

The Hard of Hearing Club: A Social Framework for Audiologic Rehabilitation for Seniors with Severe Hearing Difficulties

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Abstract

Due to the nature of auditory aging, communication challenges in the elderly may not be adequately addressed by amplification, and require the use of additional audiologic rehabilitation, including behavioural communication strategies practiced in a meaningful context. Seniors with severe hearing loss are often unable to communicate effectively and participate in social activities. The challenges and frustrations presented by attempts to participate socially result in exclusion, avoidance and withdrawal. Exacerbated by other physical and cognitive changes associated with aging, the resulting social isolation often leads to loneliness and depression, and can have a significant impact on quality of life. The Hard of Hearing Club at Baycrest, a centre for geriatric care in Toronto, offers a different approach to audiologic rehabilitation for these clients who are at risk due to social isolation. The Club employs a social framework where supportive communication strategies are presented in the context of meaningful social interaction. The goals, components and outcomes of the Club are described, and reasons for the group's success are proposed and discussed.

Introduction

Hearing loss in the elderly has a profound effect on communication and quality of life. Many studies have shown that the inability to communicate effectively af-

fects socialisation, independence, participation in activities of daily living (ADLs), and consequently, emotional, psychological and social well-being (Bess et al, 1989; Mulrow et al, 1990; Carabellese et al, 1993; Lubinski, 1995; Weinstein, 2000).

Social interaction is a key determinant of successful aging. Interpersonal relationships are defined by communication behaviors and can have a substantial impact on life satisfaction (QOL) as well as mental and physical health (Kricos, 1995). Due to the nature of auditory aging, communication difficulties in the elderly may not be adequately addressed by amplification, and require the use of additional audiologic rehabilitation (AR), including behavioural communication strategies practiced in a meaningful context (Erber, 1994).

Baycrest is a geriatric health care facility comprised of a hospital, a nursing home, community day centres and ambulatory care clinics that serves a wide range of seniors in all stages of physical and cognitive decline. One of the biggest challenges for the audiologists is to provide effective AR for seniors with severe hearing loss and communication difficulties, who typically receive limited benefit from hearing aids.

The impact of their hearing loss is further compounded by other physical and cognitive changes that occur with aging. The challenges and frustrations presented by attempts to participate in social activities result in exclusion, avoidance and withdrawal.

The resulting social isolation has a significant impact on quality of life, affecting their well-being and often leading to loneliness and depression (Kricos, 1995; Davis, 1995).

It is argued here that older adults with severe hearing loss need a different form of AR that addresses their isolation and need for social participation. Such an approach employs a social model with communication

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partners, where supportive communication strategies are presented in the context of meaningful social interaction.

Program Philosophy and Origins

The Hard of Hearing Club is a combination of a social and educational group, with a synergy between socialization as a vehicle for learning and learning as a vehicle for socialization. Use of the word “club” is deliberate because we are using social activities to provide rehabilitation in a broader context, to reach a larger goal that conventional AR might fail to achieve.

Hearing rehabilitation in a social group like the Hard of Hearing Club is a communication work-out, the equivalent of going to the gym, where hard of hearing seniors can practice effective communication behaviours with one another. It addresses activity and participation needs by providing partners for motivating and enabling communication in a social context where members are not only educated about communication strategies, but where they can also practice them in a meaningful way. It enables discussion of common problems and collaborative problem solving, and provides an opportunity for mutual support and empowerment.

The group also allows for the inclusion of family and friends, who are not hearing impaired, but share the effects of their partners’ hearing problems. Though most members do not have family members who are willing or able to be included on a weekly basis, many attend the Club’s anniversary celebration lunch.

The Club was established at Baycrest in 2000 in response to the referral of a profoundly hard of hearing client, Nusia, now 85, who is representative of the patient population described above. Nusia was referred to audiology by her psychiatrist because of her depression and social isolation resulting from her hearing loss and the death of her husband, who had acted as her “ears”.

