“What brings you here today?” The role of self-assessment in help-seeking for age-related hearing loss

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Abstract

Why do persons with age-related hearing problems typically wait years from the time hearing difficulties are noticed until hearing health care is sought? This article presents findings of a grounded theory study exploring perspectives of older women on help-seeking for hearing problems. Findings indicate that participants engaged in protracted self-assessment of their hearing before, during, and after seeking help for hearing problems. Many factors were found to facilitate or delay help-seeking; some factors may do both at different times. These factors combine to produce a “push–pull” effect that moves persons iteratively toward and away from help-seeking. A preliminary model of self-assessing is presented including three themes identified as significant in self-assessing: contrasting/comparing, cost vs. benefit, and control. The findings may have relevance beyond the study of hearing loss to the more general investigation of help-seeking for chronic health conditions in aging.

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1. Introduction

“What brings you here today?” As an audiologist, this is how I often initiated my first conversation with a patient. Many older patients with age-related hearing loss, known as presbycusis, relayed a litany of communication problems that stretched back many years; yet this was their first hearing test. My clinical experience is consistent with research that indicates a lag of eight to more than 20 years between

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the time one is first aware of hearing difficulties and when professional hearing help is sought (e.g., see Brooks, 1979; Kyle, Jones, & Wood, 1985). For every person who seeks help, many more never make an appointment for a hearing assessment.

Why do persons with hearing problems wait so long to seek help? What factors trigger the hard-of-hearing person to finally book a hearing test? This article explores these questions with older women at the time of their first audiology assessment. A major goal was to construct substantive theory, through the use of qualitative grounded theory methodology, to link individuals’ experiences living with a hearing loss with the process of help-seeking. A preliminary model of help-seeking developed from the data is presented.

Shortcomings of previous research were addressed by adopting a research design that was unique in three respects. First, in-depth interview data were collected at several points in time before and after each participant’s first audiology appointment. Second, data were collected from a close family member and from the assessing audiologist to capture unique perspectives on the study questions. Third, inclusion of the audiologic appointment as data provided important information on the clinician–patient interaction in a typical clinical context. This approach studied help-seeking in context, considered how it evolved over time, and how it was influenced by both personal and environmental factors.

2. Review of the literature

2.1. Presbycusis: prevalence and impact

It is difficult to reconcile hard-of-hearing persons’ reticence to seek help with the data on presbycusis. Hearing loss has been identified as the third most prevalent chronic disability among older adults, surpassed only by arthritis and hypertension (Haber, 1994). More than 50% of community-based adults aged 75–79 years have some degree of measurable hearing loss (Willott, 1991). The societal impact of presbycusis will increase in coming years, because older adults are the fastest growing segment of society and life expectancy continues to increase. In Canada and the United States, approximately 21% of the population in 2035 is expected to be aged 65 and over, compared with 12% in 2000 (Statistics Canada, 1992; US Census Bureau, 2003). Thus, presbycusis is well documented as a significant and escalating population health issue. The fact that older women outnumber older men calls for more research to discover how the needs of the expanding cohort of older women may be better met.

Hearing loss leads to adverse effects on the physical, cognitive, emotional, behavioural, and social function of older adults (see Mulrow et al., 1990, for a comprehensive list of studies). It results in increased stress levels, anxiety, and social withdrawal. Altered self-concepts manifested in lowered self-esteem, feelings of inferiority, depression, insecurity, and loss of autonomy may ensue. There is also evidence that cognitive deficits can arise from perceptual deficits in vision and hearing (Schneider & Pichora-Fuller, 2000). Such findings highlight potential wide-ranging secondary effects of hearing loss in terms of functional health status, in addition to the more intangible effects on quality of life.

The psychosocial effects of presbycusis, however, are highly variable, for several reasons. One, its insidious onset and progression in both ears, starting in the high frequencies, may result in ongoing adaptation to tiny increments in hearing loss rather than recognition of the problem. Presbycusis parallels other chronic conditions associated with aging, such as arthritis, in that symptoms may be ‘normalized’ and explained away as one is “just getting old” (e.g., the aches and pains of arthritis). Two, the psychosocial effects of presbycusis are influenced by a range of factors associated with aging and life
experience that evolve over time. These include physiological changes, such as those incurred as a result of cumulative exposure to harmful noise levels, and psychological changes, such as may accompany altered occupational and family roles. Three, the effects of hearing loss are not restricted to the person with the impairment but affect, and are affected by, communication partners. One’s experience of presbycusis is thus shaped by many influences over many years, leading to a complex but subtle and highly variable interplay of factors that determine the overall psychosocial impact of hearing loss.

