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Third-Party Disability in Spouses of Older People With Hearing Impairment

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Abstract

Hearing impairment is the most common communication disability in older people. The wide-ranging impact of hearing impairment means that not only does the person with hearing impairment experience the consequences, but his or her frequent communication partners do also. In this article, the authors discuss the impact of hearing impairment in older people on spouses with normal hearing using the conceptualization of “third-party disability” created by members of the World Health Organization (WHO, 2001, p. 251). Results of a series of studies conducted by the authors demonstrate that spouses experience a range of activity limitations and participation restrictions due to their partner’s hearing impairment, including a variety of stresses involving lifestyle changes, communication difficulties, and emotional consequences. In this article, the authors highlight the important role of family-centered intervention in audiologic rehabilitation for older adults and emphasize the need to increase inclusion of spouses and significant others in the rehabilitation process.

Older people with hearing impairment experience a range of activity limitations and participation restrictions because of their hearing difficulties. People with hearing impairment often do not live alone; hence, their significant others also experience the effects of the loss. This is especially true when the significant other is the most frequent communication partner with the person who has hearing impairment, as is often the case in older couples. Although individuals with hearing impairment directly experience the hearing loss, significant others can experience participation restrictions and activity limitations in their interactions with their partner. In this article, we discuss the impact of hearing impairment in older people on spouses using the term third-party disability as defined by members of the World Health Organization (WHO, 2001, p. 251). Results of a series of studies conducted by the authors will be summarized and used to highlight the important role of family-centered intervention in rehabilitation of older adults with hearing impairment.

Members of the WHO have increasingly acknowledged the effect of hearing impairment on spouses and other family members as a significant issue in the older population. They have labeled this phenomenon third-party disability, and identified it as an area for future research. Third-party disability refers to “the study of disability and functioning of family members due

to the health condition of significant others” (WHO, 2001, p. 251). Spouses of individuals with hearing impairment can experience impairments, activity limitations, and participation restrictions as a result of their partner’s hearing disability. To visualize the potential effects of third-party disability and the interaction of various components, we provide a modified model of the WHO’s International Classification of Functioning, Disability, and Health (ICF), which is shown in Figure 1.

Figure 1. Application of the International Classification of Functioning, Disability, and Health to Third-Party Hearing Disability in Spouses of Older People With Hearing Impairment