Nusia felt that other isolated hard of hearing seniors like her in the Baycrest community would benefit from the opportunity to participate in a social club, where they could meet others with similar challenges, discuss their common problems and perhaps make friends.

Nusia is far from techno-phobic; she is always interested in new technology and has tried 12 different hearing aids over the last 9 years. Like many others, she is ever hopeful that one day, technology will “fix” her hearing problems, but the benefit she receives from hearing aids alone is very limited. She uses an

FM system, and finds it helpful. She is unable to hear on the phone and instead uses visual messaging via Blackberry, FAX, e-mail and Voice Carry Over phone through a phone operator relay service. She also uses many other types of assistive technology including strobe lights, loud alarm signals and vibrating devices to alert her to stimuli in her environment. She is proud of the fact that her grandsons call her “techno granny”. She will try anything that will help her to hear better and tells other group members more wary of technology and its attached stigma, that she would gladly wear a third hearing aid in her nose if it would help.

Nusia had participated in other AR groups and repeated speech reading classes at another Audiology Centre, but had not found what she needed to address the dreadful isolation she felt despite the devoted attention of her sons. To provide this, we needed to address the psycho-social issues associated with her severe hearing loss as well as the as the day to day communication difficulties.

Designing an Appropriate AR Program

The advantages of providing AR in a group setting have long been recognized (Lesner, 1995; Hawkins, 1995 & 2005; Kricos, 2000; Bally, 2009); groups offer the opportunity for mutual support and facilitate empowerment through self-help or the support of other members who share the same problems. AR groups typically tend to be aimed at new hearing aid users and limited to a period of several weeks, with an educational rather than social focus. Audiologists are encouraged by Erdman (2009), among others, to routinely offer rehabilitation services that address the psycho-social impact of hearing loss on the whole person, instead of limiting our scope of practice by focusing on the hearing impairment. In order to do this, we needed to create an opportunity for regular social interaction in a supportive environment where Nusia, and others like her, could function effectively as communicators, so that, instead of the usual frustrating negative experience, they had a positive experience in a social group.

The International Classification of Functioning, Disability and Health (ICF; WHO, 2001) considers not only impairment but also the activity and participation limitations it causes (see Figure 1). Using the ICF model as a conceptual framework, ASHA (2006) defines AR as a facilitative process that provides intervention to address all of the components of the ICF model: the impairments, activity limitations, par-

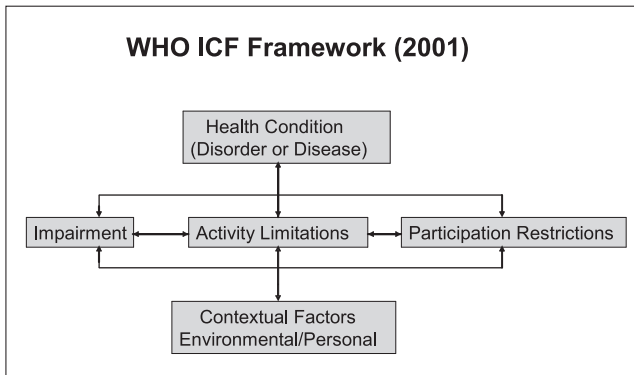


Figure 1. Model of the International Classification of Functioning, Disability and Health (WHO, 2001).

participation restrictions, and personal and environmental factors that may affect communication, functional health and well-being of persons with hearing impairment or by others who participate with them in those activities.

The ICF model serves the needs of this patient population well as a framework for rehabilitation, as it addresses the whole person in their environment and the impact of their hearing loss on their ability to function in their daily lives (Hickson & Scarinci, 2007; Worrall & Hickson, 2003; Gagne et al, 2009).

Auditory aging affects the functions of hearing, listening, comprehending and communicating crucial for activity and participation in daily life (Kiessling et al., 2003).

