

Holistic Aural Rehabilitation – a Challenge

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Holistic Aural Rehabilitation – a Challenge

Abstract: Despite more than 40 years of medical and technical rehabilitation offered to hearing-impaired people in Norway, there are still considerable barriers to rehabilitation outcome. This paper presents the current state of aural rehabilitation in Norway. The need for a change of aural rehabilitation from being mainly a medical and technical matter into a holistic, cross-professional and multi-disciplinary approach is argued. Educational audiology as well as other professional fields must be included, e.g. the currently lacking aspects on psychosocial factors, accept of hearing loss and communicative skills training. Reports and articles from other countries support the arguments for a change in aural rehabilitation practice, not only in Norway. There is also a need for a change in the educational programmes for professionals, emphasizing scientific skills and research work.

Introduction

Aural rehabilitation, denoted as “A problem solving process aimed at minimising disability and avoiding or minimising the resultant handicap” (Stephens, 1996:57), is at the beginning of the 21st century a considerable challenge for professionals. A substantial reason for this is that the number of hearing-impaired individuals in the society is rapidly increasing, and that hearing impairment in adults over 18 years of age is increasingly the most frequent communication disorder (Rosenhall, Jönsson & Söderlind, 1999, Sorri, Junio-Ervasti, Uimonen & Huttunen, 2001). Another reason is that aural rehabilitation in many countries is fragmented and insufficient (Tesch-Römer, 1996, Falkenberg & Antonsen, 1997, Sweetow, 1999, Lieth, 2001, Lorentzen & Berge, 2003). This in spite of the fact that the serious effects of hearing loss on a person’s communicative and social function (Kyle, Jones & Wood, 1985, Noble, 1986) can lead to emotional problems with a severe impact on the quality of life (Hull, 1995, Skollerud, 1996, Tesch-Römer, 1996, Røykjær & Pedersen, 1997, Carmen, 2001).

Up to the middle of the 20th century, schools for the hearing-impaired were in charge of rehabilitation for the deaf and hard of hearing in the Scandinavian countries.

Around 1950, medical audiologists (ENT doctors) brought aural rehabilitation into the hospitals and made it a medical matter (Lieth, 2002). The same pattern was seen in other countries as well (Hull, 2001). The use of technology, which includes hearing aids as well as other amplifying equipment and diagnostic machines, has been considered part of medical audiology. Thus, rehabilitation in the audiological field fits into the tradition of other fields, where rehabilitation is

considered to be mainly a health issue, and where patients as well as health authorities have focused primarily on bodily function and repair.

A recent considerable change of paradigm has transformed the view of rehabilitation into a holistic process, a user-oriented approach based on the individual user's own goals and preferences. Such a rehabilitation practice is "all what it takes" for the person to obtain these goals (Hanssen & Lindqvist, 2003). Thus, rehabilitation can no longer be limited to the repair of physical functional deficiencies or, more generally, to what the *health sector* does. The individual must receive assistance to be able to achieve the greatest possible independence and to participate in society on his own terms on a par with others. This means that other sectors, in addition to the health sector, must be brought on board to help the individual (Normann, Sandvin & Thommesen, 2004).

This paper will focus on the system and the unmet needs of *adult* aural rehabilitation mainly from a Norwegian point of view. Mainly based on a literature review, a presentation of traditional practice and results from evaluation studies on rehabilitation programmes for the past 20 years, the need for a change – both in the programmes and in the education of professionals to work in this field – is argued. Some of the results referred to show that these unmet needs have been described in other countries as well. So this paper can be considered to be of global relevance.

Initially, basic concepts will be defined, prevalence, needs and the present situation will be described. Then, suggestions for changes needed to facilitate holistic rehabilitation for the hearing-impaired and individuals with other auditory symptoms that require professional help are presented. Finally, presumed barriers to development and outcome in the aural rehabilitation field are suggested.

