HELP-SEEKING FOR ADVANCED REHABILITATION
BY ADULTS WITH HEARING LOSS:
AN ECOLOGICAL MODEL

by

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Abstract

Hearing loss affects the lives of many individuals, making communication difficult and often negatively influencing family, social, and occupational relationships, and self-image. The aim of hearing rehabilitation is the reduction of communication problems encountered by individuals with hearing loss. While participants highly value group hearing rehabilitative programs, there is an underutilization of these rehabilitation services.

This study explores help-seeking for advanced hearing rehabilitation by attempting to answer the research question 'what are the factors that prevent or promote individuals with hearing loss from seeking advanced rehabilitation in the form of group hearing rehabilitation'? Twenty individuals participated in this study. Seven participants reported on previous experience with a hearing rehabilitation program. The remaining individuals were invited to participate in a program as part of the study. Four participants declined to participate, seven completed the nine-week program, and two dropped out before the program was completed. For those who participated in the program, data were collected before, during, and after the program. Sources of data included one-to-one interview sessions, journal entries, and questionnaires.

The research approach followed the principles of grounded theory, one tradition of qualitative research. A systematic analysis of the data led to a theoretical framework. Interview transcripts and journal entries were coded and the codes were grouped into categories. Five categories emerged from the data: understanding hearing loss, personal experience with hearing loss, interaction between the person with hearing loss and society, taking action, and reflections on rehabilitation experience. Each of these categories could also be considered as responses to additional questions that emerged as the study progressed. Throughout these categories, three recurrent themes appeared: identity, challenge, and adjustment. These themes and categories were incorporated into the development of the core category as a model of ecological balance.

The findings of this study indicate that participants' help-seeking involves an iterative process whereby identity is assessed, challenges are recognized, and adjustments are made to address the challenges. This model has implications for audiological practice based on the contribution it makes to our understanding of help-seeking behavior for hearing loss, in particular, and possibly other health issues more generally.

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Acknowledgments

This has been the most incredible journey, and there are many people to thank.

Chapter 1: Introduction

Identification of the Problem

Hearing loss affects the lives of many individuals, making communication difficult and often negatively influencing family, social, and occupational relationships, and self-image. The impact of hearing loss has been well documented. For example, Trychin (1993) identified 12 recurring psychological issues for working with adults who are hard-of-hearing and their families; these were: depression, isolation, anger, exhaustion, anxiety, insecurity, despair, negative self-image, inability to relax, loss of group affiliation, paranoia, and loss of intimacy. In a study conducted by Mulrow and colleagues (1990), the impaired quality of life areas most associated with hearing loss included social, emotional, and communication function. Psychological and somatic distress can occur as a result of communication difficulties (Eriksson-Mangold & Carlsson, 1991), and a cognitive toll can also result (Pichora-Fuller & Kirson, 1994). Hearing loss impacts familial (McKellin, 1995), occupational (Getty & Hetú, 1994), educational (McCormick, Pichora-Fuller, Paccioretti, & Lamb, 1994), social, and cultural environments (McKellin, 1994). In turn, the impact of all of these factors can affect a person's approach to managing hearing loss and the rehabilitative process (Stephens, 1996a).

There is a history of resistance to seeking help for problems resulting from hearing loss, with individuals waiting a significant amount of time before consulting an audiologist, scheduling a hearing test, and/or obtaining assistive technology in the form of hearing aids and assistive listening devices (Carson, 2000; Stephens, Barcham, Corcoran, & Parsons, 1976; Swan & Gatehouse, 1990).

Hearing rehabilitation[1] is generally defined as the effort to reduce communication problems encountered by individuals with hearing loss. Gagné (2000, p.65S) defines the goal of audiological rehabilitation to be:

> "to restore or optimize participation in activities considered limitative by persons who have a hearing impairment or by other individuals who partake in activities that include persons with a hearing impairment".

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[1] The terms "hearing rehabilitation", "audiological rehabilitation", and "aural rehabilitation" will be used interchangeably throughout this document.

Throughout this document, and for the purpose of the current study, hearing rehabilitation is considered to be advanced therapy, as it reaches beyond the help found through more basic hearing tests and conventional hearing aids. Group hearing rehabilitation courses may include topics such as speechreading, assertiveness training, general and situation-specific strategies, vocational counseling, speech conservation, and training for communication partners (Abrahamson, 1991; Alpiner & McCarthy, 2000; Tye-Murray, 1998). Hearing rehabilitation has the potential to help many individuals by reducing the barriers to communication resulting from hearing loss, but it is an underutilized component of audiologic practice (Pichora-Fuller & Schow, 2002).

Individuals who have completed group hearing rehabilitation programs have expressed the idea that all individuals with hearing loss should participate in such a program; some individuals believe that rehabilitation programs should be included in services associated with the purchase of a hearing aid. Despite the expressed enthusiasm, many of the rehabilitation 'graduates' admit there was a time when they were not 'ready' to participate in such a group. This observation of delayed help-seeking for advanced rehabilitation, from my personal experience as a rehabilitative audiologist, was also confirmed by Israelite and Jennings (1995) and Backenroth and Ahlner (2000). What makes some individuals feel they are ready to participate? What factors would make more clients want to participate? What do clients gain from participating in group hearing rehabilitation programs? Are there clients who are not helped by these programs?

There are a number of possible reasons why these services are used by a small number of people who are hard-of-hearing. In addition to the psychological and psycho-social factors suggested above, the field of audiology likely contributes to such underutilization. Audiologists are unsure who is an appropriate candidate for a rehabilitation program. As well, many audiologists do not include group rehabilitation sessions as a facet of their job description, and there is a shortage of rehabilitation audiologists; in fact, Carmen and Tye-Murray (2000, p.36) report that "aural rehabilitation has remained a rather elusive component of practice for most hearing healthcare practitioners". Consequently, potential clients may be unaware of the possibility of hearing rehabilitation, or these possibilities may not be available.

The Purpose of this Study

The primary research question of this study was: *What are the factors that promote and prevent individuals with hearing loss from seeking advanced rehabilitation in the form of group hearing rehabilitation?* Additional research questions emerged through the course of the study. These supplementary questions, which ultimately became the categories of the framework, were: How do individuals who are hard-of-hearing understand their hearing loss? What is the personal experience of living with hearing loss? What are the social implications of living with hearing loss? What can individuals do to cope with hearing loss? What are the implications of participating in a hearing rehabilitation program?

By identifying the factors that promote and prevent individuals from seeking advanced rehabilitation, the first practical aim of the proposed research is to contribute to an improvement in audiologic services. Understanding these factors will better enable audiologists to appropriately recommend and deliver more effective hearing rehabilitation services to a greater number of individuals. The proposed research may benefit the community of people who are hard-of-hearing by suggesting how to improve access to rehabilitation services and, in turn, reducing communication barriers resulting from hearing loss.

A second equally important and complementary issue is to provide audiologists with the information needed to determine which clients are not yet ready, or which clients do not need rehabilitation classes as a component of their audiological service. It is expected that this research will help audiologists to determine which clients are ready to participate in group rehabilitation sessions.

The Rationale for this Study

The purpose of this study was to explain why some people seek help through group hearing rehabilitation programs, while others do not seek this support. Group rehabilitation classes for individuals who are hard-of-hearing are presumed to reduce the communication barriers resulting from hearing loss and reduce the handicapping effects of hearing loss that are experienced in social, familial, educational, and occupational environments. These classes aim to help individuals regain control over their communicative experiences by increasing personal skills and raising confidence, awareness, and knowledge. A very small percentage of those who seek help through

hearing tests or hearing aids continue their search for advanced rehabilitation opportunities.

There is a paucity of empirical and theoretical works that illuminate the assumptions that have been made about the need for and usefulness of advanced audiological rehabilitation. More specifically, there are only a small number of studies in the audiology literature that address help-seeking for hearing loss (for instance, see Mahoney, Stephens, & Cadge, 1996; Swan & Gatehouse, 1990; van den Brink, Wit, Kempen, & van Heuvelen, 1996). Fewer studies have examined help-seeking issues through a qualitative approach (see Carson, 2000; Getty, Gagné, & McDuff, 1996). However, the current study is unique in its qualitative focus on advanced help-seeking through rehabilitation programs. It specifically addresses the discrepancies that make this problem interesting. Importantly, there is a discrepancy between the low proportion of individuals seeking help through group hearing rehabilitation programs, and the apparent excitement, satisfaction, and eagerness to recommend these programs by individuals who have completed them.

This is a qualitative study, which will capture different perspectives from participants; some participants have prior experience with hearing rehabilitation programs. Other participants chose to participate in a group hearing rehabilitation program as a part of the study, while others did not. This research study hopes to provide valuable insights that can improve the experiences of individuals with hearing loss, broaden audiology services by understanding the factors that affect the underutilization of group hearing rehabilitation programs, and supplement current literature in audiology, help-seeking, and health psychology.

<center>Relevant Theoretical Models</center>

Models and theoretical frameworks from several areas will be considered. A model of audiological rehabilitation (Schow & Nerbonne, 2002), and models from related fields concerning health beliefs (Becker, 1974; Becker & Maiman, 1975; Evans & Stoddard, 1990) and the consequences of a health condition (WHO, 2001) will provide an understanding of health behaviors. Theories relating to identity (Goffman, 1963), social learning (Bandura, 1986) and social comparison (Festinger, 1954), coping and adjustment (Lazarus & Folkman, 1984; Moos, 1986) will provide a greater

understanding of help-seeking behaviors. Each of these theoretical frameworks will be discussed and related to the current research.

Summary

This chapter introduced the problems that can face individuals with hearing loss and the underutilization of group hearing rehabilitation programs. It also described the purpose and rationale for the current study, and it introduced literature to support the study. A more comprehensive literature review is presented in the next chapter.

Chapter 2: Review of the Literature

Overview

The purpose of this chapter is to review the literature relevant to the current study: advanced help-seeking for adults with hearing loss through group hearing rehabilitation programs. The conceptual issues relevant to the research question will be discussed, including the evolution of audiological practice and the ecological framework for understanding the dimensions of disablement and functioning. An empirical review of the relevant research concerning the consequences of hearing loss will be presented, and methodological considerations will be addressed. This chapter will close with a presentation of the rationale for the current study.

Statement of the Problem

Hearing rehabilitation programs aim to reduce the difficulties experienced by individuals with hearing loss. However, group programs as a form of hearing rehabilitation and, indeed, audiological consultation in general, are considered by many to be underutilized (Schow & Nerbonne, 2002). Evidence shows that many people wait a significant amount of time before consulting a professional for hearing loss (Carson, 2000; Swan & Gatehouse, 1990). As well, Franks (1985) and Kochkin (1992) have shown that individuals also postpone obtaining appropriate amplification devices. The current study focuses on another step in the rehabilitative process, namely group hearing rehabilitation programs that focus on aspects other than hearing instrument fitting and orientation. Such programs typically include speechreading, assertiveness training, and factors that affect the ability to hear and speechread (e.g., Abrahamson, 1991; Alpiner & McCarthy, 2000; Pichora-Fuller & Schow, 2002; Tye-Murray, 1998).

The current study attempts to address the issue of underutilization of advanced rehabilitation programs by identifying the factors that prevent and promote advanced help-seeking for hearing loss in the form of group hearing rehabilitation programs. A discussion of issues relevant to audiologic rehabilitation, a model that discusses the consequences of health conditions, and theories of health beliefs, behavior change, coping, and adaptation are presented as possible support for understanding this issue. However, as proposed by grounded theory methods to reduce imposition of existing theoretical views, the literature review was completed after the data collection was

complete and the analysis was concluded. This chapter also presents research findings that document the impact of hearing loss and further support the relevance and need for the current study.

Conceptual Background

This section will describe the evolution of audiology as a profession and rehabilitative audiology as a specialty field. The World Health Organization ICF model (WHO, 2001) will be used as a framework to organize the description of rehabilitative audiology. To complete the conceptual foundation for the current study, the section will also describe relevant theories of health beliefs, behavior change, coping, and adaptation.

Audiology and Audiologic Rehabilitation

Audiology involves the study of hearing and hearing disorders; its goal is the identification of hearing impairment, measurement of the impairment, and rehabilitation of those with the hearing impairment (Newby & Popelka, 1992). A distinction is often made between audiologists who diagnose a hearing loss and those who focus on the rehabilitation needs of the individual. A paradigm shift (Kuhn, 1970) has emerged in audiology and significant changes are occurring in all areas of the field. Diagnostic tests have progressed from deliberate whispers across a room and tests performed with tuning forks that emitted one of a few available frequencies. Experimentation with electrical hearing-testing devices was conducted in the nineteenth century and led to the first prototype of the modern audiometer in the 1920's (Newby & Popelka, 1992). This technological advance was the precursor to what would become a division in the field of audiology. According to Hull:

> "As instrumentation became more elaborate during the 1950s and particularly during the 1960s, and the field became more sophisticated in the area of research, a shift of emphasis toward pure and applied research and in the diagnosis of site of lesion of auditory disorders in medical environments became evident. It was apparent that the emphasis among the majority of professionals and training programs was turning toward diagnosis, instrumentation, and research and away from aural rehabilitation. Results from an automated piece of equipment or from a research project were more tangible than the emerging signs of improvement in social communication observed in an adult client who was hearing impaired." (Hull, 1992, p.9)

This visionary discrepancy remains in audiology today. Some audiologists view aural rehabilitation as an attempt to reduce both the communication barriers that exist as a result of the hearing impairment and the psychological impact of the impairment. Assessment of the hearing impairment can be an important first step in the rehabilitation process. However, others have used assessment as the only step in this process, effectively disregarding therapeutic efforts. Many gains have been made to decrease the gulf that exists between those promoting aural rehabilitation and those promoting technology; however, some clinicians are not convinced of the benefits of aural rehabilitation. Unfortunately, "aural rehabilitation has been relegated to secondary status, carrying less prestige, recognition, and awards" (Ross, 1997, p.11).

The economic influence on audiological services differs in Canada, the United States, Europe, and Australia; monetary coverage for audiological services varies to a great degree even within Canada. It is important to recognize the impact of these social and economic factors on audiologic practice. Consumerism has flourished, and the focus on selling devices has driven the evolution of audiologic practice; private and public parties pay for, or partially pay for, hearing aids as an accustomed standard. However, the development and execution of rehabilitation programs has lagged due to political and economic factors; coverage of advanced rehabilitation services are not provided by third-party insurers, and private payment is difficult for many individuals.

A Historical Perspective

The historical origins of the profession of audiology and the clinical specialty of aural rehabilitation are much more intertwined than their present day relationship would suggest. Although there were individuals working with people with hearing loss before the 1940s, the professional field of audiology in North America developed rapidly around the time of World War II (Newby & Popelka, 1992; Schow & Nerbonne, 2002), when servicemen and women who suffered serious hearing losses due to noise exposure or head injury were returning from the war. The military aural rehabilitation programs that were developed in the United States to help these individuals provided the birthplace of North American audiology (Hull, 1992), and they laid the foundation for the profession that would become responsible for the identification and measurement of hearing loss and the rehabilitation of those with hearing impairments. This new profession of audiology was first described in 1946, and Raymond Carhart, who

pioneered in the audiologic rehabilitation of WWII servicemen, helped name the profession and started the first training program for audiologists. Efforts to provide rehabilitation to individuals with hearing loss, however, have existed much longer; Pedro Ponce de León of Spain has been reported to be the first teacher of those with hearing loss as early as the 1500s (Schow & Nerbonne, 2002).

<u>Goals of Aural Rehabilitation</u>

Tye-Murray (1998, p.2) defines aural rehabilitation as "intervention aimed at minimizing and alleviating the communication difficulties associated with hearing loss". While Schow and Nerbonne's definition of aural rehabilitation is comparable, they also specify that aural rehabilitation doesn't not follow a strict medical model, but is a process "designed to counsel and work with persons who are deaf and hard-of-hearing so that they can actualize their own resources in order to meet their unique life situations" (Schow & Nerbonne, 2002, p.4).

Important considerations in the planning, application, and evaluation of the outcomes of hearing rehabilitation include both hearing loss characteristics and non-hearing-related variables. Schow and Nerbonne (2002) define the characteristics of hearing loss as the degree and configuration of impairment, time of onset, type of loss, and auditory speech recognition ability. Tye-Murray (1998) identifies non-auditory variables such as stage of life, socioeconomic status, race and ethnicity, gender, life factors, and psychological adjustment. Kricos (2000) identifies additional influential factors that might affect rehabilitation such as personality, self-efficacy, social support, health status, and motivation. Finally, Karasek and Theorell (1990) report that work conditions, such as job demands and control, as well as trends in the workplace, such as downsizing and unemployment, are related to health in general.

The goals of an aural rehabilitation program, as defined by Montgomery and Houston (2000) are presented in Table 2.1, with the accompanying time frame for action by the client. This example shows the broad variation of goals are related to emotion, attitudes, knowledge, perception, and behavior. The time course is also varied; some goals occur during the program, while others continue upon completion of the program.

Table 2.1. Goal activities of aural rehabilitation   (from Montgomery and Houston, 2000)

Goal Activities	Time Frame for Action by Client
Reducing negative emotional reactions related to communication difficulties	Long-term
Making cognitive processes and attitudes towards hearing impairment more realistic	Long-term
Increasing contextual knowledge of communication situations	Before and during rehabilitation
Maximizing auditory input through hearing aids and assistive listening devices	Before and during rehabilitation
Using assertive behavior and applying educational knowledge	Before and during difficult situation
Integrating auditory and visual input	During situation
Minimizing communication breakdown through preventative action or repair strategies	After something is missed or misunderstood

<u>A Model of Aural Rehabilitation</u>

Schow and Nerbonne (2002) present a comprehensive model for aural rehabilitation. This aural rehabilitation model, presented in Figure 2.1, is based on Goldstein and Stephens (1981), Stephens (1996a), and the current terms used by the WHO (2001). The model consists of two major components: assessment and management. The assessment procedures focus on communication status, overall participation variables, related personal factors, and environmental factors (abbreviated CORE). The four aspects of management, as defined by this model, are: counseling and psychosocial aspects, audibility or amplification, remediation of communication activity, and environmental coordination or participation improvement (abbreviated CARE). See Schow and Nerbonne (2002) for a detailed explanation of this model, and see Pichora-Fuller and Schow (2002) for its application to adults who are hard-of-hearing.

