analyzed their occurrence in video-taped authentic interactions. Exceptions are the analysis of video-taped interactions between deaf children, some of whom use hearing aids, and hearing schoolchildren (Keating/Mirus 2003b) and a collection of video-taped audiological and private interactions of persons with severe and profound hearing loss (Kaul 2003; Skelt 2006; 2007). Therefore, we need to understand better how participants in communication orient to problems associated with hearing loss of varying degrees and to the use of hearing aids.

It is most timely to bring this hitherto neglected interactional perspective on hearing loss into the focus of applied research on social interaction. This move promises to help to discover social factors of hearing impairment in more realistic detail. Thus it can open up access to new means for the improvement of hearing impaired persons' conditions of life. To locate and analyze these problems and to find points of departure for change is the motivation driving the research in this book. Our analysis includes the multimodality of interaction, i.e. the verbal conduct, nonverbal behaviors, the orientation to technology and all other characteristics of the interpersonal situation to which the interactants attribute relevance. For the first time, we are integrating Conversation Analysis ("CA"), linguistics, audiology and User Centered Design to study hearing loss and the use of hearing aids directly where it happens: in real-life, authentic interaction, which we have videotaped in private conversation, school and health care settings in Australia, Denmark, Finland, Germany and Switzerland.

To understand human interaction and the use of technologies, CA rigorously examines the participants' perspective through their actions in situ. To gain an empirical basis for technological innovation, developers in User Centered Design take as point of departure how users actually interact with technologies and other people in the flow of their work and everyday lives. Audiologists and rehabilitation specialists contribute by providing access to the professional communication situations, by integrating their perspective in the analysis of interactional data, and by participating in the innovation process.

In the social sciences and the humanities, CA has proved to be a reliable methodology yielding new insights into all kinds of everyday and institutional interaction, including medical encounters (e.g., Heritage/Clayman 2010). The conversation analysts in this edited volume are the pioneers in researching communication with hearing loss and hearing aids. These analyses of social interactions will be relevant to persons with hearing loss and their communication partners, audiological and rehabilitation professionals, as well as to representatives of macro systems, such as national health care systems, education programs for hearing health professionals, the hearing aid industry, and national economies.

Methodologies using subjective reports have identified important problems.

There is a need to study how these problems emerge and are handled in authentic interaction.

- We address this need by presenting pilot studies of naturally occurring interaction from different settings and countries.
- We innovate in international and interdisciplinary collaboration.
- We integrate Conversation Analysis, audiology and User Centered Design.
- We build on successful conversation analytical research on medical encounters and on interaction with technologies.

This applied research is geared towards change and innovation by integrating the Scandinavian approach of User Centered Design, and in particular its current evolution of Participatory Innovation (Buur/Matthews 2008). Finding possibilities for change and implementing them should then involve representatives from all stake holder groups, in particular, persons with hearing disabilities, users and non-users of hearing technologies, audiological professionals and educators, institutional administrators, industrial partners, and politicians.

The work presented in this book is the product of our interdisciplinary collaboration, rooted in the SPIRE centre for participatory innovation, a federally funded research center for innovation established at the University of Southern Denmark, funded by the Danish Council for Strategic Research. The goal of SPIRE (which stands for “Sønderborg Participatory Innovation Research Centre”) is to promote the approach of User Centered Design in industry and in research (cf. Buur/Bagger 1999; Ylirisku/Buur 2007; Buur/Matthews 2008). In a pilot project we discovered that our industrial partner was expecting high-speed innovation and exclusive focus on the technology. We also realized that we needed to build a stronger bridge between conversation analysts and audiologists. Centrally, it became obvious that the process from research to innovation we envision needs to be exemplified in order to show how the different contributions, combined in this way, offer unique value.

This edited volume addresses these needs in the following ways: Case studies of authentic interaction are analyzed from the perspective of CA and audiology, revealing that both angles need to be integrated. In addition, each case analysis is taken as a point of departure for generating ideas for change. By including data from a variety of western countries with different health care systems, the differences and their relevance for compliance generate ideas for innovation. The empirical analysis is grounded in a theory of Science, Technology and Society (“STS”), which allows for an understanding of the micro, meso, macro and global dimensions of hearing disability and the use of technology in interaction. Finally, we have asked internationally recognized scientists, practitioners and hearing aid users to comment on the book from their respective perspectives.

Therefore, this edited volume consists of two parts:

Part One lays out the theoretical and methodological foundations of the contributions rooted in the perspectives of the affected persons in authentic interaction. Part One also introduces basic facts about audiology and compares the relevant health care systems.