Basic concepts

The term *hearing-impaired* as a group subject to aural rehabilitation includes all types and degrees of annoying hearing loss, i.e. both the hard of hearing and the profoundly deaf.

Different terms are used related to rehabilitation for the hearing-impaired. The term *aural rehabilitation* has traditionally encompassed training in lip reading, speech reading and auditory skills (Matonak, 1999). At the end of the 20th century, another term was brought into the field: *Audiologic rehabilitation*, also known as *rehabilitative audiology*. These terms encompass the evaluation and management of overall communication skills, the psychosocial aspects of hearing loss, the education of significant others (e.g. parents, siblings and close friends), hearing aid orientation, an emphasis on improving conversational and interactive skills, and the use of assistive listening devices (Kricos & Lesner, 1996). In the paper the term *holistic aural rehabilitation* will be used, including medical, technical and educational audiology. In Norway to-day *educational/ pedagogical audiologists* are the ones who are professionally skilled to perform communicational training and to be counsellors advising hearing impaired in psychosocial coping. In this paper the term *educational audiologist* will be used. The concept *multi-disciplinary* includes professionals from these three fields and from other relevant fields, e.g. psychologists, social workers and professionals from the vocational field.

Prevalence and needs

Some studies consider the prevalence of hearing impairment in adults over 18 years of age to be 15%, with a projected increase up to 25% in 2020 (Rosenhall et al. 1999, Sorri et al. 2001). According to surveys carried out the past ten years, approximately

400,000 people in Norway have a hearing loss that requires rehabilitation services. More than one third of these have a hearing loss due to the aging process (Falkenberg & Kvam, 2001). As the group of *elderly* constantly increases, the need for aural rehabilitation will increase as well.

Tinnitus, also denoted as “the perception of sound within the head in the absence of external auditory stimulation” (Hazell & Jastreboff, 1990), as well as *hyperacusis*, described as the collapse of loudness tolerance (Vernon & Press, 1998), affect the auditory system. Individuals suffering from these symptoms are therefore considered to be subjects for aural rehabilitation. A number of these are also hearing impaired. Fabianska, Rogowski, Bartnik & Skarzynski (1999) suggests that tinnitus affects about 17% of the general population around the world. Sanchez & Stephens (1997) found that 8% of tinnitus sufferers have *hyperacusis*. The prevalence rate of individuals with hyperacusis is unknown. The co-morbidity of hyperacusis with many other diseases, leads one to believe that hyperacusis is not an extremely rare disease (Demaree, 1998).

Cochlear implant is a fairly new, but rapidly growing field in aural habilitation and rehabilitation. Due to technological and medical development, profoundly deaf children can develop a hearing status that is functional for a spoken-language development functional for communication based on spoken language (Preisler, Tvingstedt & Ahlstrom, 2005, Wie, 2005). Deafened adults can obtain functional hearing as well, provided that adequate rehabilitation programmes are offered.

The increasing number of hearing-impaired *immigrants* to Norway in the past decades calls for new knowledge in order to provide adequate rehabilitation programmes tailored to these groups.

A number of persons in the groups mentioned above have *additional disabilities*, such as *vision loss* (Reiners, Nagel-Wolfrum, Jurgens, Marker & Wolfrum (2006, Nikolopoulos, Lioumi, Stamataki & O'Donoghue, 2006), *intellectual disabilities* (Holt & Kirk, 2005), *emotional disturbance* (Sinnott & Jones, 2005, van Eldik, 2005, Pollard, 1996, Steinberg, Sullivan & Loew 1998), situations that call for an extended range of skills in order to be able to offer adequate rehabilitation programmes as well as proper diagnoses.

During the past years, the involvement of *significant others* as a way of seeing the individual as part of the environment, has been increasingly emphasized as decisive for rehabilitation outcome (Getty & Héту, 1991, Hallberg & Barrenäs, 1994, Danermark, 1998, Rezen, 2001, Dwyer & Mawman, 2001).