Figure 2.1. Model for audiologic rehabilitation.   (from Schow & Nerbonne, 2002, p.21)
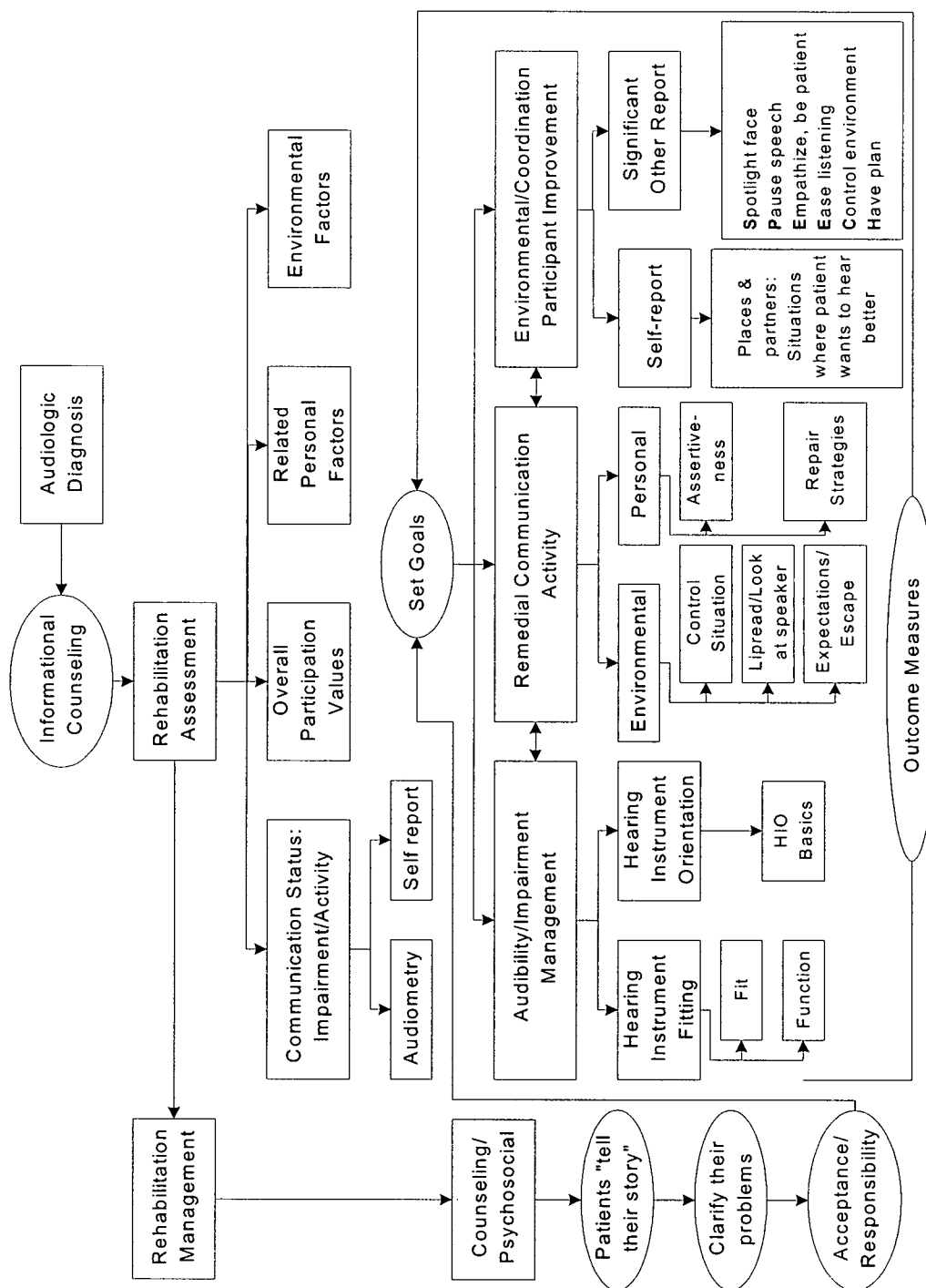
A paradigm shift has changed the starting point for rehabilitation programming; now the client begins by telling the audiologist where the most troublesome problems exist in everyday life. The relationship between the client and clinician has developed into a partnership with shared responsibilities rather than one side holding the power and making all the decisions. This process can also become a multidisciplinary experience. Because of the expanding scope of rehabilitation practice, the audiologist is no longer expected to be the ultimate expert in every area. The client may also be recognized as an expert, and referrals can be made to other professionals such as acoustic engineers, architects, marriage counselors, psychiatrists, or teachers of the deaf and hard-of-hearing.

Rehabilitative audiology does not only take place in the clinic; the significance of a client's environment has driven audiologists to work more in that environment. Group rehabilitation classes often occur in the community. Audiologists travel to places where their clients are having the most difficulty, whether that be the workplace, classroom, place of worship, or a friend's house during a bridge game. While none of these changes has come easily, the apparent relinquishing of power by the clinician or professional is viewed by many as progress toward an improved rehabilitation process, and with the client sharing the accountability for its success (Nussbaum, Pecchioni, & Crowell, 2001). In essence, the clinician is empowering the client with knowledge. This trend in audiological health care is parallel to others in the health care system (Bury, 2001).

Aural rehabilitation has exhibited growth in many areas in the past 30 years. The effect of this growth has influenced many program components; for example, the topics covered in a program have developed to include assertiveness training, counseling, and controlling the environment. The paradigm shift has brought the focus of rehabilitation to emphasize functionality and generalizability. In some respects, we have returned to Carhart's early (1946) notion of audiology.

The use of qualitative methods has shown us that important information can be obtained outside the sound booth, outside the clinic, and through questions that are neither standardized nor measured with numbers. A growing connection between audiological researchers and clinicians in the community has provided a strengthened and functionally-oriented foundation from which to collaborate and continue growing.

The power shift from clinician to client and the multidisciplinary prospects also support the substantial ongoing developments of the field (Nussbaum et al., 2001).

<u>Relevant Theoretical Models and Frameworks</u>

The Institute of Medicine (2001, p.183) recognizes that "effective programs to change individual health behavior require a multifaceted approach to helping people adopt, change, and maintain behavior." The remainder of this section will introduce a variety of theoretical models and frameworks relevant to the issue of help-seeking by adults with hearing loss.

<u>WHO Model</u>

The World Health Organization (WHO) has a mandate to develop a global language in the field of health (WHO, 1998). In 1980, the WHO developed a document, *International Classification of Impairments, Disabilities, and Handicap* (ICIDH) (WHO, 1980), which served to define the 'consequences of disease'. This document provided a means to categorize and describe the variety of experiences reported by individuals dealing with impairments, and it was developed as a complement to WHO's document, ICD, *International Classification of Disease* (WHO, 1992). The ICD classifies health conditions but does not acknowledge the experiences of the people who live with the conditions on a day-to-day basis; unlike the disease model of the ICD, the ICIDH has a biopsychosocial approach.

The ICIDH is cast in terms of three inter-related components/concepts: *impairment*: the loss or abnormality of a biological structure or function; *disability*: the resulting restriction or lack of ability to perform an activity; and *handicap*: the social disadvantage experienced by an individual with an impairment. In hindsight, we are aware of the shortcomings of this trio of concepts as defined in 1980. Figure 2.2 illustrates that the relationship between these concepts may be interpreted as representing causality and indicating a change over time, in a simple, unidirectional, linear progression. This representation does not provide information on the factors modulating relationships between the concepts, nor does it reflect the role of social and physical environments in the difficulties experienced by the person with the impairment. We now appreciate that the consequence of impairment is much more complicated.

Figure 2.2. The disablement phenomena as depicted in ICIDH in 1980.   (WHO, 1980)
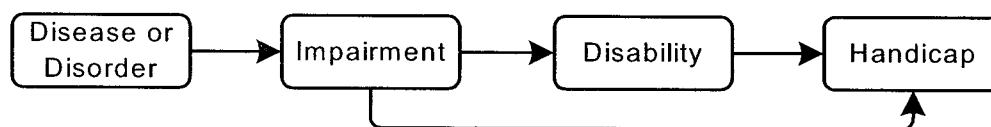
These limitations were addressed in a more recent document. Significant changes have been introduced to the revised document, *International Classification of Impairments, Activities, and Participation, ICIHD-2* (WHO, 1998), though its main purpose remains to provide a description of actual human functioning while still complementing the medically-oriented ICD. While ICIDH provided definitions of impairment, disability, and handicap, ICIDH-2 (WHO, 1998), and most recently the ICF, *International Classification of Functioning, Disability, and Health* (WHO, 2001), defines three levels of functioning in the context of a health condition: impairment, activity, and participation. These terms provide a framework for understanding the dimensions of disablement (negative aspect) and functioning (positive aspect) at three different levels: body, person, and society. "*Impairment* is a loss or abnormality of body structure or of a physiological or psychological function"; "An *activity* is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration, and quality"; and "*Participation* is the nature and extent of a person's involvement in relation to impairment, activities, health conditions, and contextual factors. Participation may be restricted in nature, duration, and quality." (WHO, 1998, p.8)

The most obvious difference between the ICIDH and the ICF is the switch from disability to activity and from handicap to participation. Figure 2.3 helps to identify other changes. "The interaction is complex, bi-directional, and dynamic. The model does not posit a causal linkage between the three dimensions of disablement; rather, at each level, disablement occurs within and by means of contextual factors." (WHO, 1998, p.7)

Figure 2.3. Model of the ICF.   (WHO, 2001)
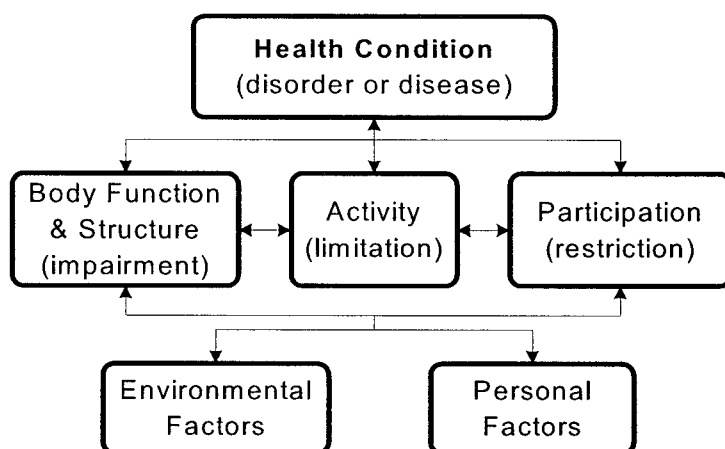
ICF was developed on the foundation of a bio-psycho-social model, which emphasizes universality; it is applicable to all people, irrespective of health condition. While a medical model views disablement as a personal problem that requires professional intervention, the social model views disablement from the viewpoint of integration of persons with disability into society. As a result of the inclusion of the social model, environmental and personal contextual factors have been included in the revised version. The environmental factors include social and physical elements such as social attitudes, architectural designs, legal and social structures, climate, and terrain. The personal factors include such things as gender, age, other health conditions, coping styles, social background, education, profession, past and current experience, overall behavior pattern, and character style. These factors can be used to identify environmental barriers and facilitators that affect participation levels (WHO, 1998). While these factors may be applied to hearing loss, they are applicable to all health conditions.

Other changes in the new version of the ICF are less evident. Impairments of structure and impairments of function are now classified separately. However, disablement is not differentiated by etiology; there should be no difference, at the activity or the participation levels, between physical and mental health conditions. All definitions are now operationally defined and judgments are based on what a person does as opposed to what they may be able to do; the basic attributes, boundaries, and measurement characteristics of the concepts are provided. A neutral language has

been used while retaining the ability to express both positive and negative aspects of each dimension (e.g., complete participation versus participation restrictions). The distinction between disability and handicap from the previous model is more explicit than the difference between activity and participation; the distinction of consequence of a health condition at the person versus the society level is blurred. Finally, the ICF was developed to support the concept of universality. The classifications are applicable to all people; it is not a means to specifically label people with disablements (WHO, 2001).

The evolution of the proposed consequences of a health condition, from the ICIDH to the ICF, has provided fuel for the revolution in aural rehabilitation. The ICF demonstrates the significant impact of, and the need to address, the environmental and personal factors of the consequences of a health condition. This impact, along with the notion of participation and participation restrictions, directly relate to the goals of aural rehabilitation and the decision to seek help. Empirical research has shown that environmental and personal factors affect the degree to which hearing impairment impacts an individual. The acknowledgement of limitations and restrictions is relevant, since these are the factors that represent the true measure of the impact of hearing loss. The shift from impairment to a more ecological approach to health care has provided impetus for the change from the focus on treatment and cure to that of management and care (Bury, 2001).

Determinants of Health

The acknowledgement of the varied determinants of health by the WHO models was preceded, for example, by the Lalonde report in 1974. This report suggests the importance of lifestyle and individual behavior as necessary targets of health interventions. Evans and Stoddard (1990) developed a model of the determinants of health (see Figure 2.4). This model demonstrated that behavior is not merely a personal choice but is shaped by multiple forces. Health and behavior are influenced by biological, psychological, and social factors, and the success of healthy interventions depends on the integration of these factors (Institute of Medicine, 2001). This model is relevant to the current research; the determinants of health and the influence of these factors might provide insight into the factors that prevent or promote help-seeking.

Figure 2.4. A model of the determinants of health.   (from Institute of Medicine, 2001, p.25)
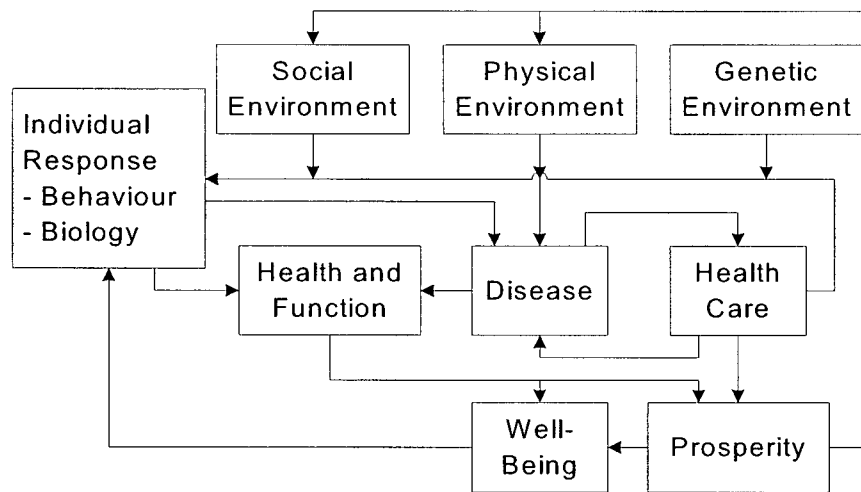
Such ideas are consistent with an ecological approach to health and behavior; the notion of ecological audiology will be revisited later in this chapter. The importance of the characteristics of the individual and his or her environment is anticipated in the theoretical models presented here.

<u>Health Belief Model</u>

There are various models that attempt to explain health beliefs. One of the earliest theoretical models developed for understanding health behaviors was the health belief model (HBM), which focuses on people's beliefs about health threats and the costs and benefits of health behavior (Becker, 1974; Becker & Maiman, 1975). Figure 2.5 presents an interpretation of the HBM. This model was developed in the 1950s in an effort to explain the lack of certain health-related behaviors to prevent or detect disease. Perceived susceptibility and severity provide motivation for adopting a health-promoting behavior, while the action taken depends on perceived benefits and barriers. The negative aspects associated with that behavior are weighed against the effectiveness of the behavior (Institute of Medicine, 2001). The significance of the HBM to the current study can be demonstrated by the potential applications of the model, as suggested by Porter and colleagues (1999, p.54); they identify key applications of the HBM as "identifying health promotion targets at individual and population levels, identifying those least likely to comply with medical treatment or advice, and understanding why some

people put their health at risk". The components of the HBM and the essence of action addressed by the model are directly related to the process of help-seeking.

Figure 2.5. Health Belief Model. (from Porter et al., 1999)
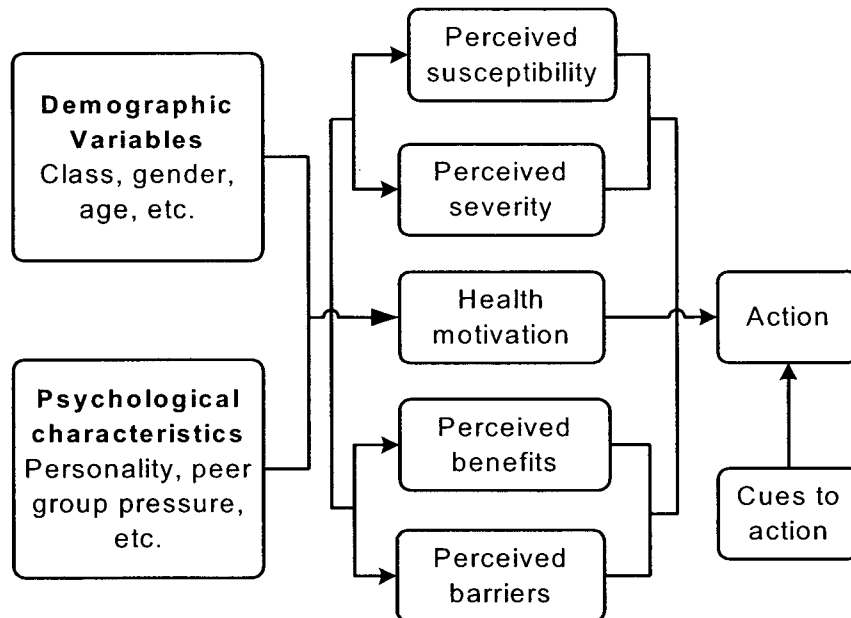
Other theories are also potentially relevant to the current study, through their relation to behavior change, coping, and adaptation, and these theories are reviewed below.

Social Learning Theory

While learning theory proposes that reinforcement is the sole determinant of behavior, cognitive social learning theory (Bandura, 1986) acknowledges that behavior also changes by observing others. Social learning theory places considerable importance on the environment, and other people constitute the most important aspect of the environment. Another important component of this theory is self-efficacy, or the belief that you are capable of making necessary behavioral changes to create a desired outcome (Institute of Medicine, 2001). Bandura explains self-efficacy as:

> "...not simply inert estimates of future action. People's beliefs about their operative capabilities function as one set of proximal determinants of how they behave, their thought patterns, and the emotional reactions they experience in taxing situations. Self-beliefs thus contribute to the quality of psychosocial functioning in diverse ways. In their daily lives people have to make decisions all the time about what courses of action to pursue and how long to continue what they have undertaken. Decisions

involving choice of activities and certain social milieus are partly
determined by judgments of personal efficacy. People tend to avoid tasks
and situations they believe exceed their capabilities, but they undertake
and perform assuredly activities they judge themselves to be capable of
handling. Any factor that influences choice behavior can have profound
effects on the course of personal development. Advantageous self-
percepts of efficacy that foster active engagement in activities contribute
to growth of competencies. In contrast, perceived self-inefficacies that
lead people to shun enriching environments and activities retard
development of potentialities and shield negative self-percepts from
corrective change. Reasonably accurate appraisal of one's own
capabilities is, therefore, of considerable value in successful functioning."

