

## **Promoting the Participation of Adults With Acquired Hearing Impairment in Their Rehabilitation**

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The aim of this tutorial is to review approaches that promote client participation in health care. More specifically, client-centeredness, joint goal setting, and shared decision making are defined; their applications to the management of people with chronic health conditions, and more specifically acquired hearing impairment, are outlined; and the evidence for their effectiveness is described. Future directions in audiology clinical practice and research are proposed to resolve whether such approaches can improve outcomes for people with acquired hearing impairment.

Chronic health conditions have reached “epidemic proportions” (Daar et al., 2007, p. 494). They are of long duration, of slow progression, and include cardiovascular diseases, chronic respiratory diseases, diabetes, and vision and hearing impairments (World Health Organization, 2005). Although chronic health conditions cannot be cured, their consequences can be minimized with self-management, that is, the adoption, modification, and/or maintenance of healthy behaviors (Lawn & Schoo, 2010; Newman, Steed, & Mulligan, 2004). Self-management refers to “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes that are inherent in living with a chronic condition” (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). Client participation is central to the success of self-management. Just as a person with diabetes can increase physical activity and

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decrease caloric intake to reduce diabetic complications, a person with hearing impairment can use hearing aids, hearing assistance technology, and apply knowledge obtained through a communication program to reduce hearing-related activity limitations and participation restrictions (for a review, see Laplante-Lévesque, Hickson, & Worrall, 2010c).

This article describes approaches that promote client participation, specifically, client-centeredness, joint goal setting, and shared decision making. These approaches are defined and their applications to the management of people with chronic health conditions, and more specifically acquired hearing impairment, are outlined. Finally, clinical and research future directions are highlighted.

### CLIENT-CENTEREDNESS

The terms client-centeredness, family-centeredness, patient-centeredness, person-centeredness, and relationship-centeredness are commonly used to describe health centeredness. In an effort to better understand the similarities and differences in the above terminologies, a review of their definitions, key elements, and components revealed many common themes (Hughes, Bamford, & May, 2008). As the different terms are very similar, a decision was made to use *client-centeredness* here as an umbrella term to include all types of health centeredness.

Historically, client-centeredness was first used in psychotherapy (Rogers, 1946). It has been described as the clinician understanding the client as a unique human being (Balint, 1969), as health professionals recognizing that client psychology influences their practice (Tait, 1974), and as an alternative to disease-centeredness or clinician-centeredness (Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986). It has strong roots in a biopsychosocial view of health (Engel, 1977) and three major schools of ethical thought (consequentialist moral theory, deontological theory, and virtue-based theory) all concluded that client-centeredness is morally right (Duggan, Geller, Cooper, & Beach, 2006).

Although client-centeredness lacks a universal definition, the paradigm is typically described according to five dimensions: biopsychosocial perspective, client as a person, shared power and responsibility, therapeutic alliance, and clinician as a person (Mead & Bower, 2000). Client-centeredness takes a biopsychosocial perspective, acknowledging that combined biological, psychological, and social perspectives are required to understand health. The World Health Organization's *International Classification of Functioning, Disability, and Health* (2001) adopts a biopsychosocial perspective. Seeing the client as a person refers to the importance of understanding his or her unique illness experience. Sharing power and responsibility promotes an egalitarian client-clinician relationship and respects the client's expertise and autonomy. The therapeutic alliance refers to the fundamental importance of a good clinician-client relationship. Finally, the clinician as a person recognizes the humanity of the clinician and its inherent influence on the client-clinician relationship. According to a systematic review, interventions for

clinicians that aim to promote client-centeredness in consultations can successfully increase client-centeredness (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2009). But what do clients think of client-centeredness?