The above-mentioned groups represent the diverse range of needs often neglected in aural rehabilitation.

The Current Situation in Aural Rehabilitation.

Through several evaluation studies, it has been concluded that a considerable number of fitted hearing aids are not worn. Kramer (1982) found this in 28% of hearing aid users. A survey carried out by Olsholt & Falkenberg (1995) showed that 30% did not wear their hearing aids, whereas Falkenberg & Antonsen (1997) found that 33% wore their aids "seldom" or "never". This low-frequency use of fitted hearing aids in Norway is confirmed by Winther, Hanche-Olsen, Poppe & Tvette, 1990, Lippestad & Natvig Aas, 1997, Gundersen & Lippestad, 2000, Antonsen, 2001 and McGlade & Solheim, 2003. This is in spite of the fact that 60-70% of the several million adults in the Nordic countries who suffer from hearing impairment are estimated to benefit from hearing aids (DACEHTA, FinOHTA, SBU & SMM, 2001). Individuals

estimated to benefit include many of those who do not wear their fitted aids. The percentage of non-users has stagnated over the past 20 years – in spite of technological development and more appropriate hearing aids (Falkenberg, Holmberg, Morken & Øygarden, 2002).

As already shown, aural rehabilitation in Norway is still mainly a medical and technical matter. There is a growing awareness in audiological practice that attention to technical matters alone may miss the point as far as the individual's needs and social circumstances are concerned (Noble, 1996, Brooks, 1990, Falkenberg & Antonsen, 1997, Brooks & Hallam, 1998, Antonsen, 2001). For instance, the fact is neglected that the educational audiologist is a necessary part of the audiological team (Lippestad, 1994, Tesch-Römer, 1996, Héту, 1996, Lippestad & Natvig Aas, 1997, Gundersen & Lippestad, 2000, Norwegian Board of Health, 2000, Antonsen, 2001). Thus communicative skills training through speech reading and auditory training programmes are scarcely carried out, which means an unfulfilled aural rehabilitation programme. Likewise, counselling for acceptance of hearing loss and a focus on psychosocial aspects is very much neglected, and little help is offered (Lorentsen & Berge, 2003). This often results in the individual experiencing hearing impairment as a threat to her social identity (Héту, 1996). Involving significant others in the rehabilitation programme is also rarely done in aural rehabilitation. In other words, the rehabilitation programmes still focus mainly on the defective ear and hearing loss as such, whereas the consequences of the loss are not taken into consideration. The programmes offered are more based on traditional routines than on an individual, user-oriented approach with the primary focus on the needs of the user. This is in spite of the fact that there is a considerable outcome from aural rehabilitation programmes that include these aspects, for instance in the increased frequency in use

of hearing aids (Montgomery, 1991, Winther et al. 1990, Falkenberg & Antonsen, 1997). A longitudinal study performed by Antonsen (2001) shows that the positive effect of such a programme is maintained for years after the patient's attending a holistic and user-oriented programme including the above-mentioned aspects.

Many hearing-impaired individuals are, in spite of having access to modern listening devices, unable to maintain their employment and their social life. Many are forced into unemployment and isolation. A recent study from Denmark shows that unemployment in this group is more than double the average for the total population (Clausen, 2003). For the majority this means a significant decrease in the quality of life. In most modern societies, including the Nordic countries, employment is arguably the most important criterion for categorising people in terms of class, status and power (Barnes, 2003). Experience shows that access to vocational rehabilitation for the hearing-impaired is haphazard and still at an unacceptable level in Norway. The current lack of this holistic, multi-disciplinary aspect is crucial in aural rehabilitation, which, due to the complex nature of audiology, can never be practised properly by one person alone (Fish, 1984).