2.2. Health behaviour and help-seeking

In addition to factors related to the specific nature of a person’s hearing-related impairment (e.g., the specific frequencies affected or the degree of central auditory deficit), personal factors affect how a hearing impairment translates to deficits in activities and participation in everyday life. These include one’s health beliefs and behaviours related to health (e.g., see Maiman & Becker, 1974) and coping (Folkman & Lazarus, 1980). The Health Belief Model states that an individual’s action to avoid disease is a function of one’s perceptions of disease susceptibility and seriousness, and a belief that taking action would not entail overcoming important social or psychological barriers (cost–benefit analysis). Cues to action (either internal or external stimuli) are posited to link perception to health-taking action (Maiman & Becker, 1974). The concept of self-efficacy (Bandura, 1977) is salient in that the kinds of coping strategies one adopts to compensate for hearing-related communication difficulties will depend in part on one’s perceptions of self-confidence and control, including one’s ability to control environmental factors contributing to communication difficulties. Perceived control over a behaviour, either based on personal experience or observation of experiences of close others, is posited to be high when one perceives few internal and external obstacles to performing the behaviour.

Work in pain research and chronic illness has noted striking variability among individual responses to seemingly comparable body states. A central component of the construct of illness behaviour (Mechanic, 1995) is the importance attached to self-attention and body awareness as individuals respond to bodily indications, monitor internal states, define and interpret symptoms, make attributions, take remedial actions, and utilize various sources of formal and informal care. Illness is therefore viewed “not only (as) a state of a person, but (as) a mode of coping” (Mechanic, 1995:1208). Kleinman (1988) goes further in describing the illness experience as a function of an individual’s unique biography, always distinctive, and culturally shaped. He elucidates the importance of ‘explanatory models,’ one’s description of what one’s illness is about, as being nothing short of the representation of one’s life experience, particularly salient in the dynamic trajectory of chronic illness. In a longitudinal study of help-seeking by Cameron, Leventhal, and Leventhal (1993) with middle-aged and older adults matched on age, gender, and health status, symptoms were identified as necessary, but insufficient, cues to help-seeking. Compared with their matched controls, help-seekers rated their symptoms as more severe and as having greater long-term consequences. The authors concluded that those who seek help engage in more active coping strategies but rate their coping efforts as less effective than matched controls. An important coping strategy was communication about the problem to significant others, who advised those with problems to seek care in fully 50% of help-seeking cases, highlighting the importance of social support and “social permission” in help-seeking (Zola, 1973). Cameron et al. also concluded that seeking help serves to relieve the load of emotional distress created by symptoms.

Women engage more frequently than men in health-directed behaviours; however, such gender differences seem to disappear for older adults (Mutran & Ferraro, 1988). These authors found that men
who assessed their health as poor were more likely to see a physician than women who assessed their health as poor. Few audiologic studies have concentrated on women, and research suggests significant differences in the way that hearing loss affects men and women, and in the ways that men and women deal with those effects. Women with hearing loss, for example, may be particularly disadvantaged due to the centrality of communication in women’s social roles and the multiplicity of their roles at home and in the community (Hétu, Jones, & Getty, 1993). On the other hand, Jones, Kyle, and Wood (1987) report that men, much more than women, expect family members to accommodate to their hearing loss.

While growing older leads to a greater average need for health care services, older adults are quite judicious in their utilization of these services. Elderly adults attribute many symptoms, especially mild chronic ones, to the aging process (Kart, 1981) and are less likely to see chronic mild symptoms as illness warnings (Prohaska, Leventhal, Leventhal, & Keller, 1985). Elderly persons also attempt to downplay the experience of stress as a coping strategy (Leventhal, Leventhal, Schaefer, & Easterling, 1993). Attitudes appear to affect usage among older adults: medical skepticism reduces usage while a stronger belief in the value of preventive health care appears to promote the use of services (Penning & Chappell, 1990). Family and spousal support appear more important than peer influences for older groups (Umberson, 1992); however, advice from friends may be influential among older persons living alone who are unsure how to interpret a physical complaint (Edwardson, Dean, & Brauner, 1995). Influences may change and/or be cumulative across the life span, highlighting the need to consider help-seeking within the social context of the individual (Haug, Musil, Warner, & Morris, 1998).¹

The few studies that have specifically explored help-seeking for hearing loss have been population based and have used questionnaires and audiometric measures of hearing impairment (i.e., the audiogram) and disability (e.g., speech recognition tests) to assess determinants of help-seeking (O’Mahoney, Stephens, & Cadge, 1996; Swan & Gatehouse, 1990; van den Brink, Wit, Kempen, & van Heuvelen, 1996). A different research tack was taken by Getty, Gagné, and McDuff (1996), who conducted focus groups to study the obstacles older hard-of-hearing persons encountered in seeking help. This qualitative study discovered a wide range of factors, some subtle but important contextually, from the personal (e.g., resistance to change) to societal (e.g., complicated referral process to get a hearing aid) that delayed or facilitated help-seeking.

In summary, the literature on help-seeking for hearing loss may be distilled to two main points. First, it is the way symptoms are interpreted and responded to in terms of their effect on functioning, rather than their presence per se, that affects decisions around help-seeking (e.g., do they develop into illness behaviour). Those who are more aware of symptoms, who interpret symptoms as severe, who perceive that they are not coping effectively with these symptoms, and who believe in the efficacy of treatment appear more likely to seek out services. Hard-of-hearing persons seek help for ‘symptoms’ related to their inability to function rather than to their impairment. Two individuals with the same impairment may differ greatly in their ability to function. Moreover, one’s ability to participate in life activities is not a fixed entity. A change in lifestyle or communication demands may lead to widely varying degrees of function at different times. Second, a wide range of determinants interacts in the dynamic process of help-seeking and health service utilization. These determinants are physiological, psychological, and social. Many agents extrinsic to a hearing loss (i.e., the environment) influence a hard-of-hearing

¹ The topic of physician consultation in help-seeking is addressed in a separate paper (submitted) on clinician–patient interaction based on this research study.
person’s decision to seek help. These include the influence of significant others (including the influential role of a family physician as gatekeeper), the social roles and communication needs of the hard-of-hearing person, the level of hearing accessibility in society, and the system of hearing health service delivery. The relative contribution of each category is not yet known.