Expanding the basic ICF model to consider the perspective of older adults with severe hearing loss (see Figure 2), the resulting activity limitations can be understood in terms of effects on speech perception and awareness of the environment through non-speech auditory cues. The impact of this on the individual's ability to function depends on their context, both personal (e.g. age, lifestyle, co-existing physical/cognitive disabilities, life experiences, coping styles) and environmental (e.g. accessibility of the environment, available supports, etc).

The inability to understand speech, especially when listening is effortful, will interfere with a person's ability to communicate effectively and participate in social activities, in person and on the telephone. They may be excluded either by others or themselves; they withdraw and avoid social encounters rather than dealing with the challenges and frustrations they present. A downward spiral of negative feedback results in a lack of opportunities to socialize, and further isolation.

This larger construct of isolation as a consequence of their inability to participate socially, represents an-

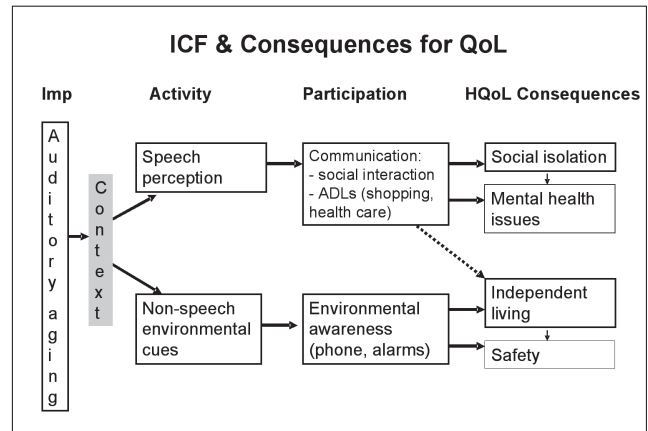


Figure 2. Model of the ICF as it applies to older adults with severe hearing impairment, with consequences for quality of life (QOL).

other level of impact on their quality of life, affecting their well-being and often leading to loneliness, sadness, insecurity, stress and, as in Nusia's case, depression.

Another activity/participation impact of communication difficulty involves their ability to cope with everyday interactions such as shopping, banking, and participating directly in health care. This increases the challenge of managing to live independently, causing additional stress.

Severe hearing loss also makes it difficult to hear non-speech environmental cues like the phone and alarm signals, which compromises safety and causes family members great concern. This places their ability to live independently further at risk and is frequently a driving force towards institutionalization (Mulrow et al., 1990; Davis, 2009).

Program Development

In order to learn more about establishing and facilitating a group that would provide the social contact that Nusia needed, I partnered with a recreational therapist in planning the Hard of Hearing Club. We invited Baycrest clients who we felt might benefit from such a group, and advertised it within the centre. We hoped that Nusia would meet others like herself with whom she could share her problems and who would understand her; that she would form friendships and feel part of a community instead of an outsider. If we could achieve this, we would hopefully be able to have a positive impact on her psychological and emotional well-being.

During the first year, the recreational therapist and I led the group together, and I learned much from her about group facilitation and program planning. As the

group evolved, it also became apparent that there was a need to provide education about technology and behavioral strategies that would assist them in coping with independent living and safety issues. Because there were many questions about hearing loss, hearing aids, AT and coping strategies, the group needed a leader who was knowledgeable about audiology issues, as well as one who was a skilled communicator and facilitator. On occasions when the recreational therapist ran the group alone, she felt lacking in the technical knowledge that the group's questions and discussions required and felt that it was important for the facilitator to be an audiologist.

Program Goals

Table 1 summarizes the goals for the Hard of Hearing Club along with how the club addresses these goals and some of the outcomes attained.

In the activity and participation domains, goals are to optimize members' communication skills and participation in activities that are challenging for them, and to improve their ability to cope with activities of daily living. By addressing these goals, the conventional components of AR could be woven into a motivational context, with the aim of giving members the skills and technical knowledge that would assist them in managing to live alone safely. It was hoped that helping them to maintain their independence and sense of security would have a positive impact on their quality of life.

Another goal in the quality of life domain was to improve overall well-being by addressing social isolation and its emotional and psychological consequences.