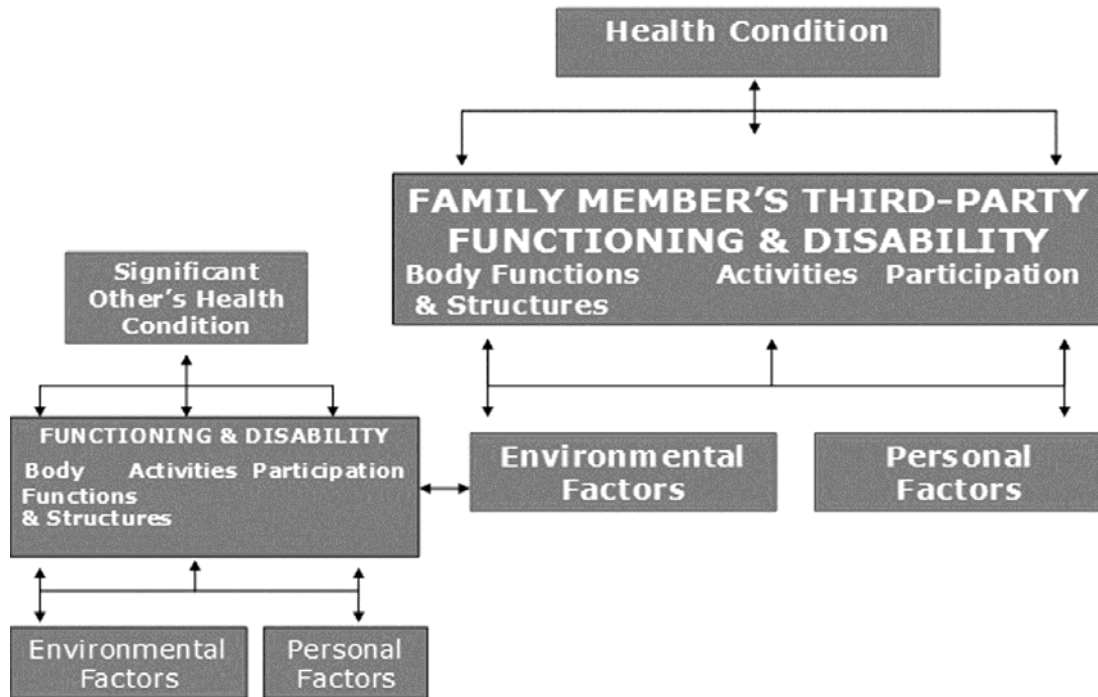


Figure 1 illustrates how third-party disability stems from a partner’s hearing impairment and disability. The functioning and disability of the person with hearing impairment is shown on the left side of the figure as a separate ICF framework. The partner’s hearing disability serves as an environmental factor that results in the spouse’s third-party hearing disability. Third-party disability can also be influenced by personal factors such as gender and coping style, and environmental factors such as the partner’s use of hearing aids and self-reported hearing disability.

In previous literature, the original WHO terminology and frameworks—the International Classification of Impairment, Disability and Handicap (ICIDH; WHO, 1980) and the International Classification of Impairments, Activities and Participation (ICIDH-2; WHO, 1997)—have been used to understand the effects of hearing loss on families and significant others (Gagné, 1998, 2000; Noble & Héту, 1994; Stephens & Héту, 1991; Stephens & Kerr, 2000). Stephens and Héту used the ICIDH framework, incorporating their work on the psychological disadvantages and functional restrictions associated with hearing loss (Héту, Lalonde, & Getty, 1987; Héту, Riverin, Lalonde, Getty, & St-Cyr, 1988). Héту and colleagues (1988) described “primary handicap” (the initial experiences of the individual’s hearing impairment on everyday life) and “secondary handicap” (the negative consequences of the individual’s attempts to reduce his or her handicap; e.g., fatigue, anxiety) associated with hearing loss and incorporated the role of significant others in the development of handicap.

Others also have focused on the effects of hearing impairment on significant others (Gagné, 1998; Gagné, Héту, Getty, & McDuff, 1995; Hallberg & Barrenäs, 1993; Héту, Jones, & Getty, 1993). In the mid-1990s, Gagné and colleagues highlighted the potential for individuals with normal hearing (e.g., spouses) to experience situations of “handicap” due to their interactions with people who have a hearing impairment (Gagné, 1998; Gagné et al., 1995).

Although the impact hearing impairment has on family members is widely recognized, research in this area to date has focused primarily on younger couples affected by noise-induced hearing loss, with few studies focusing on difficulties related to older people and factors associated with third-party hearing disability. Given the relevance of addressing the needs of significant others in clinical practice, and WHO’s recommendation that third-party disability be investigated further, this series of studies sought to examine the disability and functioning of family members—specifically, spouses—of older people with hearing impairment.

Summary of Third-Party Hearing Disability Research

In a series of studies, Scarinci, Worrall, and Hickson (2008, 2009a, 2009b) demonstrated that older spouses experience third-party hearing disability as a result of their partners’ hearing impairment. A literature review documented the lack of research on problems faced by significant others of older people with hearing impairment, providing a rationale for further investigation (Donaldson, Worrall, & Hickson, 2004). Scarinci and colleagues (2008) conducted a qualitative study in which the lived experience of 10 spouses of older people with hearing impairment was investigated through the use of semistructured in-depth interviews. The aim of the study was to describe spouses’ experiences living with someone with a hearing impairment, to describe the effect of the hearing impairment on the couples’ communication and relationship, and to identify coping strategies adopted by the spouses. Analysis revealed four general themes: the wide-ranging effects of hearing impairment on spouses’ everyday lives, spouses’ need to adapt constantly to their partner’s hearing impairment, the effect of acceptance of the hearing impairment on the spouse, and the impact of aging and retirement.