Research is needed to address what mediates between physiological, psychosocial, and environmental variables as noted above and one’s self-appraisal of health and particular health conditions (Haug et al., 1998). The studies reviewed suggest that factors underlying one’s choice of coping styles and strategies and their perceived effectiveness may play a key mediating role. More ecological research paradigms to investigate help-seeking are needed (Carson & Pichora-Fuller, 1997). The qualitative study described here expands the current knowledge base by adopting a social ecological approach to explore why help-seeking for presbycusis is delayed and the factors that hinder and promote help-seeking action.

3. Methodology

Seven women, ranging from 72 to 82 years of age, formed the core sample of participants in this study. This sample was restricted to women to avoid the potential confounds of gender and noise-induced hearing loss, which is more prevalent in older men. All participants lived independently in the city of Victoria, British Columbia (greater metropolitan population about 300,000): four lived alone, three with their husbands. All were seeking help at the same private practice audiology clinic for symptoms of presbycusis uncomplicated by other significant audiologic factors, and each had had no prior audiologic assessment or hearing aid experience. No participant had any serious medical condition or cognitive impairment. Each had English as her first language. Potential participant names were obtained from the booking secretary at this audiology facility, and women were contacted consecutively only after this secretary obtained their permission. In total, 15 women were contacted, five of whom did not meet one or more of the study criteria listed above. Three women declined to participate due to lack of interest (1), concerns about confidentiality (1), and because a spouse was quite ill (1).

In addition to this core sample, data were also collected from a family member of six participants (three husbands and three daughters identified by participants) and the audiologist who assessed all seven participants. The audiologist was chosen, from one of four practices in Victoria, based on her experience in private practice (15+ years), her work as a clinical educator, her willingness to participate, and the central location of her practice (next to a major hospital). Working with one practice was not deemed limiting to the study, because this practice is representative of the profession in appointment bookings (e.g., appointment length and waiting times), and in the audiologist’s approach to testing and counseling.

Data were of several forms: interviews, participant observation by the researcher, journal-writing by participants, and participants’ audiologic results. Semistructured interviews with the participants, their family members, and the participating audiologist were the main form of data. Each woman took part in at least four interviews: two before her audiology appointment, one immediately after, and one between

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2 Most audiologic services to adults in British Columbia, Canada, are provided by private practitioners, with all fees for services and hearing aids paid for by the client, except those on social assistance. It is not necessary to have a referral from a physician. Some audiologists, including the audiologist who took part in this study, apply the hearing assessment charge toward purchase of a hearing aid, if one is recommended.
3 and 7 weeks after the appointment. The first interview focused on the woman’s personal background, lifestyle and activities, her description of her health, her hearing and hearing problems, her coping style and strategies, and how her appointment came to be booked at this time. Interview 2 explored this last question further and also looked at the participant’s expectations and hopes for the audiolologic assessment, her knowledge of audiology and audiologists, and her knowledge of hearing aids. The third interview focused on the audiology assessment: her reactions to the test procedures and results, understanding of test results, how well expectations were met, and overall impressions of the test. The final interview(s) revisited participants’ interpretations of and feelings about the test results and explored future intended action and the reasoning underlying such intention. All interviews were conducted at participants’ homes, except for interview 3, which was held in a coffee shop next to the audiology clinic.

The goal of interviews with family members, which lasted between 25 and 40 min, was to gain the perspective of an important “other” on participants’ hearing. Interviews with the audiologist (15–20 min) focused on her perspective of the patient (participant) she had just assessed, explored perceptions of the patient’s expectations for the test and how they were met, and the audiologist’s own expectations for the assessment. The author audiotaped and transcribed all interviews verbatim, adapting a notational schema after Tannen (1984) that maintained quality of detail and consistency. Interviews were analyzed for informational content, conversational breakdowns due to hearing loss, and the reactions of, and strategies utilized by, participants in response to such breakdowns. In total, about 48 h of audiotaped data were analyzed. Each participant was also asked to keep a daily journal of thoughts related to her hearing over the course of the study.

Each participant and the audiologist consented for the investigator to attend, observe, and audiotape the audiology assessment from a corner of the test side of the audiology sound-isolated booth. The assessment lasted about 1 h, starting with a brief case history interview, followed by delivery of a standard audiology test protocol consisting of tests in each ear of pure tone thresholds, speech reception and recognition, and middle ear function. All signals were delivered through headphones to the participant, who was seated in a 5 ft by 6 ft room with a window through which she could see the audiologist on the other side of the booth. The audiologic results, a ‘client intake history’ form each participant completed before testing, and the author’s notes as participant observer of the test session were all analyzed.