Clients value client-centeredness: general practice clients mentioned wanting their clinicians to listen to them, communicate effectively, find common grounds, and provide information on disease prevention and health promotion (Little et al., 2001). When presented with two videos of medical consultations, one using a biomedical approach (i.e., with a focus on the disease and clinician-driven decision making) and one using a client-centered approach, more clients preferred the latter approach (Swenson, Zettler, & Lo, 2006). They described the client-centered clinician in the video as working with the clients, respecting them, and exploring their needs. Krupat and colleagues (2000) assessed dyads of clients and clinicians' preferences for client-centeredness and client satisfaction towards their clinicians. Clients were satisfied with clinicians that either gave the same amount of importance to client-centeredness as them or that gave more importance to client-centeredness than them. Similarly, Brody and colleagues (1989) asked clients to complete questionnaires before and after a visit to the general practitioner. Clients were most satisfied when their general practitioner valued their perspectives and provided education and counseling. More importantly, this finding was independent of the clients' stated preference prior to the visit for a general practitioner that values their perspectives and provides education and counseling; both the clients who valued and those who did not value client-centeredness beforehand reported greater satisfaction when their clinician used a client-centered approach during the visit.

### ***Client-Centeredness and Chronic Health Conditions***

A review of the literature on client-centeredness with people with chronic health conditions identified two particularly relevant components. First, eliciting and discussing clients' beliefs can promote intervention adherence and client satisfaction (Michie, Miles, & Weinman, 2003). Prompting clients to discuss their perspectives and being genuinely interested in their individual experiences of living with chronic health conditions is essential. Second, facilitating client engagement in the clinical encounter can promote long term self-management of the health condition (Michie et al., 2003). Engaging the clients in actively taking control of their health condition, for example by encouraging them to ask questions or take part in decisions, is also paramount. The clinician must recognize the expertise of the clients living with chronic health conditions in order to achieve this (Wilson, 1999).

### ***Client-Centeredness and the Rehabilitation of Adults With Acquired Hearing Impairment***

Researchers, clinicians, and policy-makers involved in the rehabilitation of adults with acquired hearing impairment have integrated aspects of the five di-

mensions of client-centeredness discussed by Mead and Bower (2000). For example, Stephens provided much support for the use of a biopsychosocial approach in hearing rehabilitation (Stephens, 1996; Stephens & Héту, 1991). The biopsychosocial model of the World Health Organization (2001) and its earlier versions are commonly applied in rehabilitative audiology (e.g., Abrams, McArdle, & Chisolm, 2005; Chisolm, Abrams, & McArdle, 2004; Gagné, 1998; Gatehouse, 1994, 2001; Hickson & Scarinci, 2007; Hickson, Worrall, & Scarinci, 2007; Kramer, Allesie, Dondorp, Zekveld, & Kapteyn, 2005; Saunders, Chisolm, & Abrams, 2005). The exploration of the client's experience of hearing impairment has been discussed to some extent in the rehabilitation of people with hearing impairment, for example through the use of open ended questionnaires (Barcham & Stephens, 1980) or through the discussion of the stigma attached to hearing impairment (Héту, 1996). The Ida Institute, a non-profit educational Danish body, builds on this and provides audiologists with information and support to help guide people with hearing impairment towards successful rehabilitation (Kirkwood, 2008). However, the literature on the other aspects of client-centeredness described by Mead and Bower (2000), for example the sharing of power and responsibility, the therapeutic alliance, and the clinician as person is rather scarce.

Many authors have advocated for client-centeredness in audiology (see, e.g., Duchan, 2004; Erdman, Wark, & Montano, 1994) and the term client-centeredness has been used in several audiology publications. For example, rehabilitative audiology was said to be "profoundly client-centered; the client reveals the predicament, helps to evolve the management plan, and ideally, drives its implementation" (Hyde & Riko, 1994, p. 356) and to be a "client-oriented problem solving process" (Danermark, 1998, p. 125). Wilkerson described a "person-centered analytic framework for outcome measurement" in rehabilitative audiology (2000, p. 81) whilst Sweetow (1999) contrasted a professional-centered approach to a client-centered approach when counseling hearing aid users. Borrowing from Carl Rogers' humanist perspective to psychology, Sweetow advocated that the audiologist working in the client-centered approach should listen with concern and empathy, provide unconditional positive regard, and counselor congruence (genuineness). Furthermore, the client was described as "empowered to make decisions (and) held responsible for decisions and outcomes" (Sweetow, 1999, p. 4).