(Bandura, 1986, p.393)

Social Comparison Theory

Although Festinger (1954) first used the term 'social comparison', research regarding
comparison processes has a history spanning many decades (Buunk, Gibbons, & Reis-
Bergan, 1997; Hyman, 1942; Sherif, 1936). Leventhal, Hudson, and Robitaille (1997,
p.411) observe that:

"social comparison theory was originally based on a fairly simple
assumption: In times of uncertainty, when other means for objective
evaluation are lacking, individuals compare themselves to similar others to
evaluate their own opinions and abilities".

Downward comparisons involve comparisons with others in similar circumstances
who are doing worse on the compared dimension, with the purpose of feeling better
about oneself. Upward comparisons are comparisons with others thought to be doing
better. There is some debate in the literature regarding the purpose of, and the
expectations associated with, these comparisons. Taylor and Lobel (1989) discuss the
direction of social comparison under stress. These authors believe that a comparison
with others who are coping well with their problems (upward comparison) may serve to
improve the current situation by providing ideas for positive coping, providing hope,
motivation, and inspiration, and enhancing the person's sense of self-efficacy; this style
implies problem-focused coping. Alternatively, individuals may also use downward
social comparisons as a means of emotion-focused coping, and as an effort to alleviate
negative emotions. By comparing the self to others seen as worse off helps the
individual feel better about him or herself. Coping styles will be discussed later in this
chapter.

Leventhal et al. (1997) propose that social comparison is a process rather than a trait; the role of social comparison is determined by the individual's motivation in each specific situation. The re-emergence of the ecological theme is present here in that social comparisons are compatible with the ecological perspective. The construct of social comparison is relevant to the current study because participants were studied with respect to involvement in a group hearing rehabilitation program. Buunk, Gibbons, and Reis-Bergan (1997) report that social comparison helps to explain the popularity of support groups; individuals under stress often prefer contact with others with similar issues and experiences. These individuals appear to be effective at providing social support, and participation in these groups "reduces feelings of uniqueness or deviance" (Buunk et al., 1997, p.7).

In addition to the group experience, social comparisons also play a role in the decision to seek help for medical problems from relatives, friends, and acquaintances (Suls, Martin, & Leventhal, 1997). People need accurate assessments of their abilities and they find uncertainty disconcerting. Before seeking medical help from a professional, an individual might seek information from their lay network to explore if there is a problem, if the problem is serious, and if professional intervention is required.

Transtheoretical Model

The transtheoretical model, or stages of change model, was proposed by Prochaska and DiClemente (1986). The model is based on three dimensions of change: level of change, stage of change, and process of change. This model entails a series of steps that people take through change. The earliest step, precontemplation, recognizes that people may be uninterested or unwilling to change. Contemplation, a step where people are considering a change, is followed by preparation, the decision to take action, and then the step of action. The stage labeled maintenance is the final step in the process. Erdman (2000) describes that:

> "readiness for change consists of a decision-making process that is driven by shifts in balance between the individual's perceived pros and cons of changing behavior."

This model provides a guide for the appropriateness of strategies based on an individual's current placement in the model. For example, cognitive interventions targeted to encourage changes in attitude are more appropriate during the

precontemplation and contemplation stages (Prochaska, Velicer, DiClemente, & Fava, 1988). This process of change and the stages identified in this model might be relevant in distinguishing between those who choose to seek help through group hearing rehabilitation programs and those who do not.

<u>Coping and Adjustment</u>

The concept of adaptation was the cornerstone of Darwin's theory of evolution and the survival of a species (1859). This biological concept has been borrowed by psychology and "renamed *adjustment* to emphasize the individual's struggle to get along or survive in his or her social and physical environments" (Lazarus, 1976, p.3). There are a large number of models designed to describe the process of coping. Lazarus and Folkman (1984) define two categories of coping as problem-focused and emotion-focused. Moos (1986) adds a third category of coping: appraisal-focused. The strategies attributed to each of these categories are presented in Table 2.2. Problem-focused coping responses are directed at the cause of the stress, while emotion-focused coping are directed at regulating stress. Gathering information and solving problems are problem-focused, but avoiding problems is emotion-focused. Adams and Bromley (1998, p.104) interpret Moos' adaptive tasks for appropriate coping as:

> "establish meaning and significance of the situation, confront reality, sustain healthy relationships, maintain a reasonable emotional balance, and preserve a satisfactory self-image"

Table 2.2. Categories of coping and their related strategies   (from Adams & Bromley, 1998, p.103)

Categories of Coping	Related Strategies
Problem-focused	Actively confronting problems and dealing with the consequences e.g., advice, information, feedback on progress
Emotion-focused	Developing skills for the management of feelings e.g., denial avoidance, relaxation therapy, humor
Appraisal-focused	Developing skills to modify and comprehend the threat of a situation

Individuals choose to cope with hearing loss in a variety of ways, and coping choices may be situation-dependent. Problem- and emotion-focused categories of coping behaviors have been documented as a means of dealing with hearing loss (Hallberg & Carlsson, 1991), and choice of coping style may relate to the reaction to hearing loss and the decision to seek help.

This section reviewed existing theoretical models that are relevant to the current study. The ICF model (WHO, 2001), the determinants of health model (Evans & Stoddard, 1990), and the health belief model (Becker, 1974; Becker & Maiman, 1975) provide an understanding of health-related behavior necessary for the further understanding of help-seeking behavior. The social learning theory (Bandura, 1986), the social comparison theory (Festinger, 1954), and the HBM (Becker, 1974; Becker & Maiman, 1975) provide an understanding of why individuals might invest in help-seeking behavior. Finally, theories relating to coping and adjustment by Lazarus and Folkman (1984) and Moos (1986) suggest how individuals might cope with difficult situations. The following section introduces relevant theories related to the concept of identity.

The Identity Perspective

Hearing loss has many implications at the level of the person. Goffman (1963) reviews the origins of *stigma* from early Greek and Christian times as signs to show a difference in moral status, signs of holy grace, or more recently, as bodily signs of a physical disorder. The modern meaning of stigma refers more to the disgrace than to the bodily evidence of difference. Goffman explains that we have anticipations of people that have become normative expectations, and we give people a *normative social identity*. Individual character traits determine a person's *actual social identity*. When a discrepancy between these two identities exists, there is "a stigma…a failing, a shortcoming, a handicap" (Goffman, 1963, p.3). However, an important distinction is whether the individual believes that others see or do not see the difference- whether his differentness is evident to others (*discredited*) or not (*discreditable*).

> "This discrepancy, when known about or apparent, spoils his social identity; it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world."
> (Goffman, 1963, p.19)

Goffman's interpretation of stigma has been studied in relation to hearing loss. Hétu (1996) examines the stigma attached to hearing loss and reports that the experience of hearing loss is a threat to a person's social identity. Hétu identifies the impact of the stigma attached to hearing loss and addresses its significance for rehabilitation. Stigma exacerbates handicap and is a major obstacle to rehabilitation insofar as accepting hearing loss is a prerequisite to rehabilitation. A possible goal of rehabilitation is normalization, or restoring the social identity of those with hearing loss. Social, cultural,

and psychological factors of normalization must be considered for each individual, as social interactions are idiosyncratic. Danermark (1998) argues that fear of losing face is crucial in interaction and that shame is an important emotion. Danermark believes that emotional problems, which are personal but have a significant social dimension, are one of the most serious consequences of hearing loss and should receive explicit attention in rehabilitation programs.

The concepts of stigma and personal identity enter into a discussion of a *hard-of-hearing identity*. People who are hard-of-hearing are often compared with Deaf people, who exhibit a very strong sense of identity. Does a similar identity exist for those with hearing loss? Laszlo (1994) addresses this topic through a discussion of awareness on the part of the hearing world and on the part of those who are hard-of-hearing. These levels of awareness have a direct impact on coping and social integration, but there is generally little visibility and general social awareness or understanding of people with hearing loss. Laszlo questions the hearing world's awareness with two questions: How many people are aware that people who are hard-of-hearing can be found in all age groups, in all walks of life, in varied occupations, professions, arts, and sciences? How many people are aware of the psychological and social problems of being hard-of-hearing? He reports that:

> "As a rule, hard-of-hearing people attempt to cope with the hearing world on its own terms. Work, education, family life, and the whole range of human interaction rely heavily on the spoken word, and more generally on the acoustical world. Thus hard-of-hearing people must make a tremendous effort to adapt to ever changing acoustical, technical, and communication circumstances; they must also overcome the barriers and obstacles that result from incomplete comprehension of the spoken word and incomplete contact with the acoustical world." (Laszlo, 1994, p.249)

Awareness on the part of the people with hearing loss is also crucial. The person with hearing loss must realize that there are other individuals who share the same experience. Laszlo also outlines four requirements on the part of the person who is hard-of-hearing in assuming personal responsibility, which is necessary for acceptance of the loss and maintenance of a fulfilling life: obtaining knowledge regarding hearing loss and maintaining realistic rehabilitation goals, participating actively in rehabilitation, taking responsibility for one's own health, and becoming familiar with technological aids. Regarding the existence of a hard-of-hearing identity, Laszlo believes the degree of difficulty, as well as personal success of coping with hearing loss, affect the feeling of

'community'. While a defined identity would have some practical benefits, the lack of a common identity that exists for the group complicates efforts to change the awareness, perceptions, and consequences of hearing loss on the part of members of society in general. An identity exists in the sense that there is a group whose difficulty with an acoustical word unites them; however, it is important to recognize that these individuals are not defined by their hearing loss.

Bury (2001, p.269), through a discussion regarding illness narratives, defines two broad concepts of disease and illness, which are relevant to this discussion of identity:

> "On the one hand there is a categorical view of illness based on the separation of the normal and the pathological, where objective signs and symptoms are differentiated from known or putative normal states, and where the onset and course of the disease is relatively clear-cut. On the other hand there is the spectral view in which the difference between disease and illness is a matter of degree and a function of social process; the occurrence of illness, especially chronic illness, is here essentially emergent in character, depending strongly on social circumstance and societal reaction."

Bury also distinguishes between two reactions of an individual to illness. A person may try to "normalize" by retaining a pre-illness lifestyle and identity. Alternatively, a person may incorporate the illness into a changed lifestyle. "Normal life is redesigned as containing the illness and being open about it." (Bury, 2001, p.272)

This section has introduced the concept of identity, through the work of Goffman (1963), and related the concept of stigma to the experiences of individuals and groups who are hard-of-hearing. The following section expands on this view to one that incorporates the environment for a more ecological understanding.

The Ecological Perspective

Many of the theoretical models and frameworks presented here have migrated from a more individualistic, decontextualized view to a more ecological view, acknowledging the influence of the environment, both social and physical, on personal well-being. For example, the WHO models (WHO, 1980; WHO, 2001) have evolved from a linear and restricted representation of the consequences of a health condition to an interactive bio-psycho-social approach, which includes the environment and personal factors as key contributors to the experience of a health condition. Daysh (1999, p.xv) states, "Health ecology, assessed in all its meanings, highlights health, which at all times provides a

penetrative and influential thread". For a comprehensive discussion of health ecology, see Honari and Boleyn (1999).

The concept of ecology has also been discussed from an audiological perspective; Borg (1998) recognizes that audiological rehabilitation and handicap have used 'ecology' as a metaphor for analysis (e.g., Foster & deCaro, 1991; Noble, 1983; Noble & Hetú, 1994). Noble (1983) contrasts the physiological aspect of hearing loss to an ecological one, where hearing is considered in terms of its day-to-day characteristics. He suggests an accessibility focus of rehabilitation:

> "Rehabilitation could come to mean not the reinduction of the stigmatized into the 'normal' world but the expansion of the normal world to accommodate a larger variety of humans" (Noble, 1983, p.325).

Pichora-Fuller (1994, p.210) also promotes an ecological viewpoint when she suggests:

> "We need to understand how the handicap experienced by individuals and by groups is modulated by context: physical context, psychological context, institutional context, and social context. Ultimately, we need to discover ways to manipulate these contexts to reduce handicap experienced by individuals and groups. This goal would supplement or perhaps even replace the more typical goal of clinicians to reduce the handicap experienced by individuals by treating the individual in isolation."

Borg (1998) presents an independent approach to ecological audiology and presents a conceptual framework for describing a handicap resulting from hearing loss in an analogy to a biological ecological system. Generally, Borg describes an ecological system to be continuously subjected to forces that create an imbalance in the system. An increase of energy or new material in the environment can re-establish balance, as can a change in the system and a re-evaluation of preferences. The primary concepts of Borg's system are interaction, resource optimization, internal milieu, and preferendum, or preferred environment, while the secondary concepts are behavior, signal, and message. (For a comprehensive explanation, see Borg, 1998). His framework is founded in the traditions of biological ecology, and it tries to bring together the internal and external environments. Essentially, perceived communication ability is compared with desired communication ability; if these signals are equal, the system is in balance. However, a difference in these signals creates a handicap and induces a mental response. These processes may lead to motivation or compensation in order to

regain balance within the system. This mental response, e.g., feeling of failure, loss of confidence, or anger, is influenced by numerous factors such as interaction, recycling, optimal use of mental resources, and the preferred environment. Borg refers to the cause of the problem as *etiological audiology*, understanding the consequences of the hearing loss and the influence on ability of the individual with hearing loss as *ecological audiology*, and the goal to re-establish balance in the system as *therapeutical audiology*.

This previous section demonstrates, using existing conceptual frameworks (e.g., Borg, 1998), the importance of an ecological perspective in understanding help-seeking behavior. The following section will describe the consequences of hearing loss, personal and social, from the empirical literature in audiology.

Empirical Background

The Impact of Hearing Loss

Revisiting the consequences of a health condition, as introduced in the WHO model (WHO, 1998), recall that there are categories relating to body, person, and society. The *impairment* is categorized by the reduction of auditory function at the body level. *Activity or activity limitation* concerns consequences at the person level; *activity* refers to what a person does, from simple activities to complex skills and behaviors. *Activity limitation* refers to a difficulty at the level of the person, and this concept was formerly referred to as disability. *Participation* is the interaction of impairments, activity limitations, contextual factors, and personal factors at the level of society. *Participation restriction* is a disadvantage at this societal level; it can be affected by contextual factors, and this concept was formerly referred to as handicap. This section will present the empirical findings concerning hearing loss as they relate to the body, personal, and social levels.

From Impairment to Handicap

An early belief of some audiologists was that degree of difficulty adjusting to a hearing loss could be determined by the degree of impairment, with the measure of impairment being the cornerstone of rehabilitative measures. Oyer and Frankmann (1975) reported that even though handicap would vary among individuals, handicap measures correlated highly with pure tone audiometry. However, Hull (1992) later

pointed out that though audiometric data provide important information for understanding a client's problem, the audiologist must be aware of the limitations of the measures; he suggested that it is difficult to generalize from formal testing to the everyday experiences of the individual.

The awareness that impairment did not reliably predict handicap led to the development of questionnaires for the assessment of communicative function as promising new tools to estimate degree of disability and handicap. There is a long list of such questionnaires including the Hearing-Handicap Scale (HHS) (High, Fairbanks, & Glorig, 1964), the Denver Scale of Communication Function (Alpiner, Chevrette, Glascoe, Metz, & Olsen, 1978), the Hearing Performance Inventory (HPI) (Giolas, Owens, Lamb, & Schubert, 1979), the Self-Assessment of Communication (Schow & Nerbonne, 1982), Hearing Handicap Inventory for Adults (HHIE) (Newman, Weinstein, Jacobson, & Hug, 1991), and the Communication Profile for the Hearing Impaired (CPHI) (Demorest & Erdmann, 1987). Some of these scales stress the attitudes of those who are hard-of-hearing while others focus on communication environments; age-specific questionnaires also sought to help to identify problem areas experienced by particular groups, for example the Hearing Inventory for the Elderly (Ventry & Weinstein, 1982). Noble (1998) provides a comprehensive review of self-assessment tools related to audiology.

While these questionnaires may be an improvement from assuming that individuals with similar impairments would experience similar handicap, there are also shortcomings of this approach. It is rare for questionnaires to adequately capture the communication difficulties experienced by an individual due to the pre-defined problems identified by the questions, and real-life priorities remain unidentified. As well, it is dangerous to assume that such handicap scores reflect coping abilities or rehabilitative goals (Dillon Edgett, Lamb, Roodenburg, Pichora-Fuller, & Johnson, 1998). Lormore and Stephens (1994) also reported that subtle but sometimes important difficulties were missed on standard disability/handicap questionnaires based on speech perception disability.

Activity

Hearing impairment has been shown to affect individuals and introduce difficulty at the level of the person. Eriksson-Mangold and Carlsson (1991) discuss the

psychological and somatic distress related to perceived hearing handicap; perception of handicap correlates to a general level of distress, particularly feelings of insecurity. These authors suggest that stress reactions could be induced by a perceived loss of control resulting from insecurity and reduced hearing ability. These findings are consistent with earlier findings of Eriksson-Mangold and Erlandsson (1984), who reported that normal hearing individuals with induced hearing loss (through temporary occlusion) reported tension, stress, feelings of insecurity, and loss of control of the situation. Depression (Gilhome Herbst, Meredith, & Stephens, 1990), isolation, acceptance, anxiety, awkwardness, worry, fear, and embarrassment (Tye-Murray, 1998) are also reported to result from hearing loss.

Luey, Glass, and Elliot (1995) address the issue of culture and the group identity of hard-of-hearing versus Deaf individuals from a social work perspective. Through a series of interviews, these authors determined that self-definition as deaf, Deaf, deafened, hard-of-hearing, or hearing-impaired, is a complex issue involving not only level of hearing ability, but also communication, language, culture, and politics. The implications for social work are described; for example, the primary goal for social workers is to establish a way to communicate based on what the client knows and prefers. Depending on the circumstances, this might mean finding a quiet, well-lit place to talk, having a notepad to write key words, or providing a professional interpreter.

This section provides evidence of the consequences of hearing loss on the individual. It is also important to acknowledge the consequences of hearing loss on individuals within their context, and the next section addresses these socially interactive consequences.

Participation: Home

The social implications of hearing loss are far-reaching, from community to occupational, and from intimate to familial. The acknowledgement of the effect of the environment on the person with hearing loss has led to a greater understanding of the impact of hearing loss. Research findings also show that hearing loss impacts not only the person with the impairment, but also those who interact with him or her.