All data were collected between October 1997 and April 1998 and analyzed according to the principles of grounded theory (Strauss & Corbin, 1998). The aim in grounded theory is to generate a model or theory that is grounded in the empirical data. Line-by-line analysis of the data, including all interview transcriptions, journal entries, audiolologic data, and researcher notes generated codes, or labels, for ideas or concepts. Through data triangulation and constant comparative analysis of these codes, the data were organized into three levels of abstraction. “Categories” represent the most abstract level of coding: the most central ideas that emerge from the data. The next level, less abstract, is “properties,” which are the general or specific characteristics or attributes of categories. The third and least abstract level of coding is termed “dimensions,” which are characteristics of a property. As concepts were named, compared, and classified, a theoretical framework was developed. A core category, “self-assessing,” was identified to integrate the theory. In the process of coding data, making links between concepts, and building theory, some concepts were noted repeatedly, with slight variation, and seemed to fit equally well into more than one category or property in the emerging framework. Such concepts, called themes, emerged later in the data analysis process. The discussion in this paper will focus on the core category of “self-assessing” and the three important themes that emerged from the data.
4. Results and discussion

4.1. The spiral of decision making

The core category that emerged from the data is the spiral of decision-making in self-assessing hearing. It consists of three iterative components: self-assessing, help-seeking, and outcomes. “Self-assessing” refers to the process whereby participants evaluate, analyze, and make decisions around their hearing, hearing challenges, and the consequences of these challenges. Questions driving self-assessing are: how much of a problem is my hearing? Does it affect my life enough to seek help? If so, what should be done? Help-seeking refers to behaviours that participants engage in at particular points in self-assessing to find out more about their hearing and possible solutions to hearing challenges. Help-seeking may take many forms, from requesting that part of a conversation be repeated, to seeking help from a professional, such as a physician or audiologist. Outcomes of help-seeking may provide a participant with new information about her hearing, which is added to her existing pool of data and which may lead to further rounds of self-assessing and help-seeking. This iterative process is termed a “spiral” to emphasize that one does not return to the same point in self-assessing after one has evaluated the outcome(s) of help-seeking.

4.2. Themes

The theme “contrasting/comparing” refers to a participant’s evaluation of her hearing problem with reference to a number of yardsticks. The women in this study contrasted or compared their hearing along dimensions related to the self (‘internal referents’) or in relation to others or the environment (‘external referents’). Internal referents were noted in relation to co-occurring health conditions, including sensory disabilities. For example, participants commonly contrasted the consequences of their hearing problem with their vision. Janet stated that she is much more concerned about her eyes than her hearing: “I’d be devastated if I couldn’t hear…mind you if I had a choice… I’d rather do without my hearing..than my eyesight.” Comparisons between hearing aids and dentures were also noted. As well, participants contrasted their hearing across different points in time, from a time in the distant past: “…you know when I was young… I had really good hearing,” to how they heard day-to-day over the course of this study and to how it might become at some future point in time. This latter comparison often included apprehension that hearing would deteriorate further. As ‘Phyllis’ remarked: “Does your hearing just keep getting worse even after a hearing aid?” Participants contrasted the situations where they have difficulty hearing with situations that pose no problem. Participants compared their hearing to their perception of other people’s hearing, most notably to a spouse or a peer. Participants also contrasted their interpretations of their audiologic test results with their real-life experiences of their hearing, remarking that their test results were worse than their perception of how they did during the test and in daily life. Such mismatch contributes to confusion about one’s hearing and may prolong self-assessment and decision making about hearing.

Contrasting/comparing helped participants put their hearing in context in order to prioritize hearing among all of their life concerns. It was an ongoing activity that participants engaged in throughout self-assessing, help-seeking, and evaluating outcomes with regard to their hearing problems. Contrasting/comparing could serve to underscore one’s hearing difficulties or could serve to downplay one’s hearing problems. Thus, in different contexts, contrasting/comparing could serve to either inhibit or promote help-seeking for hearing loss.
The “cost vs. benefit” theme refers to assessing the relation between the cost of an action and the value of the resulting benefit. Participants’ comments in interviews and their journal entries reflected the cost–benefit evaluation they engaged in as part of the process of decision making. Participants may adopt behaviours in conversation (the cost), such as persevering by asking for repetition, in order to increase their understanding (the benefit). If such behaviours are successful, other benefits accrue, such as the opportunity for increased participation in conversational interactions, improved self-esteem, and an increased sense of control. The costs are the cognitive, physical and emotional effort involved in persevering. Costs are perceived to be greater when others are called upon to assist, for example, when one asks for repetition. Such situations incur additional perceived emotional costs in the form of a potential diminution of one’s status as a conversation partner and costs associated with disclosing or drawing attention to one’s hearing problems. Such costs may involve a perceived loss of one’s sense of control (discussed further below).

In their cost vs. benefit assessment, therefore, participants appraise conversation and make decisions about the efficacy of their efforts to improve understanding. Participants remarked that they consider the comments of friends to be more important than the comments of strangers; thus, they may make more of an effort to understand friends because there is greater perceived benefit. Therefore, they weigh not only the potential improved performance an action will yield but also the importance of that improved performance to one’s life. Appraisal, furthermore, is ongoing. Participants may abandon a strategy (e.g., asking for repetition) when it is unsuccessful after a few attempts, because with each attempt, the cost escalates relative to the benefit that may eventually be achieved.