Legal Rights and Aural Rehabilitation Programmes in Norway

Hearing-impaired people in Norway have a legal right to a rehabilitation programme that includes medical, technical and educational aspects with a considerable focus on communicative skills training, acceptance of hearing loss and other psychosocial aspects (McGlade & Solheim, 2003), in other words a holistic aural rehabilitation programme. Few individuals, however, are offered such a programme.

Norwegian Ministry of Health and Ministry of Social Affairs regulations (2002) state in §1 that rehabilitation services must be provided from a user perspective, be

coordinated, cross-professional and planned, in or near the user's daily environment and in a meaningful context. This holistic approach is also described by the Norwegian Board of Health (2000).

Individuals needing aural rehabilitation are offered treatment in either one of the 30 audiological wards at public hospitals or by an ENT specialist in private practice. There are 56 of these private practices in Norway. Half of the hearing aids are fitted in hospital wards, half in private practices (Falkenberg, Holmberg, Morken & Øygarden, 2002).

The professionals seeing the patients are mostly medical doctors and technical audiologists, a rather poor manning of aural rehabilitation teams, both in public hospitals and in private practice. A few educational audiologists run their own clinics, offering programmes on speech training and communication skills, tinnitus treatment and counselling for emotional aspects of hearing loss. These professionals are, however, in spite of the fact that most of them are paid by the authorities, not officially counted as members of aural rehabilitation teams around the country.

As for tinnitus sufferers very few programmes are offered, in spite of the fact that Tinnitus Habituation Therapy, based on a neuropsychological model brings approximately 70% of tinnitus sufferers to a high level of improvement has been tested and found successful both in Norway and abroad (Falkenberg, Tunland & Skollerud, 2003, Sheldrake, Hazell & Graham, 1999). The therapy is based on a new approach to tinnitus management, presented by Jastreboff & Hazell (1993). Few professionals are skilled to perform this treatment.

Peer assistance has developed as a rather common support to hearing aid users.

Compared to professional assistance, this is inexpensive. In poor communities there is a threat that peer assistance may replace professional assistance.

As for technical equipment supplemental to hearing aids, Norway has 14 centres for distribution of technical aids. The professionals engaged to advise and assist the hearing impaired in using such equipment, are often people with very little audiological knowledge. The use of professionals with audiological training is a financial rather than a user-oriented matter.

Educational Programmes for Professionals in the Audiological Field

The educational programmes are few and far from sufficient for professionals in the Norwegian field of aural rehabilitation. There is no education for specializing in *medical audiology*. *Technical audiologists* are trained at a bachelor's degree level. *Engineers* who want to specialize in audiology have no formal audiological education. They are trained at their workplace and are more or less self-taught. *Educational audiologists* are trained at a master's degree level, and are the only professionals in the field, except for medical audiologists, who have a formal education in research work. Only a few people in Norway today have a PhD in audiology. The majority of these are educational audiologists.

This lack of higher and specialized education in the audiological field has led to the fact that Norway has very few professionals with competence in educating new students or doing scientific work in the field. Very little research for international publications has been carried out, and "Norway is in fact about to be deleted from the international map of audiology" (Laukli: 2001: 16).

What is Needed to Succeed?

As a prerequisite, and in order to accomplish the goals of holistic aural rehabilitation, and in order to follow the regulations issued by the authorities, literally, changes are needed both in practice and in the education of professionals. It will be necessary to take into consideration the recent change of paradigm onto a user-oriented approach, based on the individual user's own goals, preferences and possibilities for coping.

In the following, suggested changes will be argued by focusing on three main points: The organization, the rehabilitation programmes and the education of professionals. All the following "demands" and "suggestions" are made by the author.

The Organization of Holistic Aural Rehabilitation

Holistic aural rehabilitation calls for cross-professional and multi-disciplinary work. Both generalists and specialists are needed (Larsby, Andersson, Hallgren, Lundblad, Nyman & Carlsson, 2000).