The findings depict the effects of hearing impairment on almost every facet of spouses’ lives, with difficulties ranging from conversational problems and everyday tasks and activities such as watching television to broader effects on their marital relationship and social lives. Spouses also discussed having to adapt constantly to their partners’ hearing problems, and the difficulties they faced having to accept the hearing loss. Finally, due to the age of participants in this study, issues of aging and retirement were discussed, with spouses observing that with an increased amount of time spent together following retirement, the difficulties had become more apparent.

In the next study, we attempted to map the earlier results to the ICF to identify the ICF domains and categories that best describe third-party hearing disability of spouses of older people with hearing impairment (Scarinci et al., 2009b). The first two themes identified in the qualitative study (the wide-ranging effects on the spouses’ everyday lives and spouses’ need to adapt) represent the activity limitations and participation restrictions associated with third-party hearing disability, which were linked successfully to the ICF. The majority of themes were linked to codes in the activities and participation component, with the most relevant domains being communication, domestic life, interpersonal interactions and relationships, and community, social, and civic life. Not surprisingly, these were the most relevant domains for older spouses because they represent the impact of communication in these areas. The third and fourth themes identified in the qualitative study (the impact of acceptance on the spouse and the impact of aging and retirement) represent contextual factors influencing the spouse’s third-party hearing disability. Therefore, these themes were linked to the environmental factors component of the ICF, including products and technology, natural environment and human-made changes to environment, support and relationships, and attitudes. Personal factors such as the spouse’s gender and coping style also were found to affect third-party hearing disability.

The direct linking of themes identified by participants to such domains highlights the relevance of the ICF to third-party hearing disability and the appropriateness of the ICF framework to such a population.

Findings from the initial qualitative phase of the research also provided a foundation for the second quantitative phase in which concepts identified by participants were used to develop the Significant Other Scale for Hearing Disability (SOS-HEAR), a measure that can be used to assess third-party disability in spouses of older people with hearing impairment. A copy of the measure is available in Scarinci and colleagues (2009a). We used the SOS-HEAR to assess third-party disability in a sample of 100 spouses of older people with hearing impairment and to investigate factors associated with third-party disability. Most participants (98%) reported some degree of third-party disability on at least one item of the SOS-HEAR. Although the majority reported only a mild third-party hearing disability, there were a number of specific areas in which spouses identified more significant problems, including the impact of the hearing loss on the couple's quality and quantity of communication, the spouse's use of communication strategies, emotional problems occurring as a result of communication changes, and the spouse's need to support his or her partner's communication. A number of factors also were identified that influenced the severity of third-party hearing disability, including relationship satisfaction, the couple's difference in age, and the spouse's perception of his or her partner's hearing disability. The contribution of such factors is an important finding for professionals working with older couples because these factors can serve as "red flags" to identify spouses at risk of experiencing greater third-party hearing disability.

The difficulties reported by spouses in these studies were consistent with research conducted among other populations (e.g., aphasia, traumatic brain injury), in which spouses have reported role changes (Malone, 1969; Webster & Newhoff, 1981); emotional effects such as bitterness and irritability (Emerson, 1979; Malone, Ptacek, & Malone, 1970); changes in social interaction (Artes & Hoops, 1976; Holbrook, 1982; Malone, 1969; Malone et al., 1970; Webster & Newhoff, 1981); and communication difficulties (Artes & Hoops; Shewan & Cameron, 1984). These similarities highlight the potential application of third-party disability to other client populations affected by communication disability and indicate that future research should extend the concept of third-party disability to other client groups.

Following this study, an investigation of the psychometric properties and clinical application of the SOS-HEAR confirmed the validity of the SOS-HEAR. Further investigation is needed to establish the reliability of the instrument (Scarinci et al., 2009a).