Cost–benefit assessment evolves as an integral component of participants’ assessment of their hearing. For example, at an early point in self-assessing, hearing challenges may be infrequent and mild in consequence. The “cost” of hearing difficulty (its consequences) is low enough that there is no perceived need for action. As challenging hearing episodes increase in frequency and severity, there may be perceived benefit(s) in taking action to offset the escalating cost. Or, one may minimize one’s hearing challenges and/or their effects to minimize the perceived costs of hearing loss. Over time, as a hearing problem takes its toll on relationships and one’s sense of security, participants increasingly reflect upon and become more aware of their hearing difficulties, and they may experience more stress. The costs of not hearing come to outweigh the benefit of downplaying the problem, as Phyllis illustrates: “Now I have to let people know or I won’t know what they’re talking about.” Participants may now be more assertive in using their resources to mitigate the problem and may also consider seeking help (e.g., by talking to their doctor or booking a hearing test). In summary, help-seeking may be triggered when the costs of a hearing problem outweigh one’s resources to deal with it.

Participants also undertook a cost vs. benefit analysis in considering their need for a hearing aid. The advantages of a hearing aid are weighed, compared with the hassles of adjusting to its use and the bother of maintenance and repairs. Some wondered if they would be exchanging the problems of a hearing loss for the problems of a hearing aid. ‘Louise,’ after her hearing test, even pursued the possibility of having ear surgery (impracticable for presbycusis). She perceived the cost of ear surgery to be lower than the cost of using a hearing aid, for the same benefit (an example of contrasting/comparing). Janet wrote her reaction to a newspaper article about a new surgery in her journal: “Did you see the paper this morning?  

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3 Or, participants with little self-perceived hearing difficulty may find the “nagging” by family members to get a hearing test a greater “cost” than having the test.
That ear operation sounds like something I’d be interested in—no fuss and it’s finished.” To summarize, in self-assessing and help-seeking, and in evaluating outcomes, participants weigh the cognitive, emotional, social and other (e.g., financial) costs of particular behaviours, vs. the benefits of these behaviours.

The third theme in self-assessment, “control,” refers to participants’ perception of the power they have to direct aspects of their lives. One “cost” associated with having a hearing problem is perceived loss of control over aspects of one’s life affected by hearing. Loss or diminution of control manifested itself in two ways in this study: loss of receptivity control in participants’ communicative lives and expressive loss of control in participants’ perceptions of how they presented themselves to the world as a result of their hearing problem.

The women talked about feeling stress as a consequence of their hearing struggles in important life situations. Cheryl missed directions in her new art class. Phyllis lamented that she could no longer joke as easily with friends and had difficulty hearing her own phone ring. ‘Frances’ was troubled to miss the sounds of life that enable her to stay “aware” and “alert.” Louise missed precious conversations with her dying husband. Even Janet, reluctant to acknowledge a problem, admitted she was distressed to miss conversation in the car or when playing bridge. Reflecting on their hearing brings their sense of loss to the surface. As Louise put it, “it feels like you’ve lost something.” Loss is not just loss of hearing, but loss of intimacy, spontaneity, confidence: a lessening of a sense of control over one’s life.

One’s sense of control may be lessened if the ability to monitor one’s surroundings and pick up important environmental sounds is jeopardized by a decline in hearing. Frances voiced this concern to the audiologist: “When I’m driving I do like to know if uh…like I hear a siren or whatever ok I don’t want it on top of me before I hear it… I thought well I’d better check it {hearing}… before it gets worse if its gonna get worse I’d better know and control it.” Control is also linked to a valued personal sense of responsibility and independence, to which one may be more sensitive as the aging process threatens one’s sense of autonomy, through physical and cognitive decline. Maintaining independence is of particular importance to those, like Louise, who live alone: “Well…you’re you’re strictly alone…you know it’s um… they’re {friends}are nice to you and they try to help you but you know you’ve got to stand on your own two feet.”

Some participants may view a help-seeking step such as disclosing their hearing difficulties to others, and having a hearing test as relinquishing control, in that there is increased vulnerability in exposing one’s hearing difficulties in public. In a way, self-assessing allows the participant to maintain control, whereas help-seeking may be perceived as relinquishing control to others. In disclosing hearing problems to their doctors, participants handed over decision making regarding their hearing. They followed physicians’ directives; if the doctor said hearing was not a problem, no further action was taken (perhaps until the next physician appointment). Similarly, the audiologist was seen or expected by some participants to be in control of the hearing test and its outcomes. For example, I asked Cheryl if she thought my presence as observer during her test had any influence on her or the test. She replied: “It didn’t have any effect on it at all… I was sort of turned over to her {the audiologist} and that was it.” The costs associated with booking a hearing test may be offset by the benefits expected from the test, namely, learning more about one’s hearing, gaining closure regarding hearing issues, or getting help from a hearing aid. These outcomes may enhance participants’ sense of control. Betty, for example, was relieved she could attribute her communication difficulties to her hearing rather than deterioration of her memory or mental abilities.