The terminology of client-centeredness was also used in rehabilitative audiology to describe an "approach to patient care, which openly recognizes the desires of the patient and asks each of us to examine how these desires may best be honored as treatment is planned, initiated, and carried out" (Clark, 2007, p. 164). The benefits of motivational interviewing with hearing aid candidates, described as "a focused, goal-directed, patient-centered approach and counseling tool," were seen as reducing their ambivalence and increasing their willingness to obtain

hearing aids (Beck, Harvey, & Schum, 2007). The potential application of relationship-centeredness to audiology, with its focus on the client-audiologist interaction, has also been raised (English, 2005).

### **JOINT GOAL SETTING**

Joint goal setting refers to the client and the clinician sharing the power and responsibility by elaborating together meaningful objectives or desired outcomes, events, or processes, either specifically relevant to the client's current health status or life goals (Austin & Vancouver, 1996; Naik, Schulman-Green, McCorkle, Bradley, & Bogardus, 2005). The aims of rehabilitation goal setting identified in the healthcare literature are to: (a) enhance the client's autonomy; (b) improve rehabilitation outcomes; (c) assess individualized rehabilitation outcomes; and (d) provide information to stakeholders such as health service funders, quality auditors, accreditation agencies, and professional bodies (Levack, Dean, Siegert, & McPherson, 2006).

Goal setting can affect behaviors (Locke & Latham, 2002) and therefore joint goal setting can enhance quality of care (Bogardus et al., 2004). However, focus groups highlight that not all clients and clinicians wish to participate in goal setting (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006). Major reasons clients and clinicians gave for not wanting to participate in goal setting included limited time, health encounters focused on symptoms, perception of disinterest by the other party (clinicians believing that clients are not interested in goal setting and vice-versa), and the view that all clients' goals are similar.

#### ***Joint Goal Setting and Chronic Health Conditions***

Joint goal setting has been used successfully in the management of chronic health conditions, for example when helping diabetic clients achieve healthy behaviors (DeWalt et al., 2009). Clients with chronic health conditions naturally develop goals but joint goal setting with clinicians can improve the likelihood of these goals supporting effective self-management (Brown, Bartholomew, & Naik, 2007). After setting goals, rehabilitation clients reported greater perceived confidence in self-management (Wressle, Eeg-Olofsson, Marcusson, & Henriks-son, 2002). Clients attending neurological rehabilitation who actively participated in goal setting also reported increased satisfaction with the rehabilitation process (Holliday, Cano, Freeman, & Playford, 2007).

#### ***Joint Goal Setting and the Rehabilitation of Adults With Acquired Hearing Impairment***

Historically, the potential benefits of goal setting in rehabilitative audiology were highlighted over 20 years ago (McKenna, 1987). Roberts and Bryant (1992) identified three functions of goal setting in rehabilitative audiology: (a) motivate the client to take an active role in their rehabilitation, (b) educate the client to continue seeking information, and (c) evaluate progress towards goal

achievement. Later, research reports on behavioral intervention for adults with acquired hearing impairment mentioned the use of individualized intervention goals (Andersson, Melin, Scott, & Lindberg, 1995; Lindberg, Scott, Andersson, & Melin, 1993). Stephens (1996) also described how goal setting could be used in rehabilitative audiology. Subsequently, the importance of tailoring both the rehabilitation interventions and the outcome measures according to goals achieved prominence in the audiology literature (Cox et al., 2000; Gagné, 1998; Gagné, Héту, Getty, & McDuff, 1995; Gagné, McDuff, & Getty, 1999; Schow, 2001; Stephens, Jaworski, Kerr, & Zhao, 1998).