Applying the ICF and Third-Party Disability in Rehabilitation of Hearing Impairment

This summary has illustrated the existence of third-party hearing disability among spouses of older people with hearing impairment and how it can be coded using the ICF. Third-party disability clearly is relevant to hearing rehabilitation, addressing the impact of hearing impairment on clients and their spouses. Inasmuch as the primary aim of audiologic rehabilitation for older people and their significant others is to reduce the activity limitations and participation restrictions they experience, it is important that clinicians fully understand these limitations and restrictions. Applying the ICF to rehabilitation for such couples is a vital step in this process. It encourages the clinician, client, and significant others to consider (a) all aspects of the disability at the level of the body, (b) activity and participation, and (c) the contextual factors that affect these (Gagné, 2000; Hickson & Scarinci, 2007; Stephens, 1996). Once a clinician has used the ICF to identify the difficulties experienced by people with hearing impairment and their significant others, the goals of audiologic rehabilitation can be defined. Such a process facilitates development of intervention programs that are more likely to achieve client goals (Gagné) and enables clients, significant others, and clinicians to generate solutions

to specific difficulties encountered as a result of hearing difficulties (Gagné, McDuff, & Getty, 1999).

Other authors have used the ICF to describe difficulties faced by older people with hearing impairment and discuss the relevance of the ICF to audiologic rehabilitation (Gagné, 1998, 2000; Gagné et al., 1995; Gagné et al., 1999; Héту et al., 1987, 1988; Hickson & Scarinci, 2007; Noble & Héту, 1994; Stephens, 1996; Stephens & Héту, 1991; Stephens & Kerr, 2000). This research specifically outlined the application of the ICF to describe the difficulties faced by spouses of people affected by hearing impairment and identified the most typical and relevant domains of the ICF for spouses. Consequently, professionals working with older couples now have a theoretical framework and a tool (the SOS-HEAR) with which to include spouses in the rehabilitation process.

Inasmuch as hearing impairment in the older population is rarely treatable medically, by necessity, the emphasis in rehabilitation is on reducing the everyday effects of that impairment. Information about the couple's everyday difficulties (including activity limitations and participation restrictions) can be obtained from the case history and/or through the use of questionnaires designed specifically for this purpose. Likewise, to investigate third-party disability, the clinician can ask the spouse how the hearing disability affects them. The SOS-HEAR also can be used. Further research is needed to determine how spouses can best be included in audiologic rehabilitation. It may be appropriate for them to participate in collaborative goal-setting in which the clinician, client, and spouse discuss goals that are most important and what they hope to achieve in rehabilitation. Future research is planned in which we will investigate whether spouses wish to be involved in rehabilitation—and, if so, how they wish to be involved and how clinicians can best facilitate this involvement.

Inclusion of Spouses in Audiological Rehabilitation

The major implication of this body of research is that because both members of a couple may experience significant consequences when one has a hearing impairment, both may need help either individually and/or as a couple or family. Clearly, the benefits of audiologic rehabilitation extend from the person with hearing impairment to spouses and significant others. Recognition and resolution of difficulties within the communication dyad may help the client and significant others proceed into a hearing rehabilitation program (Armero, 2001). To the extent that family relationships can enhance or detract from the potential for rehabilitation of a person with hearing impairment (Erber, 1993), the probability of successful rehabilitation is enhanced if there is complete support from the spouse and significant others (Miller, 1983; Schow & Nerbonne, 1982). Information about the effects of hearing impairment on the significant other may, therefore, help in the identification and reduction of the negative effects of hearing impairment on the family. Hoover-Steinwart, English, and Hanley (2001) found that inclusion of significant others in discussions before a hearing aid fitting resulted in improved hearing aid benefit for the person with hearing loss. Stephens (1996) also discussed the importance of acknowledging significant others, proposing that clinicians should assess the attitude and functioning of the spouse through the use of questionnaires, discussion about the couple's problems, and observation of the couple's interactions. He further recommends direct involvement of significant others in decision making and goal setting, both in joint sessions and separately (Stephens, 1996). Gagné (1998) further emphasized the role that significant others play in audiologic rehabilitation, noting that solutions to hearing difficulties encompass not only the person with the hearing impairment but also his or her significant others; thus, significant others are also candidates for rehabilitation services (Gagné et al., 1995).