Jones, Kyle, and Wood (1987) emphasize the importance of social interaction and discuss the effect of mild and moderate hearing loss and coping with hearing loss in the context of relationships. Myers (2000) also acknowledges the problems faced by those

who are hard-of-hearing at home and at work. He recognizes that family and friends of those with hearing loss also face adjustments. Luterman (1999) advocates a true family-centered rehabilitative approach that addresses emotional aspects of hearing loss, as he recognizes the effect of hearing loss on the family. Through questionnaire administration to patients and their significant others, Stephens, France, and Lormore (1995) found that, while individuals with hearing loss reported problems of dependence, the significant others concentrated more on difficulties with live speech and psychosocial difficulties. A similar approach by Lormore and Stephens (1994) found that significant others reported more problems relating to loudness of the television and radio and to psychosocial aspects of hearing loss, such as withdrawal and unsociable behaviors, than the individuals with hearing loss. Pichora-Fuller and Carson (2001) recognize that the acoustic ecology of family and friends is altered along with that of the individuals who are hard-of-hearing.

The impact of hearing loss on intimate relationships and the resulting coping process were studied by Hétu, Jones, and Getty (1993); the results identify needs for each partner regarding information, support, and communication facilitation. Consideration from both perspectives is important because both the hearing and the individuals with hearing loss are experiencing the hearing loss, but they view the problem from different perspectives.

Erdman (2000) suggests that clinicians can help ease tension by providing information about hearing impairment, evaluating the disparate views of participating parties, identifying common ground, and offering potential explanations for the different experiences. Group counseling can provide the opportunity for couples to observe that other families struggle with similar issues. Hallberg (1996) and Abrahamson (1991) believe that spouse or family involvement is vital to the success of audiological rehabilitation programs. Erber has developed rehabilitative methods to provide therapy for both the individuals with hearing loss and their communication partners (Erber, 1988, 1993).

Participation: Work

Hearing loss affects individuals in their occupational environment. Kyle and Wood (1985) found that the vocational consequences of acquired hearing loss include greater anxiety, fewer promotion opportunities, and reduced participation with group work

activities. Hétu, Getty, and colleagues report that hearing loss is often concealed and demanding situations are avoided, imposing self-restriction on career advancement (for example, see Getty & Hetú, 1994; Hétu & Getty, 1993; Hétu, Riverin, Getty, Lalande, & St-Cyr, 1990). Industrial workers report themselves to be strongly stigmatized as being deaf especially by co-workers, and their reluctance to acknowledge hearing difficulties was expressed through various forms of denial, minimization of the problem, uneasiness in talking about the problem, and in attempts to normalize the self. These occupational implications of hearing also affect those at home. Hétu, Lalonde, and Getty (1987) discuss the effect of occupational hearing loss on the individual with hearing loss, and report that the family experiences consequences of noise exposure and of the hearing loss of the worker. There is also evidence that many employees with hearing loss have difficulty coping with full-time employment (Backenroth & Ahlner, 1997); this study also indicated that the occupational implications of hearing loss are mainly associated with social interactions with others in the workplace.

This section has introduced evidence of the consequences of hearing loss on a participation level. The following section introduces the findings of existing help-seeking literature relevant to the current study.

Help-Seeking

There have been studies that examined help-seeking for hearing loss. Many of these studies focus on the elderly population and its initial consultation for a hearing loss or obtaining a hearing aid. Where a person is in terms of adjustment to hearing loss is an important consideration. Tye-Murray (1998) reports that Jones, Kyle, and Wood (1987) identified four phases in the time course of acquired hearing loss: pre-hearing loss onset, onset of hearing loss, diagnosis, and adjustment. Regarding the first phase (pre-hearing loss), few people anticipate a hearing loss and it is usually a surprise when it begins. The time from onset to diagnosis can extend for a lengthy period of time (for a review, see Carson, 2000); during this time many individuals blame the speaker and environmental factors for their inability to communicate as they used to. At this point, many individuals will discuss the issue with others close to them, as described above in the discussion of social comparisons. In the third stage, diagnosis, a professional identifies and diagnoses the hearing loss. Anxiety is a common reaction at this stage; however, the length of time during which a hearing loss was suspected may mediate

these negative emotional reactions (Tye-Murray, 1998). In the final stage of adjustment, individuals adapt to hearing loss. This adaptation may result from counseling, hearing aids, assistive devices, or behavioral rehabilitation. Tye-Murray also recognizes the monetary and non-monetary costs related to the adjustment phase; in addition to the cost of the amplification device, transportation, lost wages and other monetary issues, 'psychic' costs include: acceptance, anxiety, awkwardness, worry, fear, and embarrassment. Psychosocial well-being and vocational status are other issues of importance relative to the adjustment phase (McCormick et al., 1994).

van den Brink, Wit, Kempen, and van Heuvelen (1996) examined attitude and help-seeking for hearing impairment. Their research, which focused on elderly subjects, found that those who did not consult for hearing loss perceived their impairment as inconsequential, demonstrated a passive acceptance of the loss with increasing age, and experienced little pressure from others to seek help. Individuals who consulted a doctor but did not obtain amplification reported the greatest stigma-related barriers to the use of hearing aids. Finally, van den Brink and colleagues reported that the most favorable attitude toward hearing aids was obtained from those individuals currently using hearing aids.

Gilhome Herbst, Meredith, and Stephens (1990), who also focus on elders, report that the social implications of hearing loss affect help-seeking activity; poor insight into the existence of hearing loss, denial of the loss, lack of support from doctors, and reduced activities out of the home affected the desire to obtain help. Mahoney, Stephens, and Cadge (1996) reported that few clients were self-motivated to seek help for hearing loss; more often, the persuasion of a family member was the impetus for help-seeking, especially for senior participants. Parker (2001) studied the effects of cost, need, and relationship strength on help-seeking; results indicate that optimal help-seeking conditions exist when the cost to the potential helper is low, the need of the potential help-seeker was high, and the relationship between the seeker and provider was strong. These conditions lead to a more direct course of help-seeking and greater likelihood of the help-seeking behavior.

Lalande, Riverin, and Lambert (1988) describe a trial rehabilitation program designed specifically for workers with occupational hearing loss and their spouses, including a consideration of the factors causing clients to seek or avoid professional assistance. Questionnaire results indicated that the main factors leading to enrollment in the

program were acknowledgement of a significant handicap, recognition of need for help with tinnitus and stress, and need to use strategies to facilitate communication. Lalande and colleagues recognized a low enrollment in the program and suggest that for this population of employees with noise-induced hearing loss, there is a need for:

> (1) A more well defined target population,
> (2) Strategies to promote greater understanding, awareness, and acceptance of hearing handicap on the part of occupational hearing loss workers and people surrounding them,
> (3) Education at the work place and in society in general to increase motivation and awareness of the benefits of aural rehabilitation services,
> (4) Integration of the program within the general health program in the work place,
> (5) Measures to enhance the credibility of professionals in the rehabilitation services,
> (6) General and specific programs and follow-up services, and
> (7) More accessible services. (Lalande et al., 1988, p.248)

This section reviewed the help-seeking literature as it has been studied regarding help-seeking for hearing loss. This work provides an important foundation for the current study, but shows that additional research is needed to fully understand the help-seeking behavior for individuals who are hard-of-hearing, particularly regarding participation in group hearing rehabilitation programs.

Qualitative Research

Methodological considerations relevant to the current study will be discussed in Chapter 3. This section will review qualitative studies relevant to this research study.

A limited number of qualitative studies have been conducted in the audiological arena; however, those qualitative studies have provided valuable insights into the experience and meaning of hearing loss. Hétu, Getty, and colleagues at the University of Montreal have conducted a series of qualitative studies that attempt to understand the experience of workers with occupational hearing loss (Getty et al., 1996; Getty & Hetú, 1994; Hetú, Getty, & Wridel, 1994; Hétu et al., 1993; Hetú, Riverin, Lalande, & St.-Cyr, 1988); this work concentrated primarily on a phenomenological approach. In an effort to determine if there is a culture of hard-of-hearing workers, Getty and Hétu (1994) concluded that this culture does not exist due to the reluctance to disclose hearing loss. This study also suggested that stigma determines the level of coping and that the support of the spouse is vital in the process of problem solving.

A group from Sweden has studied hearing impairment, hearing handicap, coping, and the consequences of hearing loss on family life (Hallberg, 1999; Hallberg & Carlsson, 1991, 1993), using primarily grounded theory methodology. Hallberg and Carlsson (1991) described coping from the perspective of their participants who were hard-of-hearing. Two patterns emerged from the data to reflect qualitatively different management patterns: control the social scene and avoid the social scene. Controlling the social scene was seen as an active and constructive way of handling difficult listening situations and captured the qualitative categories of structuring the situation, controlling the environment, striving to maintain interactions, and using both verbal and nonverbal strategies. Avoiding the social scene referred to strategies such as avoiding interactions, minimizing the disability, and using invisible non-verbal strategies. This avoidance was interpreted as a means to maintain a normal social identity. Individuals adopt a variety of coping strategies but appear to have a preference for either controlling or avoiding behaviors.

Hallberg and Carlsson (1993) described the nature of stressful situations, from the point of view of their participants with hearing loss, to gain an understanding of the handicap creation process. The findings revealed eight categories of qualitatively different situations where disability turned into handicap. These categories could be grouped into two concepts: situations related to the environment and situations related to life habits. These concepts were believed to interact with the hearing impairment to create handicap. Hallberg (1999) summarized the earlier studies, discussed the consequences of hearing loss on the spouse, and integrated the findings into a family perspective on rehabilitation.

A small number of qualitative studies have also examined the experience of participants in aural rehabilitation programs. Israelite and Jennings (1995) explored the perspectives of four adults regarding their experience of hearing loss in a group rehabilitation program. The major theme to emerge from these data was that of adjusting to hearing loss and the categories were: *identifying as hard-of-hearing, becoming aware, losing control of communication, communication strategies, perceptions of the group experience,* and *accepting hearing loss.* These authors report evidence of long-term and short-term adjustment as well as issues of control. Furthermore, Backenroth and Ahlner (2000) reported on the quality of life post-rehabilitation program. Results demonstrated increased awareness of the hearing loss,

increased demands on others to understand, and influence on attitude regarding the hearing impairment. Participants reported increased self-confidence and an increase in comfort in the use of coping strategies and hearing aid usage.

Getty, Gagné, and McDuff (1996) described the problems related to seeking help for hearing loss with seniors, and identified many personal and social issues as obstacles to help-seeking. Recently, Carson (2000) explored the perspectives of older women and the links between the experience of living with a hearing loss and the process of help-seeking in terms of making an initial appointment with an audiologist. Many people who are hard-of-hearing wait years before taking the first step to deal with a hearing loss and subsequently, may wait longer to take further action based on the hearing test results. The findings of Carson's study indicate that a self-assessing process occurs before, during, and after seeking help. Three themes were identified as significant in this process: *contrasting and comparing hearing against a variety of yardsticks*, *performing cost versus benefit analyses*, and *perceiving a loss of control related to help-seeking efforts*. This study represents an important contribution to the understanding of help-seeking of people who are hard-of-hearing and the relationship between client and audiologist. Carson's findings suggest improvements to audiology service delivery and the major issues in need of change include: less focus on the measurement of impairment, less of an expectation of speedy rehabilitative solutions, and less focus on the hearing aid as the main tool of the rehabilitation process.

<div align="center">Rationale for Approach to Current Study</div>

Help-seeking for Hearing Loss

Why don't more individuals utilize group hearing rehabilitation programs? Pichora-Fuller and Schow (2002) provide insight into this problem relative to a broader definition of aural rehabilitation. They suggest that most adults experience gradual hearing loss as a result of the aging process; as mentioned previously, a delay in help-seeking is common. However, research in this area is lacking. A small number of studies have compared adults who have consulted for hearing loss, compared to those who have not (Mahoney et al., 1996; Swan & Gatehouse, 1990; van den Brink et al., 1996). Needs vary with the population because of differences in environmental and personal factors, and such differences likely play a role in help-seeking too. Specific populations and

their rehabilitative needs have been documented: industrial workers (Getty & Hetú, 1994), seniors in care facilities (Pichora-Fuller & Robertson, 1994), youth and university populations (McCormick et al., 1994; Warick, 1994), and inmates in penitentiaries (Dahl, 1994). However, this existing research does not examine why these individuals begin to seek help when they do.

Pichora-Fuller and Schow (2002, p.357) also discuss that "the pressing need to consider adjustment to hearing loss as a dynamic process has fueled new research". For example, the incorporation of a health promotion model is evident in some interesting new programs developed in the 1990s and health promotion approaches are providing audiologists with new strategies to promote rehabilitative services (Stephens, 1996b). Carson and Pichora-Fuller (1997) describe an application of the PRECEDE-PROCEED model (Green & Kreuter, 1991) to improve the communication performance of a community of seniors living in a care facility. Noble (1998) has addressed how specific but changing needs and abilities of individuals affect adjustment to hearing loss and help-seeking behaviors. Worrall, Hickson, and colleagues (Worrall & Hickson, 1998; Hickson, Barnett, Worrall, & Yiu, 1994) developed and evaluated a health promotion program for a community-based population with an educational and preventative focus; the *Keep on Talking Program* was developed to help older people maintain communication skills as they age. An evaluation one year after the completed program revealed increased knowledge about communication, a positive change and attitude toward the importance of communication, and action-taking to maintain communication skills (Worrall & Hickson, 1998).

Advanced Help-seeking for Hearing Loss

This literature review chapter has argued that there is a scarcity of information regarding help-seeking for hearing loss in general and for advanced hearing rehabilitation in particular. Research examining this help-seeking behavior is important. Audiological rehabilitation, in general, and group rehabilitation programs specifically have been shown to benefit people who are hard-of-hearing (Backenroth & Ahlner, 2000; Israelite & Jennings, 1995). Considering the prevalence of hearing loss, it is vital to understand why individuals choose to access these services in order to optimize their utility.

Nevertheless, existing theoretical models from domains outside of Audiology provide some insight into what factors might prevent or promote adults with hearing loss from seeking help through group hearing rehabilitation programs. The WHO model (2001) provides a framework for considering the consequences of any health disorder. Possible processes can be examined through discussion of models such as the health belief model (Becker, 1974; Becker & Maiman, 1975), the transtheoretical model (Prochaska & DiClemente, 1986), the social comparison theory (Bandura, 1986), or theories on coping and adjustment (Lazarus, 1976; Lazarus & Folkman, 1984; Moos, 1986). Importantly, an ecological approach to the question motivates the choice of qualitative methodology; a true understanding of the experience of living with hearing loss and the process of choosing help-seeking behaviors will certainly incorporate the involvement of personal and environmental factors as part of this new understanding.

This study explores the research question regarding help-seeking for advanced hearing rehabilitation. This study utilized qualitative methods to determine the factors that prevent and promote adults with hearing loss from seeking advanced help through group hearing rehabilitation programs. The qualitative approach to the research question should provide a rich insightful view into this question; the grounded theory methods should illuminate the process of help-seeking for advanced rehabilitative services and add to the understanding of the differential experience of those adults with hearing loss who do seek this help in comparison and contrast to those who do not. This approach should provide the opportunity to develop a substantive theory of help-seeking for hearing loss. Chapter 3 will describe qualitative research, grounded theory, and the rationale for the methods used in the current study.

Chapter 3:   Methods

Overview

The present chapter provides a description of qualitative research, grounded theory, and the methods used in this study. A rationale is presented for the use of qualitative methodology and, more specifically, a grounded theory approach to this research study. The specifics of the study design, sources of data, and methods of analysis are discussed. The chapter closes with a discussion of other relevant methodological issues in qualitative research, including ethical considerations, issues of validity, and the assessment of the quality of the research.

The present research study focused on an exploration of the factors that prevent or promote adults from seeking advanced help for hearing loss in the form of group hearing rehabilitation. These factors were explored through the variety of views and the varied experiences of the participants. A retrospective view was gained through the participation of seven individuals who had prior experience with group hearing rehabilitation programs. A current view was gained through the participation in the study of four individuals who declined an invitation to participate in such a program. Current, prospective, and short-term retrospective views were gained through the participation of nine individuals who participated in a nine-week group hearing rehabilitation program, which was offered as a part of the current study.

Methodological Considerations

Sechrest and Sidani point out that the distinction between qualitative and quantitative methods has been "more distinctly drawn than it should be" (Sechrest & Sidani, 1995, p.77). Lincoln (1992) discusses the philosophical differences between quantitative and qualitative paradigms as including ontology ('real' reality versus 'realities'), epistemology (investigator and object of investigation are independent versus an interactive entity), and methodology (experimental and manipulative versus hermeneutic). While these differences do exist, Cox Dzurec and Abraham argue that inquiry, regardless of philosophical position, is governed by six pursuits: "the pursuit of mastery over self and world…understanding through recomposition…complexity reduction to enhance understanding…innovation…meaningfulness…and truthfulness" (Cox Dzurec & Abraham, 1993, pp.76-78). These pursuits integrate and link these research systems

and support the decision to use whatever method, either qualitative and/or quantitative, is best suited for the task. See Denzin and Lincoln (1994) for comprehensive coverage of qualitative methodology.

Guba and Lincoln (1994) analyze four competing paradigms in qualitative research with the view that questions of methods are secondary to questions of paradigms, and basic belief systems based on ontological, epistemological, and methodological assumptions. Table 3.1 presents two of the paradigm positions on selected practical issues as proposed by Guba and Lincoln (1994, p.112).

Table 3.1. Paradigm positions on selected practical issues

Issue	Positivism	Constructivism
Inquiry aim	Explanation: prediction and control	Understanding; reconstruction
Nature of knowledge	Verified hypotheses established as facts or laws	Individual reconstructions coalescing around consensus
Knowledge accumulation	Accretion- "building blocks" adding to "edifice of knowledge"; generalizations and cause-and-effect linkages	More informed and sophisticated reconstructions; vicarious experience
Goodness or quality criteria	Conventional benchmarks of "rigor": internal and external validity, reliability, and objectivity	Trustworthiness and authenticity and misapprehensions
Values	Excluded- influence denied	Included- formative
Ethics	Extrinsic; tilt toward deception	Intrinsic; process tilt toward revelation; special problems
Voice	"disinterested scientist" as informer of decision makers, policy makers, and change agents	"passionate participant" as facilitator of multi-voice reconstruction
Training	Technical and quantitative; substantive theories	Resocialization; qualitative and quantitative; history; values of altruism and empowerment
Accommodation	Commensurable	Incommensurable
Hegemony	In control of publication, funding, promotion, and tenure	Seeking recognition and input

Creswell (1998) discusses five traditions of qualitative inquiry, namely biography, phenomenology, grounded theory, ethnography, and case study; he defines qualitative research as:

"an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting." (Creswell, 1998, p.15)

Grounded theory, one example of qualitative methods, was originally presented by Glaser and Strauss (1967) and, more recently, has been developed by Strauss and Corbin (1990; 1994) who define it as:

"one that is inductively derived from the study of the phenomena it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge." (Strauss & Corbin, 1990, p.23)

The philosophical foundations of grounded theory, which guide research and interview questions, data collection, and analysis strategies, are provided by symbolic interactionism, as described by Mead (1934) and Blumer (1969). "Symbolic interactionism is a social-psychological theory of social action that is organized around the self, the world, and social action" (Hutchinson, 1993, p.182). Social context is necessary to understand individuals and their actions; each person and his or her environment is constantly changing through processes of social interaction. Grounded theory attempts to understand how a group of people defines their reality, by means of their social interactions (Stern, Allen, & Moxley, 1982). Through the attempt to understand complex interaction processes and the symbolic level of behavior, the grounded theorist develops a theory that provides a new way of understanding the observations.

