

# THE EXPERIENCE OF HEARING LOSS

Journey through aural  
rehabilitation

Edited by  
Vinaya Manchaiah  
and Berth Danermark



# THE EXPERIENCE OF HEARING LOSS

Hearing loss is a common chronic condition which is often poorly recognized but can have multiple negative impacts, not just on the lives of those directly affected, but also those living with them. People with impaired hearing may begin a long and uncertain journey involving a number of key stages, from emerging awareness and help-seeking, to diagnosis, adjustment, and self-evaluation.

Based on a model of person-centered audiological rehabilitation, this book explains why it is important to understand both patients' own experiences, and those of their communication partners, over time. It focuses particularly on the human dynamics of hearing loss, exploring the broader consequences of hearing loss for the individual, family members, and wider society. In particular the book:

- gives insight into the patients' and their communication partners' experiences and perspectives through clear and telling first-hand narrative accounts;
- examines how people understand their own hearing loss, reflect on their experiences with hearing aids – both positive and negative – and evaluate treatment options;
- considers the changes needed to conversations in order to include all communication partners, whether with impaired hearing or not; and
- discusses consequences of hearing loss using the International Classification of Functioning, Disability and Health (ICF).

With its explicit aim to increase awareness of the need to include the patient and close relatives in the process of rehabilitation, this new text makes an important contribution to further improve evidence-based practice in the field of audiological rehabilitation. An ideal text for audiology, ENT, and nursing students of all levels.

**Vinaya Manchaiah** is Jo Mayo Endowed Professor in the Department of Speech and Hearing Sciences at Lamar University, USA. He is also the co-founder of the not-for-profit and non-governmental organization Audiology India.

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# THE EXPERIENCE OF HEARING LOSS

Journey through aural rehabilitation

*Edited by Vinaya Manchaiah and  
Berth Danermark*

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# FOREWORD

The need for adult aural rehabilitation (AR) was recognized in the United States some 70 years ago, and originated because of the large number of soldiers with hearing loss returning home. At that time, veterans with service-related hearing loss benefitted from a residential program at one of three strategically located hospitals across the USA, where a comprehensive six-week program provided by a multidisciplinary team was carried out involving audiologists, speech pathologists, psychologists, and otologists. The services they received emphasized speech and lip-reading, listening exercises (auditory training), and the fitting of hearing aids (extremely primitive in comparison to today). In no other time or place since then has AR received so much focus and attention; this was the worldwide “heyday” for AR. It is important to realize, however, that the veterans who participated in this innovative effort had no choice – after all, they were soldiers following orders.

Unfortunately, we who have experienced much of the journey that audiology has traveled since then have seen how AR services have not been embraced. Despite multiple textbooks on the subject and “lip service” about how AR is needed for successfully overcoming the challenges of auditory disability, few audiology practitioners provide structured AR programs to their patients on a regular basis. In fact, in the USA, reimbursement is not available to compensate for the time that audiologists spend providing AR services.

However, the winds are shifting. Audiology research and rehabilitation is again focusing on the importance and value of AR. Increasingly, we are being reinforced by research findings and clinical experiences that show the significant benefits and improvements derived from structured AR being provided to our patients. The basic premise is the same as it was long ago – to achieve the best possible outcome through a comprehensive program tailored for each patient. However, the principles and guidelines are vastly different, because it is now known that AR encompasses the development of a wider set of activities and skills, and the focus is to improve all

abilities that contribute to understanding spoken language. With this new definition and conceptual framework, there are new approaches involving: visual aspects of communication, controlling background noise, attending to linguistic cues, developing repair strategies, applying assertive techniques, improving and situating proper positioning and lighting, eliciting the cooperation of communication partners, and a host of others. All of these aspects are covered in this text.

As the new awareness for AR is becoming more recognized, the number of publications in scholarly journals is increasing exponentially, and there have been several excellent recent AR textbooks for adults and children. Most of the work and publications has taken a clinician/research viewpoint; such work has had an “extrinsic” rather than “intrinsic” or “introspective” focus. That is, for years AR programs have taken a clinical/research view – how to approach the process as a practitioner or researcher. This perspective is important, but is severely limited because it fails to recognize the value and importance of the most critical components of the process: patients and their significant others. This unique aspect is what makes this text by Drs. Manchaiah and Danermark so different. These authors and editors have deftly focused on the introspective perspective of AR with a patient/communication partner approach. This is analogous to the now well-recognized, well-tested process of including the consumer in developing advertising campaigns to attract and entice them to purchase a product. It is clear that this process really, really works, otherwise product advertising would not be a multimillion dollar industry.