Involvement of spouses in rehabilitation reflects current trends toward client- and family-centered care, which acknowledges the importance of partnerships among clients, significant others, and service providers in intervention (Hughes, Bamford, & May, 2008). This trend supports improved and open communication among clients, families, and professionals

as well as the inclusion of clients in all aspects of clinical decision making. Of particular relevance to third-party hearing disability is the acknowledgment of the client's social context and relationships, a characteristic of family-centered care in which the needs of family are recognized in all forms of care (Hughes et al.). Family-centered care is perhaps the most relevant type of centeredness when considering third-party disability because it emphasizes the importance of partnerships that are mutually beneficial to health care professionals, clients, and families (Ahmann & Johnson, 2000). Although the term "family-centeredness" has primarily been used within pediatrics, it is applicable to all client groups in any health care setting (Hughes et al.). Its application to third-party disability is particularly relevant because it considers both the client and the family as central to therapeutic decision making and clinical practice. A family-centered approach to audiologic rehabilitation ensures that services are planned around and for the entire family, not just the individual client (Shields, Pratt, & Hunter, 2006). The application of family-centered care to older couples may be especially important because older couples may be more likely to be co-dependent and to operate as a unit.

Involvement of the spouse—and, therefore, family-centeredness—has long been promoted in the area of audiologic rehabilitation (Armero, 2001; Gagné, 1998; Hallberg, 1999; Hallberg & Barrenäs, 1993; Héту et al., 1988; Miller, 1983). Group intervention programs are one way of involving spouses in rehabilitation. Group programs allow spouses to share feelings and experiences with others having similar experiences and problems. A number of programs recently have been described in the literature that may be suitable for older people with hearing impairment and their spouses; however, a limited number of these programs provide evidence in support of their efficacy. Examples of programs that have been evaluated include those described by Beynon, Thornton, and Poole (1997); Hickson and colleagues (Hickson, Worrall, & Scarinci, 2006, 2007a, 2007b); Kemker and Holmes (2004); and Preminger (2002).

Beynon and colleagues (1997) described a 4-week program for people being fitted with hearing aids for the first time. The first week's session covered anatomy and physiology, the nature of hearing impairment, and the effects of hearing impairment in different situations. The second session covered benefits and disadvantages of hearing aids, hearing aid maintenance, adjusting the hearing aid in different listening environments, the nature of speech, the effects of hearing impairment on speech perception, and elements of lipreading. During Week 3, coping strategies and solutions to communication problems were addressed. The fourth session included lipreading, hearing tactics, stress and anxiety associated with communication, and the use of relaxation techniques. Findings indicate that those who participated in the program improved more than individuals in a control group.

The Audiological Care Model for Nursing, proposed by Tolson and Stephens (1997), offers another pathway of care for couples affected by hearing loss. It outlines care from the initial recognition of problems to evaluation, actively involving both members of the couple. This model examines the attitude and treatment expectations of both parties and carefully considers the impact of hearing impairment on the communication partner (Tolson & Stephens, 1997). However, efficacy of the model has not been reported. Preminger (2002) described another rehabilitation program for adults with hearing impairment and their significant others that consists of six 90-minute sessions focusing on educational lectures, use of communication strategies, and auditory and visual perception. The majority of participants reported an increased use of communication strategies with a significant reduction in hearing handicap for people with hearing impairment and their significant others.