Grounded theory is a qualitative method with specifically defined and systematic procedures. Grams (2001) provides a working guide for grounded theory and systematically proceeds through the analytical procedures and describes each in detail. This guide was adapted in the present study. The various forms of coding and analysis used in the current study are described later in this chapter.

Rationale for Methodology

Lincoln (1992, p.390) believes that qualitative research is "the next level of sophistication in a rapidly emerging disciplinary base" of health research. Creswell (1998) discusses the rationale for choosing a qualitative approach. His reasons for conducting a qualitative research project, which are applicable to the current study, are:

1. Nature of the research question,
2. Topic needs to be explored,
3. Need for a detailed view of the topic,
4. Desire to study individuals in their natural setting,
5. Interest in writing in a literary style,
6. Sufficient time and resources for extensive data collection,
7. Audiences are receptive to qualitative research, and
8. Emphasis on researcher's role as active learner rather than an expert who passes judgment on participants. (1998, pp.17-18)

I used grounded theory methodology. This section presents the rationale for the use of a qualitative approach. More specifically, the rationale for the use of grounded theory methodology is defended. Strauss and Corbin (1990) explore the motivation to choose a qualitative approach; these reasons may involve the research experience of the particular field of study, the inability of quantitative methods to convey the relevant issues, or the nature of the problem.

Research in Audiology

Many scientific disciplines are closely related to a specific methodology and this is reflected in the development of the field. For instance, sociology and anthropology are disciplines that were "born out of the concern" to understand others (Vidich & Lyman, 1994). For the present study, the decision to follow a qualitative methodology was chosen not because of the field of audiology, but rather in spite of it. The field of audiology is slowly emerging from a tradition of quantitative research focusing on 'impairment' (WHO, 1980) and defining improvements to service mostly by technological advancements. A paradigm shift in audiological practice has arisen with the adoption by the field of the concepts of impairment, handicap, and participation, following the evolution of the ICIDH and ICF models (WHO, 1980; 2001); this trend can be described as the expansion of focus from body to person to society. Refer to Chapter 2 for a discussion on the evolution of audiologic practice and a discussion of

the WHO documents (1980, 2001). The use of qualitative research methodology seems well-suited to the study and advancement of the expanded focus of practice in audiology; however, its use is lagging and there is an obvious need for qualitative research methodology to explore and advance changes in practice. Qualitative research holds particular promise for the development and evaluation of new audiological rehabilitation programs (Gagné, 2000).

A small number of qualitative studies in audiology have been reported, and some of these were discussed in the previous chapter. Some Swedish researchers, notably Hallberg and her colleagues, have promoted an innovative approach to audiologic research utilizing qualitative interviewing and grounded theory methods. Hallberg and Carlsson (1991, 1993) have completed several investigations concerning various aspects of hearing impairment, disability, coping, and handicap. In 1993, they developed a theory to describe the handicap creation process; the grounded data showed that a hearing disability can turn into a handicap through situations relating to environmental factors and situations relating to life habits. This distinction was based on how persons with the hearing impairment viewed their ability to control what was happening around them; that is, they perceived less control over environmental factors than those related to life habits and social roles (Hallberg & Carlsson, 1993). At the Academy for Rehabilitative Audiology's 1998 Summer Institute, Hallberg discussed a coping model indicating that individuals use a variety of strategies in response to experiences encountered due to their hearing impairment, but overall their behavior was dominated by either attempting to control the situation or to avoid the situation (Hallberg, 1998). More recently, Carson (2000) explored the perspectives of older women and the links between the experience of living with a hearing loss and the process of help-seeking. This study represents an important contribution to the understanding of help-seeking of people with hearing loss and the relationship between client and audiologist. The present study adds to the fledgling qualitative research base of the field of audiological rehabilitation.

Shortcomings of Quantitative Methodology

Quantitative methods fall short of explaining the experience of individuals who are hard-of-hearing. Hallberg (1998) presented work that supported the qualitative methodology when compared with quantitative methodologies. Specifically, after four

months of a rehabilitation program, a significant quantifiable reduction in handicap could not be obtained; however, through qualitative interviews, individuals with the hearing impairments and their accompanying spouses reported many positive changes, including increased awareness and understanding of problems related to the hearing loss and support from other couples (Hallberg, 1998). These are important findings that would have been missed through the use of existing quantitative measures.

We can look to other health disciplines that have developed a more extensive knowledge base using qualitative research methodologies for a hint of what the future of the qualitative/quantitative debate may hold for audiology. For example, MacEntee and colleagues (MacEntee, Hole, & Stolar, 1997) found that structured questions limited the responses of subjects, and to obtain a complete perspective of feelings and concerns, unrestricted responses to a global question were more informative.

Even with a significant and progressive step from the focus on impairment to an expanded focus encompassing handicap (WHO, 1980), the actual experience of individuals with hearing loss has only just opened up as a crucial domain of study for the field of audiology. The realization that impairment measures were not sufficiently informative to guide rehabilitation program development for individuals and groups led to the development of questionnaires for the assessment of communicative handicap or function, such as the Hearing-Handicap Scale (HHS) (High et al., 1964), the Denver Scale of Communication Function (Alpiner et al., 1978), the Hearing Performance Inventory (HPI) (Giolas et al., 1979), and the Communication Profile for the Hearing Impaired (CPHI) (Demorest & Erdmann, 1987). Some scales stress the attitudes of those who are hearing-impaired, while others focus on communication environments. Although these tools have been developed to capture the experience of people who are hard-of-hearing, they, too, have shortcomings.

Questionnaires represent an improvement insofar as they are not based on the assumption that individuals with similar impairments would experience similar handicap, but there are limitations to the use of questionnaires. Dillon Edgett and colleagues (Dillon Edgett, Lamb, Roodenburg, Pichora-Fuller & Johnson, 1998) provided an example of possible misinterpretation of the needs of clients when questionnaire scores were the sole source of information. They noted the overall score on the HPI (Giolas et al., 1979) completed by two individuals with hearing loss indicated that the handicap experienced was comparable for both; however, a different method used in the same

study, a guided qualitative interview, revealed that the same individuals had very different capabilities in coping with their hearing impairment and in making their environment more accessible through the use of strategies and assistive technology, and that they had different attitudes and reactions to their hearing abilities. One participant used few strategies, was more familiar with assistive devices, and attempted to hide his hearing loss. The second participant used a wide variety of strategies, was less familiar with devices, and commonly disclosed her hearing loss. This is a significant finding; the course of rehabilitation based on the questionnaire findings alone, if an interview or comparable method was not conducted, would not have adequately addressed the concerns and abilities of both clients through an aural rehabilitative program. Questionnaires represent only a small step in the direction of a more complete understanding of the actual experiences and goals of people who are hard-of-hearing. Qualitative research should help to explain the experience of hearing loss, the effect of hearing loss on an individual's life, and provide insight into the decision-making process involved in the choice to participate or not in a hearing rehabilitation program.

Nature of the Problem

The attempt to understand the experiences of others is an area of study that is well suited to a qualitative approach. These methods can be used effectively to uncover a new perspective or delve into a phenomenon that is relatively unknown. As mentioned above, there are relatively few examples of qualitative research in the audiology literature. Although Carson (2000) explores the idea of help-seeking for first-time audiology visits, the exploration of advanced help-seeking for hearing loss, beyond a hearing test and amplification, has not been examined. The research findings from this study should provide innovative and vital information to the audiology literature.

Appropriateness of Grounded Theory

This research study followed the principles of grounded theory methods, which is one tradition of qualitative research. The appropriateness of a grounded theory method for this study can be demonstrated with respect to the research question, the sources of data, and the method of analysis.

Recall that the research question for the current study is: *What are the factors that prevent or promote adults from seeking advanced help for hearing loss in the form of group hearing rehabilitation?* "The research question in a grounded theory study is a statement that identifies the phenomenon being studied...Grounded theory questions tend to be oriented toward action and process" (Strauss & Corbin, 1990, p.38). The research question proposed in the present study fits with the grounded theory style in that the phenomenon is that some people seek advanced help for hearing loss in the form of group hearing rehabilitation. Its goal attempts to understand the process of advanced help-seeking by identifying what prevents or promotes this process.

Morse agrees that the choice of grounded theory methodology instead of other qualitative methodologies is determined by the nature of the research question and the purpose of the study (1994). The research question concerns a process or an experience, and this type of research question is best suited to grounded theory methodology. Alternatively, a question concerned with the meaning of a phenomenon or essence of an experience is best suited to phenomenological methodology, and a question concerning the nature of a phenomenon is best suited to ethnographic methodology (Morse, 1994). The data sources and strategy for analysis are consistent with grounded theory methods.

Grams (2001) explains that grounded theory allows the researcher to learn what people who have experienced the phenomenon say about their experiences. This study explores the views of 20 individuals who are hard-of-hearing, who have different degrees of experience with a hearing rehabilitation program. These experiences are captured from three unique views: a retrospective view, a current view, and a prospective view. The data sources used in this study are typical of grounded theory: guided interviews, journal entries, and other documents such as questionnaires, evaluations, and memos.

Finally, grounded theory is a "general methodology for developing theory that is grounded in data systematically gathered and analyzed" (Strauss & Corbin, 1994). The findings of this study should contribute to the development of a substantive theory that describes and helps understand why and when certain people seek out advanced rehabilitation for hearing loss. The following sections will exhibit that the data were gathered and analyzed in a systematic fashion.

The Study Design

The discussion of the study design includes a description and justification for the choice of the site, participant recruitment strategy, the participants, and the rehabilitation program.

The Site

All study participants were clients of the Western Institute for the Deaf and Hard of Hearing (WIDHH), a non-profit agency in Vancouver, British Columbia. This clinic employs four audiologists and two technicians to provide audiologic diagnostic and rehabilitative services to hard-of-hearing, late-deafened, and Deaf clients. The clinic has a large adult-based clientele, and an encompassing philosophy of care for its clients who are hard-of-hearing that links audiological services to other programs at the facility (see Appendix A for WIDHH's vision statement and list of services). Importantly, in the past, WIDHH has been one of the few agencies in the city to offer group hearing rehabilitation courses, and it has facilities to accommodate the type of hearing rehabilitation program that was planned as part of the current study.

Recruitment of participants, all research interviews, and the group hearing rehabilitation classes provided as part of the present study occurred at WIDHH. All participants had prior audiology experience at WIDHH, and I believed this ensured a level of comfort with the study for the participants. The alternative, conducting the study at UBC, would have introduced an unknown environment that might have negatively affected the participants' decision to participate and their general response to the study. Interviews were scheduled around office availability in the audiology department. Group hearing rehabilitation classes were held in a meeting room with washroom facilities and an adjacent kitchen, in the WIDHH basement. The clinic was accessible during business hours on the weekdays and on Saturdays.

In addition to being an excellent clinical service site, WIDHH was also well suited as a site for research. Its staff have previously been involved in collaborative research including consumers, practicing professionals, and academic researchers, and they have a well-established role as providers of clinical education to Audiology students attending UBC. Therefore, institutional support for the present research project was readily secured.

To promote assistance with participant recruitment for this particular study and to establish a general understanding of my presence in the clinic, I made a brief presentation during an audiology staff meeting to explain my study and its goals. The nature of the involvement of the staff in recruiting participants was explained, and the cooperation of individual clinicians was readily secured.

Participant Recruitment

At the time of the initial meeting with audiology staff, I left recruitment notices (see Appendix B) that could be placed in the waiting room and distributed to clients. Several restrictions on participation in this study were established. Study participants had to be clients of WIDHH, have a diagnosed hearing loss (defined as a pure-tone threshold average above 25 dB HL), be at least 18 years of age, and have no health problems that would interfere with participation in a rehabilitation course. No past or future hearing rehabilitation participation was required. Participant recruitment for those individuals with prior experience with a hearing rehabilitation program did, however, differ from that of those with no prior experience.

To recruit 'experienced' individuals, the names of 15 individuals who had attended group rehabilitation classes were identified by staff, and letters inviting them to participate in the study were sent by the Executive Director of WIDHH (see Appendix C). Three hearing rehabilitative programs had occurred at WIDHH within three years of the current study. The program instructors provided class lists and all those whose addresses could be located were invited to participate. Of those 15 letters, one was returned due to a change of address.

To recruit clients with no prior experience with a rehabilitation course, approximately 100 recruitment notices were given to the audiology staff. These yellow notices were ever-present throughout the clinic: posted on walls, left in the waiting room, and present in each of the audiology and technician offices where client intake and counseling occurred. Some notices were also placed in the counseling department of WIDHH. Clients were given a variety of response methods to indicate their interest in the study; they could telephone me, express interest to their audiologist, leave the signed form at the WIDHH front desk, or fax, email or mail the form to me. The variety of options attempted to accommodate all possible communication methods and provide an opportunity for response to the greatest possible number of WIDHH clients.

<u>Study Participants</u>

From the 14 invitations to participate mailed and assumed to have been delivered to 'experienced' clients who had participated in rehabilitation courses in the past, 11 individuals responded and agreed to participate. Of the 11 who indicated interest, seven were able to arrange the time for an interview and all who were scheduled for an interview completed one.

In addition, I received 26 forms over a five month period during which the notices were displayed[2]. Responses came in slowly over the summer months; most responses were obtained in the Fall. Thirteen people who responded indicated interest but did not participate in the study[3]. Thirteen individuals with no prior experience in a hearing rehabilitation program agreed and completed interviews. Each of these 13 participants was invited to participate in a 10-week hearing rehabilitation program. The decision to participate separated these 13 individuals into three groups: declined rehabilitation ('No to rehabilitation' group; N=4), accepted rehabilitation ('Yes to rehabilitation' group; N=7), and accepted but then dropped-out of rehabilitation ('Dropout' group; N=2)[4].

In total, 20 individuals participated in this study (see Figure 3.1). Fourteen of the participants were female; six participants were male.

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[2] Notices were available from May to September.

[3] There were a variety of reasons why the 13 interested parties did not participate: not returning my calls placed once I received the completed recruitment forms (5), transportation issues (2), illness (1), concerns regarding recording of the sessions (1), conflicting travel commitments (2), interest indicated after the group rehabilitation program was already in progress (1), and prior involvement in a hearing rehabilitation program (1).

[4] Two individuals initially participated in the group rehabilitation classes but dropped out, one after two sessions and the other after three sessions.

Figure 3.1. Numbers of participants in each of four groups: experienced, no rehabilitation, yes to rehabilitation, and dropout.
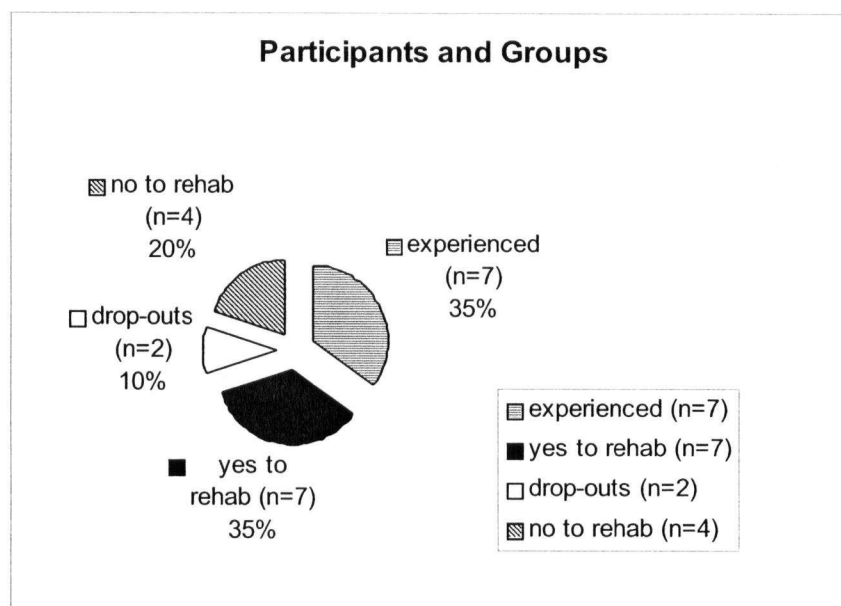
The participants in this study were considered to be representative of the cross-section of the clientele of WIDHH who are hard-of-hearing. The clientele of WIDHH are typical of the broader population of people who are hard-of-hearing insofar as these clients have the following characteristics: their ages cover the entire lifespan; they come from diverse cultures; their degrees of hearing loss range from mild to profound; the experience of hearing loss varies from recent to long-standing; and they span novices to experts in using hearing aids and assistive technology. The WIDHH clientele may differ from the population seen at other clinics because some individuals have opted to seek services in a non-medical setting. It may also be that they include a higher proportion of CHHA members than may be the case in other clinics. Furthermore, many people who are hard-of-hearing do not seek professional help for hearing loss from any service provider, either WIDHH or more traditional medical practices. Overall, these participants are considered representative of those who do seek services.

I arranged an interview time with participants via their preferred method of communication, by fax, email or phone. Interview sessions were scheduled depending on the availability of an office at WIDHH and at the convenience of the participant. See Appendix D for the interview schedule with dates for all participants. All participants were informed prior to the interview that it would be audio- and video-recorded. One

participant requested not to be videotaped during her interview sessions. I agreed not to videotape her interview sessions but did audiotape them. Participants received no payment for their participation; however, those individuals who agreed to participate in the hearing rehabilitation program did so free of charge.

The Rehabilitation Program

The rehabilitation program that was delivered in the current study was comparable to programs I have facilitated in the past. Although I begin with a list of possible topics to discuss throughout the course, the needs and interests of the participants influence the specific topics chosen and the depth to which these topics are discussed. In principle, it is also possible to add an unanticipated topic, but this did not occur in the present program. The nine sessions in this rehabilitation program included topics such as speechreading, relaxation exercises, factors affecting the ability to hear and speechread, general and specific communication strategies, and assertive behavior. Appendix E provides a list of many of the topics discussed in this rehabilitation program.