The prospect of a hearing aid may also threaten one’s sense of control, because a hearing aid announces that you are a hard-of-hearing person (hence the preference for inconspicuous hearing aids).
Participants’ language reflects their association of hearing aids with loss of control or surrender. Cheryl, for example, stated that “most of my friends have given in to hearing aids” and talked of how her husband “didn’t fight it {getting hearing aids} at all.” The mystery surrounding hearing aids may evoke a fear of loss of control. Issues of self-efficacy arise when participants express apprehension about their ability to operate and adjust to a hearing aid. There is also hearing aid-related anxiety connected again to the perception that the audiologist is in control. Cheryl continues to self-assess her need for a hearing aid after her hearing test and is reluctant to proceed with a hearing aid trial, partly because she thinks that if she proceeds, she will have somehow turned over control in decision making to the audiologist and will not be able to turn back. She sums up her feelings by saying: “if I don’t really want this {the hearing aid} at all can I just say no forget it?”

Control may be an interpersonal as well as an intrapersonal issue. Family members who suggest or insist that a relative get a hearing test may meet with resistance, perhaps because they are perceived to be imposing control over her sense of autonomy. A spouse who interprets for his wife may enjoy helping his wife but also enjoy the element of control interpreting provides him in conversation, knowing that his wife depends on him for information. For example, I asked Betty if her husband G thought she needed a hearing aid. This was G’s response when she called him from the next room to solicit his opinion: “No I don’t think you need a hearing aid...as long as I’m around I can...interpret for you.” Betty’s husband fosters his wife’s dependency on him and his own sense of control by discouraging her from trying a hearing aid. In summary, hearing loss involves change and adjustment and a changing sense of identity that threatens one’s control over one’s autonomy and independence. Presbycusis adds to other physiologic changes and to societal attitudes that foster dependency to reduce one’s sense of personal control in aging.

4.3. Model of help-seeking

Four points help to integrate the iterative process of self-assessment, help-seeking, and evaluating outcomes. First, the two main categories identified from the data, self-assessing and help-seeking, and their associated outcomes, do not exist in isolation. Decision making is fluid and ongoing across these two categories and their properties and dimensions. Second, the process of paramount importance in participants’ decision making around their hearing is self-assessing. Comments of participants and family members indicated that self-assessing began before this study started, years prior to booking a hearing test. Self-assessment, however, did not end with the audiology appointment. On the contrary, the data revealed a return to, and continuation of, self-assessing after a help-seeking step was taken and after its outcomes were evaluated. Participants demonstrated that the outcome(s) of the audiology assessment may not necessarily resolve issues around hearing but may raise new questions and dilemmas in decision making. Third, persons do not usually return to the same point in the self-assessing and decision-making process after evaluating outcomes. The term “spiral” (rather than “cycle”) better captures the dynamic and evolving nature of self-assessing and the many influences upon it. Finally, some factors facilitated help-seeking while other factors delayed help-seeking. The influence of a physician, for example, may have either delayed or facilitated help-seeking at different points in time. The changing balance of these cumulative influences on participants over time is reflected in the term “push–pull,” which describes how influences vary to move a participant toward or, alternately, away from either taking a help-seeking step, or from a decision already taken to seek help. Fig. 1 is a preliminary model of how decision making regarding hearing may unfold, incorporating the themes and categories that have evolved from the data. The following examples illustrate this model.
Frequent self-contradictions peppered Cheryl’s comments as she tried to decide if her hearing was enough of a problem to seek help. When asked how long she thought she had had problems hearing, she replied: “Well I think probably I’ve had problems for about five years now I think (1 sec) if it’s a problem.” She contrasted/compared her hearing with her husband’s and concluded that she did not now hear as well as he did with his hearing aid. Her journal comments reflected the cost–benefit evaluation she performed as she anticipated her upcoming hearing test and its outcomes. In there she listed, after our first interview, the problems her husband has had with repairs to his hearing aid. She concluded: “For the above reasons, if I am offered a hearing aid for a minor hearing problem I will hesitate to agree. The hearing problem may be less than the hassle of coping with the aforementioned problems.”

Following her hearing test and the audiologist’s recommendation of a hearing aid, Cheryl returns to self-assessing her hearing, as the following successive journal entries she makes after her hearing test on October 16th indicate:

“Fri. Oct 17: Bridge game here. I discussed my hearing loss to partners. They had known but only because I had advised them of my difficulties. I was testing my loss as they spoke. Had no difficulties even though one bridge partner speaks very softly. However, this may be because she was directly across from me and there were no other noise distractions.

Sat. Oct 18: Talked on the phone to a sympathetic friend (with a hearing aid) and asked her if my hearing problem was noticeable to her. What I’m trying to do here is trying to find out if my hearing loss is a problem to others. I am not sure it is a problem for me. As you may gather, I am reconsidering the necessity of a hearing aid. And is the cost worth it, especially as hearing aids can be a nuisance.

Mon. Oct 20: Had difficulty with the group conversation at my art class. Made the decision to postpone the appointment for a hearing aid ear mold.