By fulfilling Nusia's need to connect with others, we hoped to improve her self-esteem, her mood and provide optimism and hope. Erdman (2009) discusses theories of hope and optimism with respect to understanding AR

Table 1. Hard of Hearing Club goals in activity/participation and quality of life domains, the program features that address them and related outcomes.

Goals		Program methods/features to address goals	Reported outcomes (key themes from qualitative evaluation)
Activity/Participation Domain	Quality of Life Domain		
<p>Reduce Social Isolation</p> <p>Improve social interactions Increase participation in group activities Develop friendships, social network</p>	<p>Address loneliness/sadness/depression</p> <p>Acquire sense of belonging to community Increase confidence and self-esteem Improve mood Provide optimism and hope</p>	<p>Regular, weekly meetings over extended period Limited group size Accessible environment Shared personal factors Facilitator with strong communication skills Enforcement of communication "rules" Practice of strategies with facilitator and each other</p>	<p>Meet others like themselves; "all in the same boat" Form relationships; make friends; Social participation; closeness; warmth Feeling valued and included; respected Support; share problems with honesty, tolerance and understanding Enables communication; "only place I can hear and be heard" Feel wanted, with friends, "at home"</p>
<p>Coping with ADLs</p> <p>Improved communication skills Self-efficacy; confidence in daily interactions Participation in health care Access to environment and alarms through use of AT</p>	<p>Independent living/safety</p> <p>Manage ADLs independently. Enhance safety through use of technology and behavioural strategies. Improve access for clients, family and friends. Know about and use available resources effectively to support independent living.</p>	<p>Education about technology and behavioral strategies. Experiential learning: strategies practiced with facilitator and each other. Facilitator with strong technical knowledge. Assertiveness training. Self and group advocacy.</p>	<p>Educational; "learn something new every time" Provides communication strategies for social interactions Encourages assertiveness and provides tools for others to help Helps to manage ADLs Educates about and encourages use of AT Collective voice for advocacy empowers.</p>

goals and designing effective interventions, and suggests that both have an important role in the promotion of adjustment to hearing loss. She suggests that audiologists are responsible for providing our patients with the knowledge, self-efficacy, hope and motivation to manage their hearing problems.

Self-efficacy is achieved through practice and the gaining of confidence in relation to developing new communication skills or becoming more assertive in difficult communication situations, and plays a role in the success of AR activities (Smith & West, 2006). With respect to the WHO ICF model, self-efficacy mediates the behavior changes the patient goes through in reducing activity limitations and participation restrictions resulting from hearing loss, as it influences choice of activities (Bandura, 1997).

Individuals with high self-efficacy would persist in their efforts to make participation possible despite the existence of barriers to communication. By incorporating self-efficacy into our AR goals, we aimed to enhance the success of our interventions.

Program Features

Scheduling and duration: The fact that the group has been meeting regularly and often (weekly) over a long period of time means that members have been able to get to know one-another, and become familiar with voices, personalities and communication styles, which facilitates speech understanding and conversation. Regular meetings also enable the formation of social bonds between members who become one-another's "family" or community.

Group Size: Keeping the group to a manageable size has always been a challenge. Ideally, there would be no more than ten members for the group to function effectively, but this has been balanced with the need to accommodate referrals, and consequently membership varies between 12–15. The total number of members and over 9 years is approximately 40.

Group Member Selection: Members range in age from 80–100 years and vary in physical and cognitive ability. They also come from a variety of living environments, from the community to long-term care. Despite this, they have many common problems and concerns. Shared personal characteristics are important to the ability to form bonds and provide support. The most important of these is hearing loss, but others are advanced age and its associated challenges, the Jewish culture (for most, but not all), European origins, and several mem-

bers are Holocaust survivors. This enables discussion of common experiences, concerns and solutions, and fosters tolerance and mutual understanding. While there are many social and self-help groups for seniors, most having themes (e.g. widows, Holocaust survivors) they have not worked for seniors in this group because they are not fully accessible to them because of their hearing loss.