The Study Design: Sources of Data

Data were collected using a variety of sources: semi-structured one-to-one interviews, pre-rehabilitation questions, summaries of audiotaped rehabilitation classes, instructor/researcher observations (from the rehabilitation classes), journal entries by the participants, questionnaire results, audiological test results, and researcher notes. Each source of data will be described in more detail below.

Interviews

Semi-structured one-to-one interviews were the source of most data for this study. An interview guide was developed, and the line of questioning began with general comments and progressed to more specific lines of inquiry. Grams (2001) states the importance of beginning the interview with the most abstract, open-ended question[5]. The wording of the questions was revised several times to ensure the questions sounded natural and unambiguous, but also to develop rapport between myself as interviewer and each participant. The interview guide is discussed in detail below.

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[5] "Tell me about your hearing loss."

All interview sessions were audio- and videotaped[6]. The audiotapes were necessary for the purposes of transcription. The videotapes were used as a backup of the audio signal and also as a means to capture the various nonverbal cues that occurred during the communication between each participant and me. All participants were told the sessions would be taped; the equipment surprised no one. The only comments made regarding the taping set-up were made in regard to the superior quality of the equipment. All participants were assured that the videos would not be used for purposes other than the immediate use of the researchers unless their prior consent was given. The recordings of all interview sessions were transcribed verbatim and subsequently analyzed.

An audio mixer provided the ability to combine two microphone sources to a single output connected to the recording equipment. A digital video mixer provided the ability to capture a split-screen image, with the researcher-interviewer on one side and the client being interviewed on the other side. Figure 3.2 shows the equipment set-up. I attempted to be as inconspicuous as possible with the taping; wireless microphones were clipped to our lapels, and the cameras were set up behind the shoulder of each conversational partner so as to provide distance between the camera and the participant (see Figure 3.3).

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[6] There is one exception: one participant asked that her interviews not be videotaped.

Figure 3.2. Equipment set-up for interview sessions.
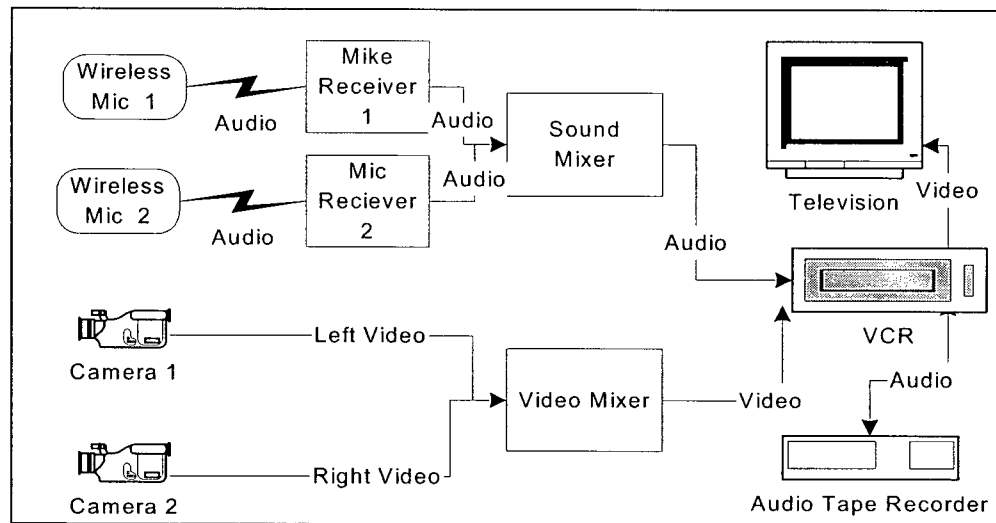
Figure 3.3. Positioning of cameras and interview participants and the resulting split screen image.
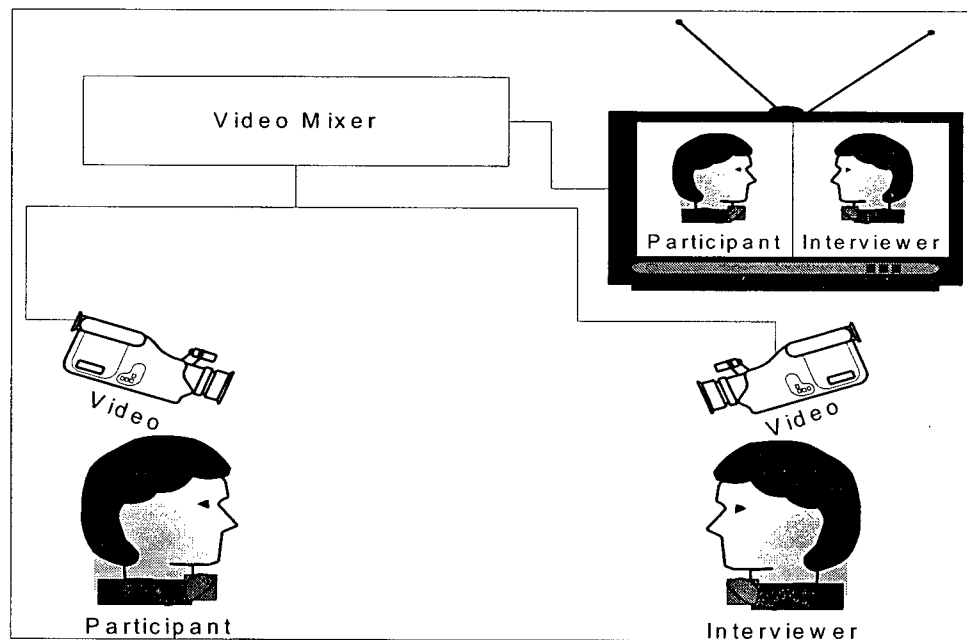
Several interview guides were developed: an interview regarding past rehabilitation experience, a preliminary interview for those with no past rehabilitation experience, an interview for those who rejected the invitation to partake in a rehabilitation program, and a mid-rehabilitation interview and a post-rehabilitation interview for those who did partake in the rehabilitation program. The guide used in each interview session was determined by participants' experience; those individuals with prior experience with a hearing rehabilitation program were asked different questions than those without prior experience. Specific responses to questions also determined the line of questioning; when a participant suggested that he or she wasn't interested in participating in a group hearing rehabilitation program, the 'rehabilitation rejection' guide was added to the 'preliminary' guide. Each guide provided a series of primary questions, followed by a more probing line of questioning if the participant didn't initially respond to the question as it was intended. Participants were also given the opportunity to discuss any issues and to ask any questions they had. Although most participants were expected to be able to communicate easily in a quiet and controlled environment, I always kept a pen and pad of paper on the desk for use in the event that any miscommunications occurred which could not be resolved using spoken language[7].

A series of core questions provided the foundation of each guide (see Appendix F). The core questions were: *Tell me about your hearing loss. On a day-to-day basis, when are you aware of your hearing loss? Has your hearing loss changed your lifestyle? Are there negative attitudes attached to hearing loss? Is there anyone who should do more about making it easier to listen? What efforts have you made to reduce your hearing difficulties?* They formed the basis of the first encounter with each participant.

The questions focused on several issues concerning the experience of hearing loss: *Tell me about your hearing loss.* I wanted to learn about the participants' hearing loss history, including how long they had known about the hearing loss, the signs that indicated there was a problem, the reasons for initiating a doctor or audiology appointment, and reactions to the diagnosis of hearing loss. *On a day-to-day basis, when are you aware of your hearing loss?* I wanted to know how often they thought of their hearing loss, and when they thought about it. I wanted to learn about decisions

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[7] I did use the pen and paper with two 'experienced' participants at various times during the interview.

they made that were affected by their hearing loss. I explored their emotional reactions, knowledge, and abilities by asking them to relay a personal experience of a difficult listening situation and to tell me what they did and how they felt about not being able to hear or understand what was happening. *Has your hearing loss changed your lifestyle?* I wanted to know if the people they spent time with, or if the things they liked to do, had changed as a result of the hearing loss. *Are there negative attitudes attached to hearing loss?* I wanted to understand how they had been treated as a person who was hard-of-hearing and how they felt about telling others they had a hearing loss. I explored what they believed the general public understood by the term 'hearing loss' and what others needed to learn. *Is there anyone who should do more about making it easier to listen?* I wanted to learn about their expectations of others. *What efforts have you made to reduce your hearing difficulties?* I wanted to learn about their hearing aid experiences and their awareness and use of other assistive listening devices (ALDs). I wanted to be aware of their experience with other individuals who were hard-of-hearing and the Canadian Hard of Hearing Association. I was interested in what they perceived to have had the most value in helping them to deal with their hearing loss.

See Appendices E through I for the complete guide for each interview situation.

Interviews with the Experienced Group

As previously mentioned, all interviews were held in an office at WIDHH and scheduled at the convenience of the participant. Seven participants with prior experience in a hearing rehabilitation program were interviewed. These seven interviews occurred over a period of 13 days. The interviews lasted from 40 minutes to two hours. While other individuals were willing to serve as participants in the experienced group, I did not conduct interviews with them. Once the seven interviews had been transcribed and coded, I felt that the information gained from the participants regarding their attitude and their experience with a hearing rehabilitation program was 'saturated'; I was not learning novel information and many ideas were being repeated across participants.

In addition to the core questions discussed above, I also asked the participants in the experienced group questions to help me to understand their hearing rehabilitation program experience (see Appendix G). *Tell me about the rehabilitative class that you participated in.* I wanted to understand what they learned in the program and also what

information they used and benefited from in their daily lives. I wanted to learn about their experience with their classmates. *What did you consider in your decision to participate?* I wanted to know if the decision to participate was easy or difficult, what kind of support they received from others, and what were the personal implications of having participated. *What would you say to someone who is thinking about classes but is having trouble deciding?* I wanted to get their thoughts on the factors that might prevent or promote someone from participating, from the point of view of someone who has already had the experience.

Other Preliminary Interviews

The remaining thirteen participants in this study had no prior experience with a hearing rehabilitation program. These individuals were self-selected in that they responded to the call for participation they encountered at WIDHH. The first of these interviews was held approximately 11 weeks after the last interview with a participant with prior experience. This hiatus occurred to enable transcription time, commencement of the analysis of the first group's interviews, and accommodation of the summer holiday season. The thirteen interviews occurred within a period of seven weeks. Each interview lasted between 45 minutes and one hour 45 minutes.

In addition to the core questions discussed above, these individuals were questioned about their interest in participating in a hearing rehabilitation program (see Appendix H). *Have you thought about participating in a rehabilitation class?* I wanted to know if they had ever heard of such a class, what their expectations were, and what they believed an ideal course for them would involve. *Would you be interested in enrolling in a class here at WIDHH?* This provided a decision point for the interview participants: did they want to participate in a hearing rehabilitation program or not? If they did want to participate, I wanted to understand what they expected to gain from the experience. All participants were informed that the class would take place at WIDHH on Saturday mornings from 9:30 to 11:30am. The program would run for 10 consecutive weeks. I also told them that a friend or family member was welcome to join them and participate

in the classes. Ten people indicated they would be interested in participating in the hearing rehabilitation program.[8]

Rehabilitation Rejection Interviews

Those individuals who indicated that they were not interested in participating in the hearing rehabilitation program were asked questions to determine the reason for, and conviction of, their decision (see Appendix I). In addition to the core and preliminary interview questions, they were asked: *How strongly do you feel about not participating?* I was interested if anything I could tell them would change their minds. *Can you explain why you do not want to participate in a rehab class?* I was interested whether the decision was related to content, lifestyle, or other concerns. *Do you think you might enroll in the future?* If yes, what did they think might change? I wondered if any circumstances might compel them to seek such help. *Do you think you would get support from family and friends to enroll?* I wondered if they were influenced by the attitudes and beliefs of those around them. *Do you have preferences for other ways to meet your needs?* Finally, I wanted to understand if they had other methods of coping with hearing difficulties or, alternatively, if they did not believe they had any current hearing needs. Three individuals declined to participate in the hearing rehabilitation program during the initial interview session. There were a variety of reasons for choosing not to participate; one woman did not enjoy groups, a second woman was interested only in a speechreading class, not a comprehensive program and also believed that hearing problems were private matters, and a third woman worked on Saturdays. The fourth person in this group, as mentioned above, initially indicated she would participate but later decided the time commitment was too great.

Due to the nature of the study design, I was unsure how many individuals I would need to interview to complete the study. I continued to interview new participants until I had recruited enough people who were interested in participating in a hearing rehabilitation program to provide an appropriate class size. From prior experience in facilitating such classes, I believed the ideal number was between six and ten participants. I had hoped that I would encounter some participants who did not want to

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[8] One participant decided that she would come to the first class to see if she liked it. On the morning of the first class, however, she phoned the clinic to say that she would not be coming. I was able to speak to her at a later date and determined that she didn't have the time to participate. She has been included in the 'no to rehabilitation' group.

participate in the program; I believed that learning the reasons they could not or did not want to participate would provide insight into what 'prevented' people from seeking this sort of support. Once I had obtained 10 individuals interested in participating in the hearing rehabilitation program, I conducted no further preliminary interviews. The maximum size for the hearing rehabilitation program was 10. Analysis of these interviews determined that saturation had been achieved. If this had not been the case, a second hearing rehabilitation program would have been conducted. At this point, I moved on to the next component of the study: conducting the 10-week hearing rehabilitation program.

I interviewed each participant from the rehabilitation program one or two additional times (mid-way in the rehabilitation program and post rehabilitation). The interview guides used for the mid- and post-rehabilitation interviews will be discussed below.

<u>Mid-rehabilitation Interviews</u>

Once approximately half of the classes had occurred[9], the class participants were invited to participate in a second interview session. I was able to interview four of the seven class participants regarding their class experiences[10]. Before each second interview session, I reviewed the preliminary interview transcript and noted specific instances where I wanted to clarify ideas presented in the earlier interview. Such instances included apparent contradictions, ambiguous statements unresolved in the first interview, or clarification of an idea or belief. I also made notes of comments or experiences discussed during the rehabilitation classes that I wanted to explore further. This practice of reviewing past interviews better enabled me to achieve saturation for each participant. In addition to my notes and revisiting any of the relevant core questions, I followed a mid-rehabilitation interview guide (see Appendix J) that explored the first half of the rehabilitation program experience. *Is this class what you thought it would be? Would you like to continue with the remaining classes?* I was interested in the participants' views of the experience of the classes compared to their expectations

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[9] The program was advertised as a 10-week program. However, the fifth class fell on the long weekend commemorating Remembrance Day, and WIDHH was closed. Unable to find an alternate time, we decided to cancel that session. In the end, the program consisted of nine sessions.

[10] One additional participant completed the questions via email. This interview session was not applicable to two participants, as they had to drop out of the program. This interview information was not obtained for two participants until the final interview session due to unavailability.

of the classes. I was also interested in learning what they wanted to accomplish in the remaining classes.

Post-rehabilitation Interviews

The final interview session provided closure to the hearing rehabilitation program and the study participation experience. These interview sessions took place once the program was completed and the Christmas holiday season was over[11]. All post-rehabilitation interviews were completed within five weeks of the final class. As with the mid-rehabilitation interviews, I reviewed transcripts of prior interviews and made notes of items to discuss in the final session. The core questions were revisited, and the participants were also asked questions regarding their satisfaction with the program and the apparent validity of the information learned by them in the class (see Appendix K). *Were you satisfied with the program?* I wanted to learn which topics were the most and least helpful. I was interested in their opinions on the specifics of the class location, time, and length of the program. I wanted to explore how their feelings about the classes changed over the course of the 10 weeks. *Have you used the things you learned in this class?* I wanted to understand the personal validity of the topics covered throughout the program. I wondered if they could identify the single most important experience in the class. I questioned what they would like to change about the program and if any experiences stood out in their memory. By the end of the final interview, I believed that saturation for each participant had been obtained. Throughout the months of their participation in the study, I developed a strong positive rapport with the participants and obtained permission to 'keep in touch'. This enabled me to confer with them as the analysis of the information progressed and evolved.

Pre-rehabilitation Questions

I contacted the participants who had volunteered to participate in the rehabilitation program before the first class to learn how they were feeling about the upcoming classes and what they expected from the rehabilitation program. I gave them a list of questions to think about and asked them to write answers to the following questions[12]: *How do you feel about the upcoming class? What are your goals for the classes?*

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[11] The final class took place on December 15th.

[12] Time restrictions and participant availability prevented personal interview sessions.

You'll be meeting other people who are hard-of-hearing; how do you feel about that?
Will a friend or family member be attending classes with you? I wanted to know if they had received enough information to feel 'ready' for the classes, and I wondered if they had been thinking about the program. I wanted to know what each participant wanted to gain from the program and what he or she expected their classmates might be like. Participants either emailed their responses to me or brought them to the first class.

Rehabilitation Class Summaries

Each of the nine two-hour rehabilitation classes was tape-recorded[13]. While the class recordings were not transcribed verbatim, I reviewed each tape. For each class, I made notes of class attendance, listed the topics covered in the class, summarized my comments, and summarized the comments of the participants. These notes were helpful for a variety of reasons. Participants often asked the others in the class for advice or offered suggestions. At times, they talked about a frustrating or embarrassing situation they had experienced. They shared humorous stories. During the first class, we did introductions around the table; I was able to compare what each participant had told me about his or her hearing loss experience to what he or she shared within the class. The tapes and subsequent notes captured interactions between classmates and group brainstorming sessions during the classes. In addition to the obvious informational benefit, these notes triggered questions for individuals that I could ask at their next interview.

Course Evaluations

Each participant was asked to complete a written rehabilitation program evaluation (see Appendix L). These were distributed during the second-to-last class and participants could return them during the last class or at the time of the final interview. The evaluations enabled me to gain information about the participants' experiences in the class and provided a check of the information obtained in the final interview. They rated their overall satisfaction with class and instructor, listed most and least helpful topics, and identified topics that they wished had been covered. They evaluated timing, location, and length of the program, and commented on what they would like to change

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[13] Unfortunately the tapes from class #2 were blank; I believe the microphones were not functioning. The first of two tapes from class #9 was blank; I forgot to turn the microphone on. Notes were made from memory.

about the program. They provided a measure of course utility by writing about the most important thing learned in the class and about their personal application of the knowledge gained in the program. I explained to the class that I would appreciate their honesty on the evaluations; I appreciated constructive criticisms on evaluations since they enabled me to improve the hearing rehabilitation experience for future classes.

Journals

Clandinin and Connelly (1994, p.421) support journal writing as "a powerful way for individuals to give accounts of their experience". The benefit of this method of data collection is threefold: the recording of the information shortly after an event promotes greater accuracy of the account when compared to later recall in an interview, the reporting level of incidents is higher, and the perceptions of the participants are often captured (Burns & Grove, 1993). A weakness of the method is the disparate level of comfort amongst participants with writing in a journal (Creswell, 1998), which became obvious as the data collection concluded.