The use of educational audiologists who are trained for counselling work to deal with psychosocial and communicative aspects is necessary for the audiological team, both in public clinics and in private practice. In Norway, this is already required by the authorities, and should be a rather easy task to accomplish, assuming that necessary changes in the payment regulations are carried out.

To be able to fulfil the needs and the already existing requirements from the authorities, the departments in charge must consider their responsibilities, do a cost-benefit evaluation and be willing, through the established payment routine, to provide for a functional payment system to carry out holistic aural rehabilitation.

Unworn, fitted hearing aids represent a considerable amount of money, in Norway estimated to be approximately 16 million US dollars per year. Some of these people would do better with other technical aids, or may not be able to use any technical equipment. Perhaps they just need educational rehabilitation. Unworn hearing aids or other unused audiothechnical equipment represent a financial resource and should be fitted to someone else. Thus, considerable resources could be diverted from the technical part of aural rehabilitation into another area, for instance educational rehabilitation. The need for proficiency in tinnitus treatment is part of the picture.

There is a need for greater accessibility to professionals, multi-disciplinary work and more focus on the perspective of the user (Hørselshemmedes Landsforbund, 1997, McGlade & Solheim, 2003, Lorentzen & Berge (2003). Normann et al. (2004) state that there are numerous examples of the consequences of education and training (rehabilitation) not being carried out or started too late, stressing the need for accessibility to professional rehabilitation programmes. Such an effort is anticipated to bring a positive change into the cost-benefit discussion, as more people will be able to keep their jobs instead of going into long-term invalidity. It is decisive for rehabilitation outcome to start the intervention soon after the problems start. The teams must focus on diagnostic work as a basis for rehabilitation. This includes not only an audiological diagnosis, but also a functional assessment, for example of psychosocial factors and communication skills.

The Rehabilitation Programmes

In order to achieve holistic aural rehabilitation, the rehabilitation programmes must be considerably developed into holistic rehabilitation as described in the introduction, by considering the needs of the individual as a starting-point, and with a

programme tailored accordingly. The programme must be based on skilled diagnostic work as a prerequisite for adequate rehabilitation outcome, including not only medical-audiological diagnosis, but also psychosocial function, for instance by using psychological tests intended to detect subjective hearing problems and communication skills. Furthermore the programmes must emphasize counselling for coping and empowerment. Helping people to cope so that they feel capable is an important part of rehabilitation (Normann et al., 2004). According to Askheim (1998), empowerment deals with the transfer of power. "Power must be given or taken back by those who today are clients or users of the rehabilitation services so that they can gain or regain control over their own lives." Normann et al. (2004:46) comment on this by saying that "An understanding of coping such as this, which is not just limited to mental processes or practical skills but which also includes the infusion and mobilization of power, captures the meaning of the user perspective which holds a central place in rehabilitation." These statements require a programme tailored for each individual, where the client herself participates in and contributes to the content and the progress of the programme.

As for the psychosocial aspects of the rehabilitation process, positive information can increase rehabilitation effectiveness by a) identifying positive factors in people's experience of hearing loss that can be included in an aural rehabilitation programme which seeks to maximize effective self management of hearing loss and b) generate positive outcome indicators of functioning for inclusion in the assessment and rehabilitation components of the rehabilitation process (Kerr & Stephens, 2001). The education of significant others must be integrated in the rehabilitation programmes (Rezen, 2001). There is a need for implementing the rehabilitation programme in or close to the user's daily environment.

Scientific Aspects

There is an unfulfilled need for trans-disciplinary research in the field and for people who are skilled in doing such work. Information on consumer satisfaction, not only with a focus on hearing equipment, but also on satisfaction and unfulfilled needs in the area of psychosocial function and communicative skills, is decisive for further practice. The results from such scientific work should lead to needed changes and adjustments in aural rehabilitation programmes.