Part Two is the heart of this book. It consists of analyses of authentic interactions with hearing loss; some of them involve also how hearing aids are dealt with in interaction. Special emphasis is put on medical, audiological, and rehabilitational concerns and potentials for innovation to be derived by close attention to interactional practice. Studies from two other fields of impairment in interaction are added to show which directions research on hearing loss in interaction might take for innovation.

Part One opens up with Eleni Mourtou and Markus Meis, who provide *Some basics about hearing loss, hearing technologies and barriers to hearing aid use* (ch.2). This is a primer concerning hearing loss. It deals with the different degrees of hearing loss, their measurement and their relevance to communication, and it introduces the technology of hearing aids. Socio-psychological aspects related to stigma and avoidance are discussed as they can account for barriers against hearing aid use.

In ch.3, Maria Egbert, Simone Groeber, Jette Damsø Johansen, Eila Lonka, Markus Meis, Kati Pajo, Johanna Ruusuvoori, and Louise Skelt give an overview over *Hearing health care provision in the national systems of*

- The framework for innovation is the Scandinavian approach of User Centered Design/Participatory Innovation.

The SPIRE centre for participatory innovation “[...] will comparatively investigate user innovation (how people innovate) and user-driven innovation (how companies innovate through various forms of collaboration with users) as a means of advancing innovation theory and developing new methods for the integration of these theories into industrial practices.” (SPIRE director Jacob Buur 2007).

Approach and theory

Structure of this volume:

- Ch.2: Basics on hearing loss
- Ch.3: Comparison of health care systems

Australia, Denmark, Finland, Germany, and Switzerland. Although these countries share highly developed medical and technological provisions, they differ in the compliance rates for hearing aid usage. The authors compare the health care systems of the five countries in order to discover how properties of them (e.g., access to help, costs, support for users after fitting) may foster or rather discourage hearing aid use.

Elizabeth Keating and Pirkko Raudaskoski set the scene for a socio-interactive approach to hearing impairment and the use of hearing aids as social practice with ch.4: *Theoretical framework: Communicative technology for augmented interaction within the field of Science, Technology and Society ("STS")*. They discuss how ideological conceptions and cultural practices influence the ways technology is used and how technology impacts various areas of social life, social interaction and the users' sense of self, to name the most important factors. The greatest obstacles to the use of hearing aid technology are rooted in social practices. The authors make clear that the popular sender-receiver communication model known from cybernetics needs to be replaced by an understanding of effective communication as a collaborative endeavor of both speakers and hearers in order to arrive at a more adequate view of hearing impairment in social interaction.

Since Conversation Analysis as the study of social action is little known in audiology, Maria Egbert and Arnulf Deppermann provide an *Introduction with examples from audiology* in ch.5. Basic concepts are explained to prepare for the analytical chapters, including turn-taking, sequence, repair and the role of nonverbal conduct. In addition, transcription notations are described.

In ch.6., *User Centered Design: From understanding the hearing aid user towards understanding interaction*, Maria Egbert and Ben Matthews propose an innovatory approach with User Centered Design as the framework to integrate audiology and Conversation Analysis in order to develop solutions. Innovation may take as point of departure both interaction ('best practices') and the hearing aid as a social technology. The authors argue that innovation crucially has to include the users' perspective and to study the sites of interaction where hearing disability and hearing aids become relevant. Conversation Analysis is the methodology which gives access to interactional contexts, problems, and consequences of the everyday use of technology in authentic settings. User Centered Design and Participatory Innovation are introduced as approaches which involve both users, producers and care-givers in a collaborative process of designing and adapting products and interaction, and they report on first experiences with the collaboration of audiology, Conversation Analysis, and User Centered Design in Denmark.

Part Two examines hearing loss in video-taped authentic interactions. The chapters deal with four interactional settings which are most relevant for how hearing loss is experienced, becomes socially relevant and is treated, namely, everyday interaction, classroom interaction, doctor-patient interaction, and hearing aid fitting. The analyses draw on data from Australia, Denmark, Finland, Germany, and Switzerland.