Group Communication Rules: Social fulfillment depends on all being able to participate, and so an important component of group behavior is that all members observe the "rules" that they themselves compiled. One of the first things we did as a group was to establish these "rules" of communication (see Table 2). Although they are the same rules you'll see in any AR book, they were proposed, discussed and determined by the consensus of the members. In this way, they own them and expect me to reinforce them, which I do constantly. I have had much feedback about how it is absolutely necessary in order for the group to function, and is a key difference between this and other groups.

Members are encouraged to share the rules with their families and to practice them outside the group also, so that work in the clinic transfers directly to their real-life situation. Because they evolved the rules together and see them working, they are empowered to advocate for better communication strategies in their extended social environment.

Experiential learning and facilitation: Experiential learning is a key component of the group and is enabled by the facilitator, who makes an effort to ensure that all do participate and designs exercises that enable members to practice communicating directly with each other,

Table 2. Hard of Hearing Club Rules for Communication

- One speaker at a time!
- No side conversations with your neighbour
- Ensure others can see your face for speech reading
- Keep your hands away from your mouth
- Speak slowly using "Clear Speech"
- Paraphrase when repeating
- Pay attention to the group, and the speaker; watch the speaker's face
- Be (politely) assertive about not hearing
- Raise your hand to let others know you can't hear, or wish to speak
- Choose a seat that optimizes your ability to see and hear the group

even though some have multiple disabilities. Effective facilitation is critical to the success of the group as the facilitator must ensure that everyone is given an opportunity to participate and feel included. It is important to draw all members into discussion and encourage them to actively engage in problem-solving. This requires being an active listener and a skilled communicator, helping group members to express their feelings.

Assertiveness Training: Assertiveness training is important for developing self-efficacy by building confidence, self-esteem and a sense of empowerment (Kemp, 1990; Weinstein, 2000; Erdman, 2009). From the facilitator and one another, members learn about and practice assertiveness that gives them the confidence to tell family, friends, health care providers, bank tellers, etc that they are hard of hearing and how they can help them as communication partners. Many members now carry an ID card that informs others of their hearing loss and key communication strategies. They are discouraged from the common practice of bluffing and encouraged to use every opportunity to educate others about the use of appropriate communication strategies.

Self and group advocacy: Self and group advocacy also play an important role in boosting confidence and self-empowerment. Members learn how to advocate for themselves and on behalf of those with hearing loss. They are encouraged to raise awareness of others by speaking out about their hearing loss and telling others how they can help them. The group has had some successes with social advocacy; examples include advocating for the provision of assistive technology to make public political meetings accessible, resulting in a very positive response in the form of a letter from a Member of Parliament, and for visual messaging on the subway train after Nusia was stranded on a train that went out of service because she did not hear the announcement. This too received a positive response from the local Transit Company and was an example of the group exercising its new-found efficacy.

Informational counseling: As part of the educational component, the facilitator introduces new developments in hearing technology and invites guest speakers who present on topics of interest to the group. Some examples are talks about cochlear implants, fire safety for seniors, and Hearing Ear dogs.

Meeting Environment: Provision of an accessible, supportive meeting environment and communication partners with common problems and concerns speak to the environmental and personal contextual factors, respectively, of the WHO ICF.

An accessible meeting environment is vitally important for successful communication, and the group tried a number of meeting rooms before finding an acceptable one with good acoustics, natural lighting and space for an appropriate seating arrangement. Another critical environmental factor was the ability to make tea and provide refreshments in a kosher facility.

Session Conclusion: The informal social “tea-time” is important “down time” when members are able to have relaxed conversations with each other and the social bonds become the driver of audiologic rehabilitation.

Evaluation and Outcomes

One of the expected outcomes of audiologic rehabilitation is the enhancement of well-being and quality of life, and the challenge to the clinician is measuring the extent to which an improvement in health-related quality of life (HRQoL) has been achieved (Abrams & Chisolm, 2009). Studies measuring the benefits of AR on quality of life have produced mixed findings and there is only a small body of high quality evidence to support group AR as an effective treatment for adults with hearing loss (Hickson, 2009).