Mon. Oct 27: Art class. Had difficulty deciphering conversations—even with the lady sitting next to me. She speaks very quickly but I really would like to catch her humourous comments. I am reconsidering my decision re the hearing aid. Too bad I can’t try it out with my class (classes over soon) as this situation is a real test case...

Tues. Nov. 11: I have decided to follow through on the hearing aid. Is it possible that my hearing has deteriorated more since my test? Had problems at my art class...”
These entries highlight the word “decision” and document Cheryl’s flip-flops away and toward a hearing aid trial. Her cost vs. benefit evaluation with respect to getting a hearing aid incorporates different forms of contrasting/comparing: she compares how much her hearing is a problem for others vs. herself and, in her last entry above, compares her hearing on Nov 11 with her hearing on the day of her assessment. She eventually is fitted with a hearing aid, but even then, Cheryl’s journal entries continue to reflect her doubts: “At times I wonder if this {the hearing aid} is an extravagance. Is it helping or not? I’ll persist.” Cheryl exemplifies how a help-seeking step and its outcomes, rather than representing a watershed or turning point in decision making, may instead be a springboard for further self-assessing.

Frances’s journal entries also contain many references to self-assessing. Her very first entry, after her first interview and 16 days before her hearing test, begins: “I gave myself a little test today, the left ear was getting sounds of a lower range the right ear could hear higher notes, the clock was used for this in a quiet room.” Frances also continues self-assessing after her hearing test. “Had examination yesterday and didn’t seem to find out any more than I already believed. I may change my mind as I will take a different attitude toward the problem and test myself more.” Four full weeks after her hearing test her “experiment” continues: “Still trying to find if and where the problem lies.”

These examples demonstrate that participants’ self-assessing may occur on many levels, from decisions as to whether hearing is a problem to issues of self-efficacy around hearing aid use. Overall, the findings do not suggest that decision making associated with self-assessment and help-seeking for hearing loss follows a smooth course toward rehabilitative solutions. Participants wait a long time to seek help, and they are influenced by many factors that facilitate or delay help-seeking. They may delay further action after help-seeking while they return to self-assessing, incorporating their interpretation of the outcomes into ongoing self-assessment. At the time this study ended, even the women who proceeded with a hearing aid trial continued their self-assessing, as second thoughts set in about the benefits of their new device and their ability to adjust to it.

5. Conclusion and implications

This exploratory study used a systematic grounded theory approach to develop a substantive theory in one small area of inquiry from one specific sample. The framework developed represents a composite picture of findings for the seven participants: each woman’s experience is reflected in this framework, but the framework in its entirety does not reflect any one participant’s experience. The true worth of a substantive theory lies in its ability to speak specifically for the sample from which it was derived and to apply back to it (Strauss & Corbin, 1998). The findings have validity in explaining the research questions for these participants. It is the job of further research to discover the possible merit of these findings for other samples and for other populations, such as older males, or persons with hearing loss due to other etiologies.

Journal writing was a powerful data collection tool in this study not fully appreciated at the outset. It was very open-ended, in that participants could choose to write about any aspect of their hearing they wished. Cheryl, for example, did not make consistent daily entries, but she always wrote in her journal the day after her Monday night art class about her successes and failures related to hearing the previous evening. Such information provided clues, not apparent in interviews, that her art class may have been a trigger for her to book a hearing test. Another advantage of journal writing was the continuity it provided.
between interviews. Participants sometimes raised journal entries for discussion when we met for our next interview.

The findings support and contribute to the literature that documents the wide-ranging effects of hearing loss on hard-of-hearing individuals (Mulrow et al., 1990). Furthermore, participants in this study spoke of their worries about future deterioration in hearing and its impact on their sense of security. This topic, the prospective view of one’s hearing, and more generally, one’s health, has had little coverage in the literature and warrants further study in relation to help-seeking. The findings support the idea of a link between adverse effects of hearing loss and one’s responses to retain control, as suggested by others (Hallberg & Carlsson, 1991). When one considers the fact that many older persons must deal with multiple health problems, these effects, both current and projected, become of even greater concern.

This study expands the knowledge base of the effects of hearing loss on women, particularly older women. The findings confirm the importance of communication in women’s social roles and the effect of hearing loss on one’s abilities to fulfill those roles. The high value placed on self-sufficiency among some people who came of age in the 1920s and 1930s when few community services were available may make older people, especially older women, uncomfortable asking others to change to accommodate them (Trychin, 1995). The culture of medicine has also traditionally promoted the view of illness as an attribute of the individual, not society.

The findings support previous research that has established that there is not a strictly linear relationship among impairment and its effects on activities and participation (Swan & Gatehouse, 1990). The relationship between coping (both problem-based and emotion-based coping) and self-assessing was highlighted. The findings also support the hypothesis that help-seeking is a form of coping. Information seeking and hearing aid considerations associated with help-seeking fit well with Lazarus and Folkman’s (1984) description of problem-focused coping and with the link noted between information seeking and successful adaptation to a health condition (Felton, Revenson, & Hinrichsen, 1984).