Joint goal setting has since been used successfully in rehabilitative audiology. The Client-Oriented Scale of Improvement (COSI; Dillon, Birtles, & Lovegrove, 1999; Dillon, James, & Ginis, 1997) asks clients to nominate up to five rehabilitation goals and to rate their perceived reduction in disability and resulting ability to communicate in these specific situations at the conclusion of rehabilitation. It was the first goal setting tool that clinicians working with people with hearing impairment widely integrated in their practices. The individualized nature of the COSI has been generally appreciated by clients, as described by an audiologist: "it gives the client some ownership over the rehabilitation program" (Dillon & So, 2000, p. 3). Although designed more specifically as an outcome measure tool, the Glasgow Hearing Aid Benefit Profile (GHABP; Gatehouse, 1999, 2000, 2001) can also be used for goal setting. More recently, Jennings (2009) successfully used Goal Attainment Scaling (goal set along with quantifiable attainment levels) with 46 adults with hearing impairment participating in a group-based rehabilitation program. The goals were set individually prior to rehabilitation. The participants described each of their goals in terms of the environment in which they occurred, the people involved, and how participants currently addressed them. Participants also identified the extent to which they would like the goals improved. Goal attainment was reviewed after rehabilitation completion and 6 months later. The use of the COSI is well established for joint hearing aid goal setting and it has also been used for audiological interventions other than hearing aids (see, e.g., Hickson et al., 2007). Jennings provides an in-depth description of how joint goal setting can be applied to audiological interventions other than hearing aids.

### SHARED DECISION MAKING

Like joint goal setting, shared decision making is a component of client-centeredness (Mead & Bower, 2000). Some of the other terms used to describe client participation in intervention decision are informed decision making, client-clinician partnership, concordance, evidence-based client choice, client autonomy, client self-determination, active client participation, and client participation.

Decision making is best represented on a continuum, from sole clinician participation at one end to total client participation at the other end. Three main ap-

proaches to intervention decision making have been identified on this continuum: paternalistic, shared, and informed (Charles, Gafni, & Whelan, 1997, 1999). Shared decision making occupies the middle of the decision making continuum: paternalistic decision making (clinician making the decision with little client participation) is at one end and informed decision making (client making the decision with little clinician participation) is at the other end. In shared decision making, or the middle position on the continuum, the information exchange, deliberation, decision making, and intervention action are performed together by the client and the clinician (Charles et al., 1997, 1999). It signifies involving clients in decision making “to the extent that they desire” (Edwards & Elwyn, 2006, p. 317).

Client participation in intervention decisions has two main advantages. First, it respects the client’s right to autonomy and informed consent (Emanuel & Emanuel, 1992; Lidz, Appelbaum, & Meisel, 1988). Second, it achieves better intervention adherence and outcomes. A systematic review reported shared decision making to be particularly suitable for people with chronic health conditions, when more than one intervention is available, and when the interventions require more than one session (Joosten et al., 2008). Despite this, many barriers to shared decision making exist.

Clinicians report barriers to shared decision making such as health system factors (e.g., time constraints), clinician factors (e.g., insufficient availability of information), and client factors (e.g., misconceptions about the health condition or the intervention, high level of anxiety, or poor understanding of the information conveyed by the clinician; Gravel, Légaré, & Graham, 2006). From the client’s perspective, 52% of Americans reported preferring paternalistic decision making (Levinson, Kao, Kuby, & Thisted, 2005) whilst 96% of Swedes reported preferring shared decision making (Rosén, Anell, & Hjortsberg, 2001). Such disparities in client preferences across studies may be attributed to methodological differences. The former study surveyed the general population whilst the latter study surveyed clients just after a medical visit when they may have been more inclined to reflect on their preferences. Decision making preferences were determined differently in the two studies as well. The American study asked the participants to rate their agreement with the statement “I prefer to leave decisions about my medical care up to my doctor” and those who strongly agreed, moderately agreed, or slightly agreed were deemed as preferring paternalistic decision making. The Swedish study asked participants to complete the statement “If there are alternative therapies, the choice of treatment should be made by . . .” and those who answered “myself and the doctor who treats me but the doctor has the deciding vote” or “myself and the doctor who treats me but I have the deciding vote” were deemed as preferring shared decision making. The disparity in these surveys’ results shows how preferences for shared decision making are influenced by contextual factors such as recent experience with health care. Cultural

aspects may also come into play and demographic differences also exist in client preferences for shared decision making. In general, younger clients, clients with more years of formal education, and female clients are more likely to prefer participation in health decisions (for a review, see Say, Murtagh, & Thomson, 2006). It is still unclear whether the influence of age is indeed an age effect or rather a cohort effect, with the new generation of older adults expected to prefer more participation than their predecessors.