Systematic reviews of group and individual AR (Hawkins, 2005; Sweetow & Palmer, 2005) showed that the research was variable in nature and did not provide overwhelming evidence to support the benefits of group AR programs.

In a recent 2007 randomized controlled trial study by Hickson, Worrall and Scarinci, findings of a number of different self-report outcome measures indicated that their program, Active Communication Education (ACE) was effective in reducing activity limitations and participation restrictions associated with mild to moderate hearing impairment and improving quality of life.

Evaluation of the Hard of Hearing Club is underway, and while there are many positive indicators of the group’s success (e.g. high attendance, consistent referrals, positive testimonials from group members), it has not been possible to demonstrate that Nusia has benefited from attending HOH Club meetings through the application of formal disease-specific quantitative measures, such as the Hearing Handicap Inventory for the Elderly (HHIE; Ventry & Weinstein, 1982) over a six-year period.

The HHIE was chosen as a quantitative measure of outcome as it is designed to assess self-perceived psycho-social effects of hearing loss on the elderly and has been widely used in the context of audiologic rehabilita-

tion (Hawkins, 2005; Sweetow & Palmer, 2005). Figure 3 shows the HHIE scores for Nusia (NE) and another group member, Ruth (RH) over a 6-year time period.

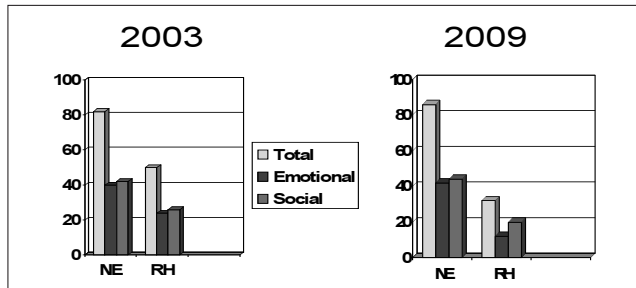


Figure 3. HHIE Scores for Nusia (NE) and Ruth (RH) over a span of six years.

Nusia's scores are remarkably similar over time and very high indicating a high level of perceived activity limitations and participation restrictions. In comparison, Ruth has scores that are much lower than Nusia's and have decreased over time, indicating a reduction in activity limitations and participation restrictions. The differences between Nusia and Ruth may be explained by their different hearing losses and experiences with amplification. Ruth has noticed marked improvements in her functional hearing over time as she has benefited greatly from new hearing aid technology. In contrast, Nusia's benefit from amplification has always been very limited, and has continued to decline. It may be that Nusia's scores will always be high because the HHIE, as a disease-specific measure focuses more on hearing, rather than on the larger Health Related Quality of Life (HRQoL) construct of isolation.

Few studies have used generic measures to examine the impact of audiologic rehabilitation on HRQoL (Abrams & Hnath-Chisolm, 2009). The MOS SF-36 (SF-36, Ware & Sherbourne, 1992) is a popular generic measure that assesses several areas related to overall health-related well-being including physical, social and emotional function and mental health. When this test was administered recently to Nusia, she obtained a surprisingly high score of 75 on the social functioning dimension of the SF-36. This measure was used by Hickson, Worrall and Scarinci (2007) in reporting a randomized controlled trial using a placebo social interaction group as a control for their AR group focused on communication training. The control social group demonstrated a significant change on the mental component summary (MCS) scores of the SF-36 which contains questions about social functioning, rather than about

hearing and communication, while the AR group did not. These results suggested that the social interaction rather than the communication-specific training resulted in changes in the self-perceived HRQoL as measured by the SF-36 (Abrams & Hnath Chisolm, 2009), and may also explain Nusia's high score. This may be a useful test in the measurement of the Hard of Hearing Club outcomes, and warrants further investigation.