At the time of the first interview, each participant was given a small lined notebook to use as a journal; see Appendix M for 'Instructions for Journal Writing'. Participants were asked to make journal entries about their daily experiences with hearing, whether positive, negative, or neutral. Emphasis was placed on the content of the entries, rather than style or spelling, and tips to aid in the journal-writing process were given. Ten of the 20 participants returned a journal in which they had made entries[14]. Returned journals contained between 4 and 70 pages of entries. Because I saw the participants from the 'experienced' group and the 'no to rehabilitation' group only once, these people were given an addressed stamped envelope to return the journals. The study participants who attended the rehabilitation program returned their journals on either the last day of class, at the time of the final interview, or as an email attachment. Although I did not explicitly state that participants could make entries electronically, I accepted submissions in this form. Lack of clarity about acceptable forms for the journal is a shortcoming of my instructions. Two individuals told me that if they had realized they could use the computer instead of the notebook, they would have made journal entries.

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[14] Only one participant declined to take a journal at the interview session. The remaining nine participants did not return or complete the journals because they couldn't find the journal, never wrote in a journal and found the experience difficult, forgot to make entries, were either too involved with a difficult situation or had forgotten about the situation, or supplied no reason.

In addition to regular journal entries, rehabilitation program participants were encouraged to write about experiences they wanted to discuss in class and to describe experiences where they used information learned through the class material or from classmates. The entries provided information about life experiences and difficulties with strangers, family members, and co-workers. They provided insight and explanations of behaviors and moods exhibited in class. By reading the journals, I gained a deeper understanding of who each writer was, what made him or her that way, and better understood what he or she wanted to accomplish. I read the journals after the program was completed. Later, all journals were analyzed in detail as documents.

Questionnaires

Each of the 20 study participants was given three questionnaires following the first interview. Participants were also given an addressed stamped envelope so that the questionnaires could be returned at their convenience. Questionnaires were analyzed at the end of the study.

Client-oriented Scale of Improvement

Each participant was asked to complete the Client-oriented Scale of Improvement (COSI). The COSI (Dillon, James, & Ginis, 1997) requires that the client nominate up to five situations in which he or she would like to hear and cope better. The COSI is short, easy to administer, and highly relevant to each individual, as he or she essentially chooses his or her own questionnaire items. I asked each participant to complete the COSI because it provides a baseline view of personal hearing difficulties. It also served to identify specific problem environments for the participants.

The Communication Profile for the Hearing Impaired

Each participant was asked to complete the Communication Profile for the Hearing Impaired (CPHI). The CPHI (Demorest & Erdmann, 1987) is a 145-item self-assessment inventory that yields scores in four major areas: communication performance, communication environment, communication strategies, and personal adjustment. It was chosen over other existing audiological questionnaires because of its well-defined psychometrics and extensive use in the field of rehabilitative audiology. The CPHI has a variety of clinical applications, including assessment of rehabilitative needs, assessment of change, and determination of counseling priorities (Erdman &

Demorest, 1990). I asked participants to complete this questionnaire to learn more about their attitudes and difficulties, and to determine if the profiles could distinguish between those who participated in the rehabilitation program from those who did not.

The Readiness to Change Questionnaire

Each participant was asked to complete the 12-item Readiness to Change Questionnaire- Hearing version (RTCQ-H). The RTCQ was originally developed by Rollnick, Heather, Gold and Hall (1992) and was based on the Prochaska and DiClemente's stages of change model (1986). Specifically, the questionnaire identifies a subject profile as corresponding to the precontemplation, contemplation, or action stage of change. The original questionnaire provides a short and convenient tool capable of measuring an individual's readiness to resolve a drinking problem. I wanted the participants to complete the RTCQ to determine if the interview data and decision to participate in a hearing rehabilitation program would be consistent with the prediction of the stage of change of each participant as identified by the questionnaire results. I adapted the RTCQ to address a hearing problem instead of a drinking problem, and the hearing version of the RTCQ can be found in Appendix N.

Additional Administrations

Each participant in the hearing rehabilitation program, including the two participants who did not complete the program, was asked to complete a second administration of each of the three questionnaires. The COSI was re-administered during the final interview session; we reviewed the responses on the original administration and each participant discussed any changes in the situations nominated. In addition to new situations, or a change in ranking of importance of the original situations, any improvements or deteriorations in the identified situations were noted. The second administrations of the CPHI and the RTCQ were completed at home by the participants and returned in an addressed stamped envelope. All questionnaire responses were collected and entered into a computer spreadsheet for analysis. A comparison was made between the first and second administrations and group differences were observed and discussed in Chapter 11.

In an attempt to capture and describe aspects of client and clinician relationships and clinician intuition and perception, I also completed a copy of the CPHI for each class participant, predicting their responses on the 145-item questionnaire based on the

information obtained in the initial interview. My predictions were compared with the first administration of the CPHI for each participant. These results are also presented in Chapter 11.

Audiological Results

Each participant gave consent for me to obtain a copy of his or her most recent audiogram, or hearing test results. All audiograms were obtained from WIDHH. I did not use the information gained through the test results for the purposes of this study. However, one class participant asked if I would explain her test results to her, and I used my copy of the audiogram at that time. Audiological results are summarized for each participant in Chapter 4.

Researcher Notes

I kept a journal of thoughts and observations related to this study from its conception; I developed ideas that grew into the proposal for this study. From the first interview, I kept a record of observations of participants; these observations included my expectations of meeting them (based on brief interactions to schedule an interview), observations after the initial interview session, and if applicable, observations throughout the course of the hearing rehabilitation program. I kept a list of questions, topics, and ideas for each participant as a reminder of areas to cover in a subsequent interview session. A final set of notes consisted of a collection of my predictions of how each participant would respond to the questions posed during the final interview: satisfaction with the hearing rehabilitation program, its efficacy, and its relevance for him or her. I kept a large desk calendar and recorded personal events in order to facilitate connections between what was happening to me and what I saw or how I reacted to the data.

In several situations, study participants shared information with me after the tape and video camera had been shut off. If this information was an afterthought, I made notes on the conversation. However, in several situations, I believed this postponement in sharing information was purposeful, and I treated that information with the utmost respect by not making notes on these issues; instead, I made reminders to trigger the memory of the conversation, should it become relevant.

I believe this variety of data exemplifies the hearing loss experience of these 20 individuals. The following section describes how the data were analyzed.

Data Analysis Strategy

An important distinction between qualitative research and quantitative research is that in qualitative research, data collection and data analysis are simultaneous rather than sequential. Data management techniques are key to maintaining control over an expanding data pool, with additional data being collected to saturate the information, and feeding into the interpretation of the data. The qualitative approach begins with a concrete and specific focus and progresses to one of increasing abstraction and interpretation. The progression of data management and reduction moves from interview transcription, to various forms of coding or labeling, to framework development, and the emergence of themes and a core category.

This section describes the analytic procedures followed in this study, as specified by grounded theory. The interview transcription process, the first crucial step that provided the foundation for all others, will be described. The coding process, the development of frameworks, and the subsequent framework comparisons will be discussed, and examples of memo-writing will be provided. Finally, the process of identifying themes, the core category, and the subsequent model development will be described.

Transcribing

Thirty-three interviews were conducted as part of this study. Eleven of these interviews were one-time meetings with the participant[15]. All participants in the hearing rehabilitation program were interviewed at least twice[16]. These 33 interviews yielded 753 pages of transcription from approximately 32 hours of tape recordings. Each interview was transcribed verbatim, requiring at least two passes of the audio recording. I transcribed all interviews myself. In several situations, the videotaped recording was used to reduce difficulty understanding the participant or to confirm the use of nonverbal cues when no verbal response was made[17]. The process of transcription was a time-consuming and sometimes arduous experience. However, the process of transcription

[15] The 11 individuals who participated in one interview included the seven participants in the 'experienced' group and the four participants in the 'no rehab' group.

[16] Four of the program participants were able to arrange a third interview.

[17] The video helped to confirm head nods, shakes, and shoulder shrugs.

gave me an opportunity to revisit the interviews and think about the participants. The insight gained from this procedure would not have occurred had I read transcriptions typed by someone else.

When I began transcribing the first interviews, I attempted to use voice recognition software to aid in the process; I trained the program for my voice characteristics, as I was unable to train the program to reliably interpret the voices of the participants. I listened to the interview tapes through headphones, and repeated the conversations aloud to a microphone. I became dissatisfied with the computer program after completing a couple of transcriptions and decided to finish the subsequent interviews by listening under headphones and typing the text myself. The clarity of the tapes was superb as I used lapel microphones and a quality recording system; there was generally no difficulty in understanding the speech on the audiotapes. Pauses of more than three seconds were noted, as were laughter and tears. Each interview was saved in a word processing program with a generous margin on the right side to allow for open coding of the transcriptions.

An additional 15 hours of audio recordings were captured from the hearing rehabilitation classes. While these tapes were not transcribed on a word-for-word basis, I did listen to each tape to capture the spirit of the discussions and comments from the participants. I also noted the class topics from each agenda.

Coding

A guide outlining a step-by-step process for grounded theory methods helped me to progress through the stages of data management and interpretation. Grams (2001) provided specific and detailed directions, which proved instrumental in this study. A highly simplified way of describing the analytic process is to compare it to a funnel; complete transcripts are represented by codes, which are then condensed into groups of similar codes. Once the properties and categories of the codes are discovered and placed in a framework, themes emerge from the data, and a model that explains the phenomenon of interest is developed. Throughout each of the stages of analysis, I consulted with my supervisory committee, and these consultations took many forms. For example, we reviewed quotes and initial coding decisions, discussed labels, and debated similarities and differences of codes within the categories and dimensions of the framework. These interactions culminated in mutually agreed upon decisions.

<u>Open Coding</u>

The first step of the process is coding the data line-by-line; the identification of every idea represented in the interview provides the foundation for the grounding of the study. I progressed through this process of "open coding" (Grams, 2001) on a hard copy of the interview. I worked on a hard copy of the interview, rather than directly on the computer, since printed copies were portable and provided a reprieve from sitting at a computer for long hours. The process of picking a code name was not "belabored" (Grams, 2001) and became more comfortable as I progressed through the interview transcripts. I coded the participants' contributions[18] for each interview in its entirety. Figure 3.4 represents a reproduction[19] of the open coding process on a portion of the first interview with Robert[20], the first participant. Although I was aware that this process produced codes that were repetitive, I chose to capture every idea in each interview. The repetition of some codes and, therefore, the repetition of ideas within one participant's interview provided information that would not have been captured if only novel ideas were coded. This duplication of ideas was captured in the next steps of analysis: axial coding and framework development.

The process of open coding was also performed for journal entries. My approach to coding the journals was less strict, and I progressed through the entries and coded only novel ideas or compelling examples of ideas already identified. With this exception of open coding, the analysis of the journal entries was the same as that of the interview transcripts.

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[18] I did not code my questions, as I believe that, if relevant, these notions would reveal themselves in the participants' responses.

[19] A reproduction is necessary as actual coding occurred on a hard copy of the interview.

[20] To maintain confidentiality of the participants in this study, each participant is identified by a pseudonym. Chapter 4 describes each participant.

Figure 3.4. An example of the coding process from Robert's interview.

Transcription	Codes
LDE: If you had never gone to that first class, where you think you'd be today? **Robert:** Pause. Probably a very angry person, depressed. This is the only thing I don't like about these conversations, is that it sounds like your feeling sorry for yourself **LDE:** Mmm **Robert:** but it's true though, you get angry, you get depressed and if you don't do something about it, it just gets worse and who knows where it'll end **LDE:** Mhmm **Robert:** But I think if I hadn't gone to a meeting, I would be a very disliked person, like I would be pulled back into a shell and just strike out at people. If I get angry, I am good at that **LDE:** Right **Robert:** I think I would've retreated into a shell and just said let the world go by I don't care. Like I'm not making any effort and I don't care. Because like I say, people don't seem to understand, and I thought well, then I mean you are alone, so that's it. And I always remember this blind fellow coming into the shop, just before I quit work, and he said to me, you know I feel sorry for you and I thought come on you're blind and you're feeling sorry for me. But he said it- it's a world of communication, especially now and he said it's getting more so all the time. Communicate, communicate, communicate. And he said and you can't communicate. So he said that means you're isolated and he said to me, it's like I would visualize it as being in a closet with the door closed. And I said well, it's not quite that bad but it's- I sometimes tell people it's like being in a phone booth with glass walls all around. And I said you had a family reunion but you are in this glass booth, **LDE:** Mmm **Robert:** and you can see everybody and you can see their mouth going but you have no idea what they're saying. So, without communications you're alone, even in a crowd.	without class, anger and depression dislikes focus on negative downward spiral without class, disliked, isolated aggressive angry loneliness giving up general lack of understanding hearing loss, loneliness pity from blind man comparison re: blindness communication as necessity hearing loss prevents communication analogy: communication from a phone booth alone in a crowd

Axial Coding

The process of axial coding simply involves grouping similar codes together. This process involves listing all the codes identified from the previous open coding process and grouping ideas into categories, properties and their respective dimensions (types, circumstances and conditions of the phenomena) (Grams, 2001). This process was quite intuitive and many of the groupings had become obvious to me as I transcribed the interviews. I performed this process of axial coding as a separate and independent level of analysis with only one interview[21]. In the analysis of each additional interview, I combined the processes of axial coding and framework development; this process will be described below.

Codes were grouped together for many reasons. For identical codes representing the repetition of ideas in the interview, grouping was obvious. Other codes were grouped together and "dimensionalized"; some of the dimensions that can be observed are frequency, extent, intensity, duration, amount or manner (Strauss & Corbin, 1990). To develop a category, one first examines its properties and then dimensionalizes them – this forms the basis of relationships between categories and subcategories. Each category will have several general properties, and each property will vary over dimensional continuums. A sampling of the groupings from Robert's interview codes is presented in Table 3.2.

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[21] The process of axial coding was completed for Robert's interview. Robert was the first participant of the study. Hence this interview was the first transcribed and the first to be coded. I began with this interview, in addition to the these reasons, because I believed that of the participants whom I had interviewed at the time, Robert had the most experience with hearing rehabilitation classes and the most interaction with other individuals who were hard-of-hearing.

Table 3.2. Examples of dimensions and codes from Robert's interview

Dimension	Codes
Intensity (emotional reaction to communication difficulties)	▪ frustration ▪ annoyance ▪ anger ▪ hopelessness ▪ acceptance
Extent (benefit of humor)	▪ relieves pressure ▪ relieves tension of others ▪ need for balance ▪ strategy for depression
Degree (of hearing loss)	▪ mild-to-moderate ▪ early degree: mild ▪ progression ▪ decline ▪ severe-to-profound

Developing the Framework

The specific and methodical process of coding provided the necessary elements for the development of the framework. A framework consists of an organization of the codes into columns, grouped according to their level of abstraction; more abstract codes were identified as categories and were grouped on the left of the framework, the different properties of these categories were grouped in the center, and the more concrete codes were grouped on the right. The concrete examples, the types, circumstances and conditions, are the "different facets that help us understand the different dimensions of each property" (Grams, 2001, p.25). Table 3.3 provides an example of a category, property, and type within a framework: one slice of the experienced group codes.

Table 3.3. Sample portion of experienced group framework

Categories	Properties	Types/ Circumstances/ Conditions
Personal Experience with Hearing Loss	Disclosure	Process
Personal Experience with Hearing Loss	Emotional reactions	Hearing Loss
Personal Experience with Hearing Loss	Underlying personal concerns of people who are hard-of-hearing	Humor
Personal Experience with Hearing Loss	Work & school environments	Work: context

These frameworks provided a condensed representation of the interview sessions and the building blocks from which comparisons could be made and themes could be identified.

The steps that I followed to create a framework were:

1. Progress through the list of open codes as they appeared on the interview transcript, and group similar ideas or concepts together (as described above in axial coding)[22];

2. Attach reference information with each code to facilitate finding the interview or journal text associated with each code[23];

3. Organize the groups of codes or ideas into examples, categories and properties; that is, organize the data according to the level of abstraction.

4. Progress through the transcript or journal until all ideas are represented in the framework;

5. Systematically supplement the framework with ideas from the remaining transcripts or journals from individuals in the same group, and hence, same framework[24]; and

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[22] For the first framework I developed, the experienced group interview framework, I listed all codes from the interview transcript on a separate sheet and created a framework document from it. However, with all other frameworks, I went directly from the coded interview transcript to the first version of the framework. That is, I did not list each code on a separate sheet of paper and then again on the first draft of a framework.

[23] For example, the code 'sensitive to sound' from the first interview with Linda, that came from the top of page 7, would be listed in the framework as 'sensitive to sound (Linda,7t)'. The idea of blaming the hearing loss for not participating in events, found in Michelle's second interview would be listed as 'using HL as excuse (Michelle2,4m)'. The idea promoting hearing aid disclosure, described in Leslie's journal on page 17, would be listed as 'more open re: HA (LeslieJ,17)'.

[24] For example, the interviews from participants Judy, Grace, Hanna, and Ellen were entered into the framework representing the 'no rehab' group.

6. Progress through numerous versions of the framework to further organize the ideas and develop the concepts.

A similar process was completed for each group and each interview session. Table 3.4 shows the specific data source that comprised each framework; ten frameworks were developed for this study.

Table 3.4. List of frameworks, as determined by group and information source

Framework	Group	Information Source	Number of participants contributing to framework
1	Experienced	Interview	7
2	Experienced	Journal	5
3	No to Rehabilitation	Interview	4
4	No to Rehabilitation	Journal	1
5	Yes to Rehabilitation	Initial interview	7
6	Yes to Rehabilitation	Mid-program interview	4
7	Yes to Rehabilitation	Post-program Interview	7
8	Yes to Rehabilitation	Journal	4
9	Dropout	Initial interview	2
10	Dropout	Final interview	2

In an attempt to create each of the 10 frameworks as a document independent of the others, the process of creating a framework began from the first step each time; I did not want the findings in one framework to determine the properties and categories in the frameworks that had not yet been developed. I believe this effort to reduce interference between the groups and the development of the frameworks was successful.

Group Comparisons

When all frameworks had reached a stage where comparisons between them could occur, certain concepts had to be reconciled to facilitate the analyses. After I developed the experienced group framework, several months passed before I developed the frameworks for the other groups. When I attempted to compare all frameworks in one comprehensive document, I had to return to the original codes from the interview

transcripts to ensure that the amalgamation of a certain category or property was justified and that appropriate and consistent comparisons were being made. For example, in the experienced group framework, I had identified codes dealing with people's misconceptions of a person who was hard-of-hearing who doesn't respond appropriately as being 'rude', 'snobbish', and 'inattentive' as 'fundamental problem-understanding hearing loss'. When I looked for misunderstandings about hearing loss in the 'Yes to rehabilitation' framework, I realized that I had identified similar ideas of 'incapable' and 'stupid' as 'problem- misunderstanding- regarding not understanding hearing loss'. Similar codes had to appear in similar categories. This process was vital for the comparative process to be accurate and reliable. All versions of frameworks were saved to document the addition of each participant and the development of this stage of analysis.