Understandably, clients want to be adequately prepared before participating in health decision making. Prerequisites to shared decision making include knowledge, explicit encouragement of client participation by the clinician, appreciation of the client's rights and responsibilities to play an active role in decision making, awareness of choice, and sufficient time (Fraenkel & McGraw, 2007). Client's access to information is a fundamental part of shared decision making and decision aids can provide information on the intervention options and their benefits and limitations. Decision aids are "evidence-based tools designed to prepare clients to participate in making specific and deliberated choices among healthcare options in ways they prefer. Patient decision aids supplement (rather than replace) clinician's counseling about options" (O'Connor et al., 2009, p. 3). A decision aid can take various forms such as a leaflet, a board, a poster, an audio or audiovisual recording, or an interactive computer-based presentation. Decision aids are used by the client and the clinician to enable a systematic, consistent, and unbiased presentation of the intervention options. They provide information on the benefits and limitations of the available interventions and help clients clarify their goals and values relevant to the health condition and the intervention options so that their intervention decision is compatible with those. Decision aids are important as inconsistencies in the presentation of intervention options (e.g., introducing a bias in the option presentation or omitting the option of no intervention or of deferring the decision) can intentionally or unintentionally direct the client towards a specific intervention (Ashcroft, Hope, & Parker, 2001; Elwyn, Edwards, Gwyn, & Grol, 1999; Wills & Holmes-Rovner, 2003). Decision aids should provide accurate yet parsimonious information and individualized decision aids that adapt to each client's situation have been advocated. A systematic literature review on decision aid outcomes revealed that they improve client knowledge of intervention options, facilitate decisions, and increase client participation in decision making (O'Connor et al., 2009). The quality of decision aids fluctuates greatly but decision aid standards are now available (Elwyn et al., 2009). The standards can assist clinicians and researchers wishing to develop their own decision aids.

### ***Shared Decision Making and Chronic Health Conditions***

Shared decision making appears particularly relevant to people with chronic health conditions as these conditions require self-management through sustained

behavior modifications (Paterson, Russell, & Thorne, 2001; Thorne, 2006). In contrast with a person with an acute health condition, someone with chronic health conditions does not make one single decision, but rather has recurrent decisions to make (Garfield, Smith, Francis, & Chalmers, 2007; Montori, Gafni, & Charles, 2006). Clients prefer participation in decisions pertaining to non-life threatening health conditions and to behavioral decisions (Deber, Kraetschmer, & Irvine, 1996; Say et al., 2006).

In terms of shared decision making outcomes for people with chronic health conditions, clients with myocardial infarction who chose between group cardiac rehabilitation and individual cardiac rehabilitation were more likely to complete their rehabilitation program than clients who were randomly assigned to one of the two rehabilitation programs (Wingham, Dalal, Sweeney, & Evans, 2006). Similarly, clinically depressed clients who chose to pursue counseling achieved better outcomes than their counterparts who were randomized to the same intervention (Chilvers et al., 2001). The literature on diabetes also signals favorable outcomes when clients are offered their preferred decision making role (Michie et al., 2003; van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003). Similarly, if shared decision making was to be used with adults with acquired hearing impairment, intervention adherence and outcomes may benefit.