The first section of analyses deals with hearing loss in everyday conversation and audiological encounters. Louise Skelt's ch.7, *Dealing with misunderstandings: The sensitivity of repair in hearing impaired conversation*, discusses how indicating trouble in hearing or understanding ("initiating other-repair") is avoided in interaction with hearing impaired partners. While other-repair is common in task-oriented dialogue (e.g., in audiological settings), repair directed to misunderstandings exhibited in hearing impaired persons' talk is dispreferred in more mundane contexts because other-repair is a delicate matter, which may threaten the social and cognitive status of the partner. Instead, partners let misunderstandings pass, if

- Ch.4: Theory of Science, Technology and Society
- Ch.5: Introduction to Conversation Analysis
- Ch.6: Introduction to User Centered Design
- Ch.7: Misunderstandings due to hearing loss

they do not threaten the pursuit of the main business of the talk, or they use embedded forms of correction not addressing troubles and misunderstandings explicitly. Interactants seem to orient to the heightened risk of misunderstandings by using practices of enhanced multimodal coordination, i.e. verbal, non-verbal and other contextual features, in order to pre-empt the necessity of repair.

Repair is also the topic of Kati Pajo's ch.8, *Difficulties to receive the spoken message: Analysis of a private interaction between sisters at the coffee table*. In interaction with hearing impaired partners, it remains often unclear to one or both partners, whether, or to what degree, mutual understanding has been achieved. Hearing problems can also lead to repair sequences which are much longer and more complex than usual. Pajo discusses how participants use both specific resources for signaling that a hearing problem is a trouble source and for repairing an understanding problem originating from a hearing problem. She discusses language-specific practices of repair initiation, which differ in terms of (not) attributing misunderstandings to hearing problems.

Another important interactional site, where hearing impairment causes specific difficulties, is classroom interaction. In ch.9, Simone Groeber and Simona Pekarek Doehler study *Hearing impaired adolescents in a regular classroom: On the embodied accomplishment of participation and understanding*. They focus on pupils with hearing loss who are enrolled in classes where they are co-educated with normal hearing pupils. In this setting, hearing impaired adolescents manage specific interactional demands having to do with the need to attend to two participation frameworks simultaneously, namely, the public classroom interaction with the teacher on the one hand, and supportive interaction with an assistant teacher on the other hand. The authors analyze the difficulties of coordinating participation in both contexts and show their impact on the process of repairing problems and of understanding the teacher's talk. The study displays how the hearing impaired pupils use multimodal means to signal and to disambiguate the kinds of hearing problems they experience and how embodied coordination of all participants is needed to arrive at shared meanings.

The next four papers deal with diagnostic settings. In ch.10, Arnulf Deppermann analyzes *Negotiating hearing problems in doctor-patient interaction: Practices and problems of accomplishing shared reality*. Building on the analysis of a patient's first description of the experience of hearing loss to a medical professional, the author shows how the hearing problem poses a fundamental threat to the subjective functioning and self-perception of the patient. The patient's attempts at describing hearing problems exhibit the specific difficulties to account for subjective experiences which lie outside of the everyday, intersubjectively shared life-world and which make enhanced efforts at collaborative sense-making necessary. The chapter also shows how competing theories by doctor and patient concerning the nature of the illness affect the interaction and lead to miscommunication. From an audiological perspective, these symptom descriptions warrant immediate further examination, yet the general practitioner recommends a sick leave and does not explore the symptoms further.

Maria Bonner reports on *Some linguistic observations on testing hearing* (ch.11). She criticizes problematic presuppositions incorporated in speech perception tests, which tend to yield biased and sometimes incorrect results. In particular, important parts of the sound system of a language are not represented in the test items, and perception problems tend to be confounded with features of production, because scoring does not take into account the possibility of alternative pronunciations which are common in regional varieties, as in the case of oral German. Bonner points out that hearing impaired

- Ch.8: How a hearing problem in conversation is avoided and pursued
- Ch.9: A classroom with and without hearing impaired adolescents
- Ch.10: A patient reports hearing problems to her general physician. They fail to achieve a shared reality.
- Ch.11: A hearing test tested by a linguist

persons are bound to encounter language-specific problems because different sound inventories pose different discrimination problems for hearing impaired persons, as phonetic differences amounting to phonematic differences might be more or less easy to discern and prosody may be more or less helpful.

The next two papers deal with the interaction between hearing impaired persons and audiologists in the context of fitting an already acquired hearing aid. In ch.12, *Hearing aid adjustment: Translating symptom descriptions into treatment and dealing with expectations*, Trine Heinemann, Ben Matthews and Pirkko Raudaskoski pursue the same line of inquiry as Deppermann (ch.10), i.e., the problems to describe the subjective experience of hearing loss in a way to be understood by professionals. This is most vital for audiological consultations, because the hearing aid fitter has to make technical decisions on the basis of the patient's descriptions. The authors show how an audiologist reformulates the patient's symptom explanations in order to make it suitable to treatment decisions. The patient's reportings of the functioning of the hearing aid also bring the user's implicit expectations towards the hearing aid to the surface. The analysis can thus detect whether expectations are unrealistic. The authors argue that addressing the patient's expectations is highly important, because the patient's compliance with the audiologist's recommendations and, ultimately, the hearing aid use as such crucially depends on how the patient sees his or her expectations fulfilled.