While HHIE results appear to indicate that the Hard of Hearing Club has had no effect on Nusia's degree of hearing related activity limitations and participation restrictions, there has been much qualitative evidence that the group has had a very large impact on her quality of life. It may be that more formal quantitative methods of outcome measurement do not work as well as informal qualitative indicators in capturing the impact of this type of program on an individual's perceived quality of life and well-being.

Qualitative evaluation has been attempted with a focus group of four members.

An objective interviewer, not the facilitator (in order to avoid bias) asked the following questions:

1. Why do you come here?
2. What hearing-related problems do you struggle with?
3. Which of these things does the group help you with?
4. Are there other things outside of here that the group has helped you with?
5. What have you learned in the group that has been of value to you?
6. Would you recommend this group to other people and why?

Responses were grouped according to two main questions, namely why do you come to the group (questions 1 and 2), and how does it help you (questions 3, 4, 5, and 6)

The main emerging themes for reason for attendance were:

- Reason to go out; something to look forward to; highlight of the week
- Relationships; making friends; participation; closeness; warmth
- Feeling valued and included; respected
- Support; share problems with honesty, tolerance and understanding
- Enables communication; "only place I can hear and be heard"
- Educational; "learn something new every time"
- Enjoyment
- Group facilitator

These responses are in line with the goals of the group (see Table 1) which were to reduce social isolation and to increase confidence and coping with ADLs.

Key themes for how the group has helped participants again addressed the same issues of isolation, self-efficacy and coping with ADLs. Common themes were

- Share problems with others who understand
- Feel wanted, with friends, “at home”
- Provides communication strategies for social interactions
- Encourages assertiveness and gives tools for others to help
- Helps to manage ADLs
- Educates about and encourages use of AT
- Collective voice for advocacy

They do appear to validate the group by showing that it has been able to meet its objectives of addressing the quality of life issues that were initially identified. They also fit very well with the age-specific life goals described by Lemke (2009) namely well-being, safety and security, autonomy and social participation.

Positive feedback has also been obtained from others. For example, the psychiatrist who referred Nusia has been impressed by the benefits of the Hard of Hearing Club and reported the following observations:

- “Huge impact” on depression and isolation
 - fulfills need to connect with others
 - provides regular social context, where comfortable and not stigmatized
 - rules and structure enable participation in communication
 - provides peer support
- Improved self esteem
- Enhanced self-efficacy
- Less reliant on family
- Reduced psychiatric service utilization

The psychiatrist feels it is important to educate others in psychiatry and psychology about this type of intervention and has suggested that we collaborate to develop and enhance the program methodology and evaluation.

Nusia’s sons are similarly impressed with the impact the group has had on their mother’s quality of life, reporting the following benefits:

“The Hard of Hearing Club has had a profound effect on my mother; it gives her a social life with people who understand her lack of hearing; it addresses her loneliness by giving her a wider group of people that she can socialize with; it has given her a base from which to focus, share and learn about how hard it is to live with

hearing loss...she feels that you respect and understand this loss in socializing and enhance the lives of the club members by teaching how to live with it...it has given her a positive routine to look forward to; she knows on Tuesdays she has her club, a safe venue for exposing her disability while enjoying the company of others who can understand her feelings...so for me, there is absolutely no doubt that the Hard of Hearing Club has helped my mother and continues to do so.”

Conclusion

The Hard of Hearing Club appears to provide a successful rehabilitation option for seniors with severe hearing loss whose quality of life has been adversely impacted by their inability to participate in social activities. The weekly Club meetings are not only beneficial and self-affirming for the members, but also for this audiologist facilitator.

In the words of Mark Ross (2009) group audiologic rehabilitation not only addresses the communicative and social effects of hearing loss and its impact on quality of life, “it can be fun...it gives us an opportunity to interact with our clients on a more personal, human level. Switching the focus of our attention from the hearing loss to the hearing problem of the human being can be a very rewarding and enjoyable experience.”

In a field that has become increasingly hearing aid focused, these meetings enable me to see the impact of my work within a broader perspective and are certainly the highlight of my work week.

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