### ***Shared Decision Making and the Rehabilitation of Adults With Acquired Hearing Impairment***

Rehabilitative audiology has been described as a sequence of decisions (Hyde & Riko, 1994). A person with hearing impairment faces many decisions on the road to successful rehabilitation. The person decides to seek help, to pursue an intervention, and to follow all the steps to successful implementation and maintenance of the intervention (Milhinch & Doyle, 1990). Little empirical evidence on rehabilitative audiology decision making is currently available. A paternalistic approach to decision making (clinician making the decision) has dominated historically, however for Stephens, the decision making step is “a vital stage in the rehabilitative process in which key decisions are made jointly between the professionals and the hearing impaired people together with an input from Significant Others (author’s own capitalization)” (1996, p. 61).

Shared decision making achieves particularly good outcomes with people with chronic health conditions and when several interventions requiring more than one session are available (Joosten et al., 2008). This is the case for adults with acquired hearing impairment who have many possible audiological intervention options such as hearing aid fitting, other technological interventions, and communication programs. Meta-analyses and systematic reviews have confirmed the effectiveness of hearing aids as well as group and individual communication programs in reducing activity limitations and participation restrictions and increasing quality of life (Chisolm et al., 2007; Hawkins, 2005; Sweetow & Palmer,

2005). Thus, better outcomes may be achieved if clients are made aware of all intervention options, receive quality information in the form of decision aids that highlight those, and are involved in shared decision making.

### FUTURE DIRECTIONS

This article described approaches that promote client participation, specifically, client-centeredness, joint goal setting, and shared decision making. Research evidence indicates that these approaches result in improved adherence and outcomes for people with chronic health conditions. It is suggested here that client participation may also be integrated in the rehabilitation process for adults with acquired hearing impairment. Like other people with chronic health conditions, people with hearing impairment require self-management through sustained behavior modifications. For example, people with hearing impairment constantly decide whether they will or will not use technical aids and communication strategies. Intervention adherence and successful intervention outcomes is unlikely unless clients become active partners in their management program. Rehabilitative audiologists should recognize the expertise of their clients and seek to open their approaches to promote self-management. Borrowing approaches from other disciplines that promote the participation of people with chronic health conditions in the management of their conditions could enrich the services offered to people with hearing impairment.

Research also needs to be undertaken to better understand how the various components of client participation are currently being used by rehabilitative audiologists. Their acceptability, both by clients and clinicians, benefits, and limitations must be formally investigated. For example, very little is currently known about the client-audiologist relationship. Studies performed in other fields of health, such as asking clients to describe and express their preferences for biomedical or client-centered consultations after viewing videos of clinical scenarios using both approaches, should be conducted in rehabilitative audiology. How client participation can be used to enhance the rehabilitation of adults with acquired hearing impairment remains to be determined. For example, what are the factors that clients take into account when making hearing rehabilitation decisions? What information should rehabilitative audiology decision aids include? What is the effect of client participation on rehabilitation outcomes?

A clinical trial currently underway at the University of Queensland in Brisbane, Australia, seeks to provide answers to some of these questions. The literature on intervention options for people with acquired hearing was reviewed (Laplante-Lévesque, Hickson, & Worrall, 2010c) to inform the development of a decision aid. The decision aid was used in a clinical trial of shared decision making in rehabilitative audiology. A companion article in this journal describes the shared decision making experiences of adults with acquired impairment in the shared decision making clinical trial (Laplante-Lévesque, Hickson, & Worrall,

2010b) whilst the factors influencing rehabilitation decisions of adults with acquired hearing impairment has been published elsewhere (Laplanche-Lévesque, Hickson, & Worrall, 2010a). This latter publication also includes a copy of the decision aid used.

## CONCLUSION

Approaches that promote clients' participation in their health such as client-centeredness, joint goal setting, and shared decision making hold promise for the rehabilitation of people with acquired hearing impairment. During an initial client-audiologist encounter, most of the time is typically devoted to instrumental assessment and intervention implementation, at the expense of history taking and discussion of assessment results and intervention options (Doyle, 1994). Although the importance of the hearing impairment assessment should not be overlooked, increased client participation, for example via client-centeredness, joint goal setting, and shared decision making, constitutes a more holistic approach that respects the client as a person and that may hold promise to improve the quality of life of these people. Successful client participation calls for an evolution of the client-clinician relationship from a paternalistic to a collaborative association.

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