Cathrine Brouwer and Dennis Day also focus on compliance in their chapter *WHO/ICF guidelines and compliance in a hearing aid consultation*. The authors' point of departure is to ask how the World Health Organization's International Classification of Functioning Disability and Health ("ICF") and their national adaption in Denmark can be implemented in the interaction between hearing impaired patients and audiologists. Both the WHO's and the national guidelines require that the patient is actively involved in the process of medical consultations. Ch.13 shows how the uptake of patients' concerns depends on being formulated in the right place, i.e., in the context of a problem presentation early in the consultation, whereas both audiologist and patient seek a technical solution from the outset of the interaction.

In order to demonstrate how conversation analytic methods can be brought to bear fruitfully on communicative impairment, the next two chapters present results from two fields of study where this approach has already been implemented successfully. Ch.14 by Minna Laakso deals with *Aphasia as an example of how a communication disorder affects interaction*. Aphasia has been studied in depths in Conversation Analysis in the last years, and the wealth of insights gained gives an impression of what can be accomplished by adopting the CA-approach in order to analyze the social and interactional dimensions of impairment. For example, studies have yielded that aphasics use specific strategies of turn construction, which may be faulty from a linguistic point of view, but which are most efficient tools in order to take part in an ongoing conversation more effectively. Complementarily, non-aphasic co-participants actively cooperate in making the aphasics' turns interpretable, e.g., by completing utterances. Still, the aphasics' face as a competent interactional partner is saved by avoiding open acknowledgement of difficulties or by not forcing them into situations where their speaking competence is put to the test.

Elisabeth Gülich's ch.15, *Conversation Analysis as a new approach to the differential diagnosis of epileptic and non-epileptic seizure disorders* once again leads us into a neighboring field of research, showing how CA is used successfully to aid medical diagnosis. The author shows how linguistic and communicative properties of how people describe seizures are instrumental in diagnosis to differentiate between two types of seizures, epilepsy and

- Ch.12: Hearing aid fitting as a translation problem
- Ch.13: WHO/ICF guidelines for hearing aid fitting
- Ch.14: What we can learn from applied Conversation Analysis of a different communication disorder (aphasia)
- Ch.15: What we can learn from applying Conversation Analysis to differential diagnostics (seizures)

dissociative personality disorder. Gülich shows how close observation of the patients' talk can elucidate cases which are ambiguous from a medical point of view and how conversation analytic insights can be used to develop a toolkit for differential diagnosis on linguistic and communicative grounds.

In ch.16, Arnulf Deppermann and Maria Egbert's *Conclusions and future perspectives for application and innovation* present perspectives of how the integration of User Centered Design, audiology and Conversation Analysis can lead to innovation. The chapter takes as point of departure the findings from the analyses presented in this edited volume. In this discussion, we consider the relevance to hearing impaired persons, their social network, the medical and audiological staff, but also more generally for the health care systems, legislation, and hearing aid producers. Building on the studies assembled in this book, this chapter outlines challenges for future research and it sketches opportunities how to put insights from close analysis of everyday and institutional interaction involving hearing impairment and hearing aids to innovative uses aiming at improving the communicative situation of hearing impaired persons and their interactional partners.

The book closes with comments on the approach taken in this volume by experts from various disciplines dealing with hearing loss and hearing aids, and users of hearing technologies. They point out the potentials that an interaction-oriented approach to hearing impairment promises to offer in solving long-standing problems and how it links up with their specific professional perspectives.

The contributors to this book do not purport to solve the complex problems associated with hearing loss and use of hearing aids; rather, our goal is to present an innovative methodological perspective with this first-time interdisciplinary collaboration, which we believe offers a new window on understanding the problem and a unique framework for possible solutions. The research in this collection takes a first step towards a larger empirical study with the goal of contributing to an improvement of the quality of life of persons with hearing loss and their social environment, to deeper insights into the interface between audiology and interaction, to a theory of the role of new technologies in shaping social interaction with disabilities (Keating 2000; Keating/Mirus 2003a), and to a better understanding of the role of culture in shaping the adoption of new technologies (Keating 2005; 2006). The empirical results will be used for identifying points of departure for change in the areas of interaction, technology, training and policy making.

- Ch.16: Towards application and innovation

Experts from different disciplines and persons with hearing loss comment on this volume.

The scope of this approach.