Education of Professionals

Audiology as a professional field demands skilled people to take care of all the needs described in previous sections of this paper. It seems evident that one person alone cannot acquire all of the skills necessary to provide for every need related to aural rehabilitation. To avoid the struggle for power and position among professionals and thus unnecessary barriers to aural rehabilitation outcome, it is important that everyone on the team has a common basis for their training, and that the training programmes offer the opportunity to specialize in current fields, such as multi-disabilities, cochlear implant, technical audiology, educational audiology, tinnitus habituation therapy, immigrant issue and so on. To be able to go into research work, the minimum educational level should be an advanced level and follow the Quality Reform, which might be viewed as the Norwegian follow-up to the Bologna Process. This advanced level education is urgent in countries such as Norway, where scientific work in the audiological field has been so greatly neglected. There is an urgent need for professionals in the field to educate new generations of professionals; these educators need education on a doctor's degree level. Audiology is an academic field that requires highly educated professionals.

The need for trans-disciplinary research in the field stresses the need for elevating the educational level of all professionals who work with audiology and audiological matters.

The authorities are urged to take responsibility for training professionals and providing help to the hearing-impaired and to take into account the human and financial benefits of doing so.

Barriers to development and outcome in the Aural Rehabilitation field

The developmental process in the audiological rehabilitation field in many countries during the past decades can be characterized as haphazard, influenced by different interests, and not always seen from the user's point of view. There are probably many reasons for this, and the picture is rather complicated. Some of the assumed reasons and barriers will be mentioned here.

Hanssen & Sandvin (2003) suggest that the many professional interests and the struggle for power and position among them have the disorderly and chaotic hallmarks of late modernity. Experience shows that these features are present in the audiological professional field, and are likely to represent a barrier (Falkenberg, 2001).

Anxiety about change, as often experienced by professionals, might be a hindrance to progress in the audiological field.

An additional obstacle in this field, at least in Norway, is that laws and regulations are neglected in audiological practice and rehabilitation programmes, and that no one takes financial responsibility for a holistic rehabilitation programme. No person or agency controls audiological practice – neither in hospitals, nor in private practice.

In other words: the barriers are not due to a lack of legal rights, but rather to a lack of implementation of those rights in clinical work. There is a lack, not only of adequate competence, but also of responsibility from those in authority (McGlade & Solheim, 2003).

Lorentsen & Berge (2003) furthermore report a general complaint about low accessibility to professionals due to long waiting lists. This might cause a decrease in motivation during the waiting time, which may represent another barrier to rehabilitation outcome. In our neighbouring countries Denmark and Sweden, the number of professionals engaged in aural rehabilitation is far higher than in Norway, taking into consideration the number of inhabitants (McGlade & Solheim, 2003).

Lack of proper education for professionals in the audiological field is thought to represent a barrier to rehabilitation outcome, as is the lack of educational programmes for those who want to update their skills in the field, including training for scientific research work. Current examples to be mentioned as knowledge and skills that are rarely seen in today's practice are skills in treating tinnitus and hyperacusis, skills to meet the needs of cochlear-implanted persons, as well as the needs of the multi-disabled and of individuals with a foreign language and cultural background (Falkenberg et al., 2002).

Securing the quality of rehabilitation programmes offered to the hearing-impaired is a non-existent service. This must be considered a substantial barrier. No official programme has been developed, like the ones for instance in Sweden and in the U.S.A. Aural rehabilitation services offered to the individual hearing-impaired are thus haphazard, and very much dependant on where one lives and who one meets when seeking professional help. There is considerable variation in the organisation

of hearing services in Norway, as is the situation among other Western countries (DACETHA et al., 20001). In addition to the human factor, there is also a cost-benefit factor, where the spending of government money on successful treatment would be much more appropriate than on social insurance benefits.

The total picture of aural rehabilitation seems to be influenced by money, professional interests and the struggle for power and position, rather than by user-oriented needs. These are extremely strong barriers, barriers representing a considerable challenge that calls for involvement both from the authorities, professionals and the organisations representing the hearing impaired.

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