An evidence-based approach that targets the communication disability experienced by older people with hearing impairment and their spouses is the Active Communication Education (ACE) program (Hickson et al., 2007a, 2007b). It is a community-based group program that is designed for people who identify themselves as having hearing difficulties and is appropriate for people with or without hearing aids. The importance of emotional support

and peer and family involvement is recognized; thus, significant others (e.g., spouses, relatives) are encouraged to attend. The ACE program runs for 2 hours per week over 5 weeks. The goals for older people with hearing impairment and their significant others are to improve communication abilities, reduce hearing difficulties, and improve these individuals' quality of life and well-being. ACE has been evaluated with 178 older people with hearing impairment and 29 significant others (Hickson et al., 2007a), and the outcomes indicate that, compared with a control group, those participants who attended the program reported significant reductions in activity limitations and participation restrictions along with improvements in well-being. Additionally, the outcomes for the ACE program compared favorably to those obtained for hearing aid fittings, with the ACE results being superior in terms of reported satisfaction with the intervention received. Further, the findings revealed that hearing aid use did not influence outcomes achieved with ACE. Such findings cast some doubt over the current focus on hearing aids as the central tenet of audiologic rehabilitation. Hickson and colleagues (2006) also found spouse satisfaction with the ACE program was particularly high; 97% of spouses reported on the International Outcome Inventory–Alternative Interventions–Significant Other version (IOI-AI-SO) that the ACE was at least moderately worth the trouble. The effectiveness of group intervention for spouses is clearly an area for future research, with programs such as the ACE being implemented and extended with a greater focus on couple functioning and spouse third-party disability.

In summary, the evidence regarding communication programs, and the ACE program in particular, indicates that such programs can reduce the communication difficulties experienced by older clients with hearing impairment and their significant others and that group audiologic rehabilitation involving spouses could be an appropriate means of addressing the needs of older couples affected by hearing impairment. Group programs could be offered to couples in which the spouse has been identified as at risk for greater third-party disability, providing an effective and practical means of including spouses directly in audiologic rehabilitation.

The Role of Counseling

Piercy and Piercy (2002) and Héту and colleagues (1993) emphasized the importance of couples therapy when one partner has a hearing loss. They recommend that clinicians encourage couples to discuss their communication patterns and any negative attributions so they can realize that together, they can prevent hearing problems from affecting their marriage. To the extent that couples are experiencing marital difficulties beyond the communication difficulties associated with hearing impairment, the role of other professionals—including family therapists and/or psychologists—in the counseling process should be considered.

Many researchers have discussed the importance of taking a relationship approach to coping with illness and disability (Coyne & Smith, 1991; Kayser, Sormanti, & Strainchamps, 1999; Lyons, Sullivan, Ritvo & Coyne, 1995). Acitelli and Badr (2005) proposed that when couples take a relationship perspective in adapting to and coping with disability, they are able to view the disability as a problem for the relationship rather than a problem for one individual. Consequently, they are more likely to engage in joint discussions about how to cope and maintain the relationship in the context of disability. Clinicians who help couples become aware of the implications of hearing loss on their daily functioning can enable partners to see the disability as “our” disability. Rather than each member of the couple dealing with problems in separate ways, the spouses can view themselves as a team. This encourages couples to engage in joint problem solving and employ active coping strategies and rehabilitation options. Communal coping also could be used to develop intervention programs aimed at enhancing coping skills and improving relationships (Lyons, Mickelson, Sullivan, & Coyne, 1998).

Goals for couples may include changing patterns of interaction and promoting adaptive functioning. Such intervention can be a useful vehicle for encouraging the couple to collaborate

on increasing the activity level of the partner with hearing impairment and increasing the couple's joint activities. It may be, however, that spouses of people with hearing impairment need professional counseling to cope with the social, emotional, and role adjustments they face, and if audiologists believe spouses need additional help, appropriate referrals should be made. Piercy and Piercy (2002) promote the potential role of family therapists in this situation.

Conclusion

In 2001, members of the WHO identified third-party disability as an area for further development and research. The series of studies summarized in this article provides an introduction to third-party disability among spouses of older people with hearing impairment. As poet David Wright (who himself was hearing impaired) once said, "It is the non-deaf who absorb a large part of the impact of the disability" (Ashley, 1985), something that has been highlighted in this research. Continued research is needed to elaborate on spouses' rehabilitation needs and to examine their specific requirements from the perspective of spouses, clients, and clinicians.

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