Another unique aspect of this text is reflected in the title that includes the word “journey.” A journey is a trip, it is a passage or travel from one place or stage to another, and reflects exactly what the AR process involves in order to be successful. The journey begins with initial identification or recognition of auditory disability, and the endpoint is the time of acceptance of how to live with and maximize communication in view of the inability to hear or process sound. In addition to Drs. Manchaiah and Danermark, excellent authors were chosen for each chapter based on their publication and clinical experience of the variety of topics covered by the text.

Those interested in AR and how to entice those who would benefit from a structured AR program will be more than pleased with this text. It provides the basis for delivering AR programs to those in need of therapy in a highly effective, unique way that allows the clinicians to bring AR into the limelight it so aptly deserves.

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# PREFACE

For large numbers of people, hearing loss occurs gradually. In the beginning, problems related to the hearing difficulty may only be occasional, but eventually increase to a stage where it significantly interferes with life. Consequences of hearing loss may extend to family members, friends, and colleagues. Moreover, hearing-loss related experiences of all those affected may change over time. It is noteworthy that very little attention has been paid to how these experiences change with time and what factors and mechanisms trigger these changes. Better understanding of such aspects will provide unique insight into the human dynamics associated with hearing loss.

The Ida Institute, based in Denmark, initially proposed the idea of a *patient journey*. The institute is an independent, non-profit organization with the vision to foster a better understanding of the human dynamics of hearing loss. They believe in interdisciplinary collaborative work to develop various tools that foster patient-centered care in clinical settings around the world. In 2008, the institute started a seminar series, “*The Process of Defining Hearing*.” It was during this seminar that the idea of exploring how the experiences of people with hearing loss change over time was proposed. The institute created a *possible patient journey* based on the collaborative work of over 60 professionals around the world who have worked in the area of hearing healthcare.

In 2009, Vinaya Manchaiah was made aware of this patient journey idea when he was invited to attend an Ida Institute seminar. At this time, Berth Danermark served as a faculty member of the institute. Following the seminar, Vinaya, in close collaboration with the late Professor Dafydd Stephens, started working on further developing the patient journey model by researching perspectives of those with hearing loss. After a few initial studies, in 2013, Vinaya went on to develop his doctoral thesis in this area titled, “Evaluating the process of change: Studies on patient journey, hearing disability acceptance and stages-of-change” at the Swedish Institute for Disability Research (SIDR), Linköping University, Sweden.



Since then there have been a number of publications in this area from researchers around the world. It is this research that led us to believe that there is a need for a book that provides details of these studies and ideas in a more accessible way to students and professionals who have interest in hearing loss.

In this edited book, we are happy to put together writings of numerous outstanding scholars from various fields, including: audiology, sociology, psychology, anthropology, and epidemiology. Each scholar has significant clinical and research expertise and first-hand knowledge about experiences of people with hearing loss. Multiple approaches are taken from audiological, psychological, and sociological standpoints to provide multi-dimensional understanding about experiences of people with hearing loss.

This book is aimed at future (undergraduate and graduate students) and present healthcare professionals (e.g. general medicine, gerontology, nursing, otolaryngology, psychology, etc.) to enhance reading about chronic conditions. In addition, we anticipate that this book will also be useful for early career communication disorder and audiology students to bolster reading for audiological rehabilitation courses. This book should be useful not only to professionals, students, and academics, but all those who themselves have experiences of hearing loss and their significant others.

*Vinaya Manchaiah and Berth Danermark*

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# ABBREVIATIONS

ABR	Auditory Brainstem Response
AR	Adult Aural Rehabilitation
BAHA	Bone-Anchored Hearing Aids
BICS	Brief ICF Core Sets for Hearing Loss
CICS	Comprehensive Core Sets for Hearing Loss
CP	Communication Partner
ENT	Ear, Nose, and Throat
GP	General Practitioner
HBM	Health Behavior Change Models
HHIE	Hearing Handicap Inventory for the Elderly
HHP	Hearing Health Professionals
HHQ	Hearing Handicap Questionnaire
HLAA	Hearing Loss Association of America
HRQoL	Health-related Quality of Life
ICF	International Classification of Functioning, Disability and Health
LASA	Longitudinal Aging Study Amsterdam
NL-SH	Netherlands Longitudinal Study on Hearing
OAEs	Otoacoustic Emissions
PCAR	Person-Centered Audiological Rehabilitation
PCC	Person-Centered Care
PHL	Person with Hearing Loss
SIDR	Swedish Institute for Disability Research
TMC	Transtheoretical Model of Change
WHO	World Health Organization