Other factors were identified that moved participants away from seeking help. Corroborating the literature, delay resulted from limited awareness of hearing loss, and the perception that hearing loss is a “normal” part of aging that cannot be helped (Maurer & Rupp, 1979). Participants did not seek out hearing aids, in part because they perceived them to be limited in their ability to solve hearing problems (matching the “bad” reputation of hearing aids noted by Getty et al., 1996). Participants also reported being resistant to change and lacking the ability to master the new skills necessary to use an aid (Getty et al., 1996). Cohort members also discouraged help-seeking, in that participants compared their hearing favourably to their peers or modeled friends who had hearing difficulties but were not taking action.

A number of factors that facilitate help-seeking were identified. The findings of others (Swan & Gatehouse, 1990; van den Brink et al., 1996) were corroborated, showing that perceived seriousness of hearing problems (not necessarily tied to impairment) facilitates help-seeking. A participant’s experiences with the hearing loss of other family members, either in years past with an older relative or currently with a spouse, sensitized her to how her own hearing problems may affect others. This finding does not appear to be represented in the literature. At the interpersonal level, relationships emerged as the most salient factor in help-seeking, consistent with other studies (Getty et al., 1996; Hétu et al., 1993; O’Mahoney et al., 1996). The strongest influence was the relationship with the spouse in terms of communication and security issues. Other family members, especially daughters, encouraged participants to seek help. Cohort members and friends described positive experiences related to help-seeking or uncloaked the mystery and relieved the fear surrounding hearing aids. Social pressure from family and positive role models were facilitating factors also noted by Getty et al. (1996). Both
physicians and family members may act as gatekeepers, reportedly delaying help-seeking at one point in time, but facilitating it at another point in time.

The findings in this study are compatible with theories of health behaviour, except when help was sought at the urging of significant others (e.g., Janet and Marjorie). In these cases, there was little perceived severity; however, these examples demonstrate that it may be the perceived severity of consequences to others, rather than to the hard-of-hearing person, that triggers help-seeking. Self-efficacy (Bandura, 1977) appears to be relevant in participants’ contemplation of hearing aids, particularly with regard to their beliefs about their ability to handle change and new skills required to use a hearing aid.

This study adds to Mechanic’s (1995) description of illness as a mode of coping. It appears that as long as one perceives oneself to be coping well with hearing challenges, one does not perceive the need for help. Perceived severity may be tied to help-seeking through the mediating effect of coping style and strategy and the degree to which coping behaviours are deemed effective (in certain cases by family members as well as, or instead of, the hard-of-hearing person). This link between the perceived effectiveness of coping efforts and help-seeking, as noted by Cameron et al. (1993), warrants further research. One unique factor in help-seeking for presbycusis is the paramount role that communication plays in helping one to decide the extent of a hearing problem. In general, the findings of this study suggest that help-seeking for age-related hearing loss is similar to help-seeking more generally.

Findings from this study resonate with Kleinman’s work on ‘explanatory models,’ especially with regard to chronic illness. The ‘push–pull’ effect noted in this study, for example, is similar to the oscillating, semiotic nature of chronic illness Kleinman describes. The themes that emerged in this study may inform research on illness models in medical sociology and anthropology. The theme ‘contrasting/comparing’ may be extended as a construct beyond the health psychology literature, where it is similar to the construct of social comparison (Festinger, 1954; Wood, 1989). Social comparison is posited to be a coping process (Tenn and Affleck, 1997) and plays a role in enhancement of self-esteem (Festinger, 1954) and in adjustment to chronic conditions (Helgeson, 1992). A recent study confirmed that negative cognitive and emotional states such as uncertainty about a chronic condition, lack of information, anxiety, lack of control, and frustration, are associated with a need for social comparison information about how similar others are doing, feeling, and coping (Bennion-Brook, Buunk, van der Zee, & Grol, 2002). These authors also confirmed that people in stressful situations prefer to seek information from those who are doing better (upward comparison), presumably so that they may learn how to improve their own situation and obtain hope and motivation (problem-focused coping). On the other hand, people prefer to evaluate their situation in comparison to others who are doing worse (downward comparison) in order to feel better about their own situation (emotion-focused coping). This relates to the construct of perceived controllability in that one may feel one has more control over coping strategies than over the course and severity of a chronic condition. A study by Heidrich (1996) of women with osteoarthritis or breast cancer further showed that age per se had little effect on how women cope with chronic conditions; rather it is the interpretive mechanisms (or explanatory models) that are used, including the use of positive social comparisons and beliefs about severity and controllability of the condition, that were important to psychological well-being.

It is reasonable to hypothesize that mechanisms underlying help-seeking may be similar across a variety of chronic conditions. The active, iterative process of self-assessing displayed by participants in this study of one chronic condition, presbycusis, may also be a feature of other chronic conditions where significant health-related uncertainty, stress, and the need for information prevail. The rising incidence
and prevalence of chronic conditions and co-morbidity of such conditions in an increasingly aging population calls for a program of social–ecological research to identify psychosocial factors that mediate between symptom awareness and help-seeking action. Such a program may have significant practical implications for health care providers who seek guidelines to enhance shared decision making with patients around their care. The ultimate goal is the development of effective strategies to encourage timely help-seeking for better management and prevention of chronic conditions.

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