Memos

As a grounded theory novice, I initially had difficulty with the concept of 'memos'. However, I realized it was the label that I was unfamiliar with, not the process. Memos, or notes, are vital to the qualitative research process and different types of memos were collected at different stages of the study: method memos, participant memos, reflection memos, and analysis memos. Method memos were notes about the setting, the equipment, and the general method. An example of a method memo is:

> "How to videotape? KPF feels that more info is better and it's beneficial to have too much info than regret not capturing something later on. Will use BCHRF equipment and do split screen video."

Participant memos were notes that captured information about participants as the data were being collected through interviews and the rehabilitation program. An example of a participant memo is: "Enjoyed the interview with Cathy. Very succinct but thoughtful answers to the questions." Reflection memos captured my thought processes, and they identified my reflections on how the research process was affecting me, what I was thinking, and how I felt in relation to the participants or the research experience in general. An example of a reflection memo is:

> "Robert spoke so passionately about the benefit of support groups that it had a personal effect on me- I had a Humalogue {insulin} workshop the following day and the experience of talking with other diabetics compelled me to go to CDA, join, and seek out diabetic support groups. Robert was definitely an inspiration."

Analysis memos were notes written at various stages of the analysis; they identified thought processes about coding, decisions, and ideas that emerged through framework development and group comparisons. One example of an analysis memo is:

> "Older participants ask for advice and seek opinions more than the younger participants; e.g., Judy: How do you find my hearing impairment? Ellen: Do you think I need to {attend classes}?"

Themes and Model Development

Simultaneous data collection and analysis is a characteristic of qualitative methods. In the early stages of analysis, concepts and the links between these concepts were identified, and a model was drafted that incorporated the preliminary findings from the 'experienced' group data. This rudimentary model provided a conceptual platform to which the remaining groups of participants could be compared and contrasted. As the data from the different groups were analyzed, important information was identified that enabled development of the model.

A core category and several themes emerged as the group framework comparison was analyzed. Grams (2001, p.44) defines themes as "recurrent or dominant ideas that do not fit solely in one part of the framework but appear in different parts of the theory". These concepts enabled the development of the model to evolve from its basic conception to a more complex and encompassing representation of the decision-making process for advanced help-seeking. The core category, themes, and model developed through these data are discussed in Chapter 12.

Ethical Considerations

Ethical issues considered to be relevant in this study include: obtaining informed consent, maintaining confidentiality of the participants, deciding whether or how to use information shared 'off the record', and determining whether the researcher should share personal experiences (Creswell, 1998).

Maxwell (1996) believes that "ethical concerns should be involved in *every* aspect of design". Ethical considerations must be considered at many stages of the research project; for example, in the early stages, the researcher must determine the procedure for participant recruitment. In this study, the onus was on the individual to contact me to initiate participation. The invitation to participate came from the client's hearing clinic in

the form of a personal letter[25] or through flyers and posters explaining the purpose and the specific details of the study. Ethical considerations continue through to data analysis; one possible ethical problem is the imposition of dominant theories (Lincoln, 1990) causing the researcher to see her data through a specified lens. I believe this problem was prevented in this study because the analytic process of coding and transforming the data was purposefully done prior to a literature review and without the focus on existing theories and their potential impositions.

Informed Consent

The research proposal for this study was submitted and approved by the Behavioral Research Ethics Board at the University of British Columbia. Informed consent was obtained from all participants prior to beginning the first interview (see Appendix O). Clients were given as much time as needed to read the two-page form. The consent form explained the purpose of the study and described the procedures of the study, including the need to complete questionnaires and write entries in a journal. Participants were informed that, if they had no prior experience with a hearing rehabilitation program, they would be invited to participate in one. Participation in the rehabilitation program also required two additional interview sessions. The consent form indicated that all sessions would occur at WIDHH and be audio- and videotaped. The promise of confidentiality was explained, the absence of remuneration for participation was stated, and the understanding was clarified that refusal to participate or the decision to withdraw would not affect the relationship with, or future service from, the individual's audiologist. Each participant received a copy of the consent form for his or her records.

Additional consent was required due to the video recording of the interview sessions (see Appendix P). I find the standard form for video and audio consent from the University of British Columbia rather vague; given the all-encompassing nature of the

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[25] For the individuals who had prior experience with a hearing rehabilitation program, WIDHH sent a letter supporting the study and inviting them to participate.

permission, I encouraged anyone with reservations to take the consent home to think about the decision. Video consent was received for 16 of the 20 participants[26].

Confidentiality

Maintaining confidentiality of the participants in a qualitative study is more difficult than in a quantitative study because of the small number of participants, the depth of the information gathered, and the need to present direct quotes (Burns & Grove, 1993). A coding system should allow only the researchers to know the true identity of the participants. Ford and Reutter (1990) recommend using pseudonyms and distorting certain details in the participants' stories, which do not affect the content, in order to provide an additional measure of anonymity. For this study, all raw data were identified by a participant code and pseudonyms and slight distortion of stories in the reports of findings helped to maintain confidentiality. I was also careful to not include details that might identify participants due to their descriptive or specific nature. However, signed consent to use the videotapes allows me to show portions of the interview sessions for educational purposes.

'Off the Record' Comments

Comments made to me 'off the record' were handled in different ways, and I depended on my intuition. As mentioned earlier, if the comment was an afterthought, I made a note if applicable. However, if conversations were held in confidence once the tape and video recorder were shut off, I did not include them in the analysis. There were also journal entries where the personal information was not directly relevant to the study topic, or which I considered too personal; these specific facts or entries were not included in the coding process.

Personal Experience of the Researcher

Sharing of personal experiences by the researcher should also be given ethical consideration. Other than when I was asked if I had a hearing loss (and I responded 'no'), I did not share much of my personal circumstances and beliefs with the interview

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[26] Consent for one participant was irrelevant since she was not videotaped. One woman did not grant consent since she had referred to her husband several times by name throughout the interview. Two participants did not grant consent to protect their privacy. I made a note on one participant's file that he wanted to be notified if a section of his videotape was used. One woman asked if she could watch her video before signing the consent. She borrowed it and returned the tape with the signed consent form.

participants. However, during the nine sessions of the rehabilitation program, sharing was mutual. All of us shared information of a personal nature and I believe it promoted understanding and enhanced the level of trust and comfort in the group[27]. A continuation of this discussion relating to the relationship between researcher and participant is presented below.

<p style="text-align:center">Validity of the Research</p>

Validity is a final component of research design; in general it refers to "the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account" (Maxwell, 1996). Careful consideration of the relationship between the researcher and the participants will be considered here. As well, two general threats to validity that must be considered in every qualitative research study will be discussed: researcher bias and researcher influence (Maxwell, 1996).

<u>Researcher-participant Relationships</u>

An important characteristic of qualitative research is the acknowledgement of the relationship between researcher and participant. In varying degrees, the researcher influences the participant, and the participant influences the researcher (Burns & Grove, 1993). Because this mutual influence and interaction are necessary elements of the research experience, the researcher's personality may greatly affect the success of the interview sessions. It is important for the researcher to resist attaching personal meaning to the data; she must remain open to the interpretation presented by the participants. Interaction between researcher and participants or researcher and data is also important; this issue of reflexive thought is discussed below.

This study included an interesting mix of relationships. The researcher-participant relationship was certainly predominant during the interview sessions. This relationship can be characterized by a more formal attitude and a sense of 'testing the waters'. However, for those participants who participated in the hearing rehabilitation program, a second and more developed relationship emerged; i.e., the interaction of clinician and client. I believe interaction time was an intervening variable in this change; the relationship became more trusting and open as we spent more time together.

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[27] As an example, while discussing assertive behavior during class #6, I shared my efforts to be assertiveness as a person with diabetes with the class. They responded positively to my analogy and told me that they were happy that I had shared with them.

I have noticed from past experience as an instructor of rehabilitation groups, a level of closeness, security, and trust emerge that is more encompassing than I believe it often is in a typical relationship between clinical audiologist and client. I believe we achieved this level of interaction in this group; several participants commented on "feeling safe" and feeling comfortable enough to initiate discussions on difficult topics[28]. This relationship developed over the course of the program and, I believe, was evident in the mid-rehabilitation and post-rehabilitation interview sessions. A connection, a shared understanding, and a level of comfort were present and displayed through body posture, language and references to shared knowledge or information[29].

Researcher Bias

Researcher bias is harmful to validity if the researcher specifically selects data to suit a predetermined purpose or focuses on data that 'stand out' for some reason. One solution to researcher bias in qualitative research is explaining this bias and how it was handled. Integrity of the researcher is key to this process (Maxwell, 1996). In this study, the selection of specific data was not a threat to validity because all interviews and journals were coded and analyzed in the same manner. Specific participants were chosen as the first participant for framework development in each group, and each of these decisions was explained in memos. Memos captured relevant experiences and thoughts and provided insight into the analyses. A high level of researcher self-awareness and purposeful examination of decisions helped to address the issue of researcher bias.

Reactivity

An additional threat, reactivity, is the influence of the researcher on the setting or the participants. Due to the nature of qualitative interviewing, influence is inevitable. Efforts to minimize reactivity can be accomplished by avoiding leading questions. However, a more important factor in handling such influence occurs by understanding how you influence the participants and the implications for them. In this study, I handled the

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[28] Classmates initiated and participated in a discussion of the speech production difficulties encountered by individuals with longtime or profound hearing losses.

[29] For example, Derek talked about using the telephone to communicate; in the first interview, he talked about difficulty understanding on the phone. However, in the final interview, he said he was "kind of afraid of phone calls".

initial threat of reactivity by conducting all interview sessions in an environment familiar to the participants. By following an interview guide for each participant, I ensured that the intended questions were covered during the interview independent of answers or tangential discussions. As well, all participants were asked in the post-rehabilitation interview to discuss the effect of the research on their experience; if the participants were aware of influential forces, this enabled participants to address them. This information is presented in Chapter 10.

<u>Reflexive Thought</u>

Reflexive thought is the critical thinking used to examine the dynamics between researcher and the data (Burns & Grove, 1993). For reflexive thought to occur, qualitative researchers must be consciously aware of personal factors that might influence the study. Instead of burying this influence, it is integrated into the understanding gained from the data. Writing memos and a purposeful reflection of the personal factors at play were crucial to the examination of the influence and bias in this study.

<center>Assessing Quality</center>

As in all research, whether qualitative or quantitative, it is vital to provide information as to the quality and degree of conviction in the findings. The validity or audibility (Huberman & Miles, 1994) of the research findings, and the assessment of the quality of those findings, can be supported by a variety of methods, including triangulation, and "transparency of method" (Huberman & Miles, 1994).

<u>Auditability</u>

Schwandt and Halpern (1988) support a full audit of research studies. They suggest questions that identify six required levels of attention: Are the findings grounded in the data? Are the inferences logical? Is the category structure appropriate? Can inquiry decisions and methodological shifts be justified? What is the degree of researcher bias? What strategies were used for increasing credibility? These issues are discussed below.

<u>Triangulation</u>

Triangulation involves using a variety of methods and individuals with varied characteristics and experiences to ensure "that the variance reflected is that of the trait or treatment and not that associated with the measures" (Huberman & Miles, 1994, p.438). Validity of the research findings could be called into question if they result from a single source. The ability to draw from different sources of data adds credibility to the findings and strengthens the reliability of the thematic concepts and model development. Glaser (1978) contends that theory development is strengthened by "slices of data" from multiple sources as compared to a single data source. The ability to compare and garner strength from the data in this study was accomplished through two strategies: multiple participants in each group and multiple forms of data sources. Discoveries are strengthened when similar but independent claims come from multiple participants. When comparable information is obtained through interview sessions, journal entries, questionnaire results, and researcher observations, the validity and verification of the findings are tested and confirmed.

<u>Transparency of Method</u>

It is paramount to the assessment of the research findings that reporting of the methodology be explicit and complete. While replication of the comprehensive study data is not generally pursued, it is vital that the methodology is documented in detail to allow readers to be confident in the reported conclusions. This explication also allows secondary analysis of the data and, if present, invalid processes should be more apparent (Huberman & Miles, 1994). Huberman and Miles (1994) discuss the importance of the retention of study materials, including raw materials, partially processed data, coded data, the coding theme, memos, analysis episodes, and report text. All raw materials, including tapes, videos, transcripts, journals, questionnaires, and notes were carefully saved. All versions of document development were saved to archive the evolution of the research process.

<div align="center">Summary</div>

Chapter 3 has provided a discussion of qualitative methods, grounded theory, and support for the use of this method in determining the factors that prevent or promote adults from seeking advanced help for hearing loss in the form of group hearing

rehabilitation. Design of the research study, sources of data, and analyses of data were discussed. Ethical considerations, and the issues of validity and quality of research were examined. The next chapter will introduce each of the participants.

Chapter 4:   The Participants

This chapter introduces the participants in this study. The information for each participant comes from interview sessions, observations, journal entries, and audiogram results. These introductions will be organized by group: 1. 'Experienced', 2. 'No to rehabilitation', 3. 'Yes to rehabilitation', and 4. 'Dropout'.

Experienced Group

This group consisted of seven individuals who had previous experience as participants in a hearing rehabilitation program: Robert, Matt, Roger, Kelly, Ian, Colleen and Janet[30]. Some participants may have known one another as their names had been obtained from three rehabilitation class lists.

<u>"Robert"</u>

At the time of the study, Robert was a 65-year-old male with a severe-to-profound bilateral sensorineural hearing loss. Robert attributed his hearing loss partly to noise exposure; he had been diagnosed approximately 20 years prior with a mild degree of hearing loss. Robert had used a hearing aid for 20 years, had experience with several different types of ALDs, and was on the waiting list for a cochlear implant.

Robert reported that he was constantly aware of his hearing loss due to the great difficulty he had communicating with others. He felt he had become dependent on his wife to communicate for him. Although he had great difficulty in social situations, he compromised with his wife; for example, when they attended events together, he took frequent breaks to deal with hearing difficulties. By necessity, he had developed many strategies to compensate for his hearing loss. Robert used many analogies to explain his loss, and he used disclosure and humor as coping strategies but was frustrated because others constantly forgot that he was hard-of-hearing.

He was a strong advocate for hard-of-hearing groups and had participated in four hearing rehabilitation programs over the past five years; two of the programs were taken at the Vancouver Community College and the remaining two courses were taken at WIDHH through the Canadian Hard of Hearing Association (CHHA). Robert was an active member of CHHA. He attended weekly support group meetings, and he credited these groups and meetings for support and ideas that helped him to cope with his

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[30] All participants are referred to by pseudonyms.

hearing problem. Robert claimed that acknowledging his responsibility to inform others of his hearing loss had the most value in his dealing with his own hearing problem.

"Matt"

Matt was a 47-year-old male. He was born with a hearing loss but did not receive treatment until he was in high school. His sensorineural hearing loss was moderate-to-profound in his left ear and severe-to-profound in his right ear. He received his first hearing aid when he was 16 years old, and at the time of the study he wore two behind-the-ear (BTE) hearing aids. Although he was dependent on his hearing aids, Matt had also developed a wide array of coping skills throughout his lifetime. He was highly confident in his knowledge about, and ability to cope with, his hearing loss. Matt had been married for 25 years and had one teenage daughter.

Matt was a business analyst; he had been unemployed for 3 years. He believed there should be more support for working adults due to the lack of tolerance for hearing loss in the workplace. Although he recognized the difficulties involved in organizing groups of individuals who are hard-of-hearing, he also recognized the political strength gained through numbers. Matt was involved in CHHA and believed a greater emphasis should be placed on educating the general public on the implications of hearing loss.

Matt reported that he was constantly aware of his hearing loss. He believed that becoming aware of the implications of hearing loss and the benefit of technology had had the most value for him in dealing with his loss. Awareness and recognition of the benefit he gained from his amplification was fundamental in his vision of the needs of people who are hard-of-hearing: appropriate funding for technology for all individuals with hearing loss. Matt had attended one hearing rehabilitation program several years ago that was sponsored by CHHA and held at WIDHH.

"Roger"

Roger was a 71-year-old male who had a severe-to-profound bilateral sensorineural hearing loss. Roger believed his loss to have been congenital, although he was not aware of, or treated for, the loss until high school. Roger had had a successful career as a social worker and took early retirement when he realized that the issues of working with a hearing loss were taking a personal toll on him. He credited his wife of 30 years as being a very supportive partner.

Roger used a variety of types of hearing aids over the years. He used a "button aid" in 1963. He had worn a hearing aid/eyeglasses combination device in the past, and at the time of this study, he wore two BTE hearing aids. Roger believed in assuming personal responsibility for one's own hearing loss, and he was a strong advocate for disclosure of hearing loss. He believed his most valuable experience in dealing with his loss was finding a place to go for help. He also believed that it was important for hearing services to move beyond technology and to address the issues affecting an individual in his or her environment. He attended one hearing rehabilitation program sponsored by CHHA two years ago at WIDHH; his wife accompanied him to the classes.

"Kelly"

Kelly, at the time of the study, was an 82-year-old woman. The onset of her hearing loss was gradual, and she first went to the audiologist when she noticed she was missing information in conversation. Kelly's sensorineural hearing loss was mild, sloping to moderate, and dropping to moderately-severe in the high frequencies. Kelly reported tinnitus as a problem associated with her hearing loss. She wore bilateral hearing aids that she had had for three years, and she occasionally used ALDs.

Kelly lived alone but was most aware of her hearing loss when with others. She served on her church board. Prior to becoming involved with group activities, she considered whether her hearing loss would interfere with her ability to participate. Kelly believed her hearing aids had provided the most value to her in dealing with her hearing loss.

Kelly had participated in a hearing rehabilitation group sponsored by CHHA two years before at WIDHH. From this experience, she remembered being surprised that younger people attended and by the anger that some classmates expressed toward their hearing losses. She gained awareness of hearing loss through the class and felt that more public education was important.

"Ian"

Ian was a 75-year-old male with a mild dropping to profound bilateral sensorineural hearing loss. He noticed symptoms of hearing loss in 1978 and believed his loss was

initially due to asthma medications. Ian had worn bilateral hearing aids for approximately 20 years.

Ian was constantly aware of his hearing loss. Nevertheless, he was an active participant in the Kiwanis Club, held board memberships, and attended exercise classes. He acknowledged bluffing as a typical strategy. His wife was also hard-of-hearing, and wore hearing aids, though she had a less severe hearing loss.

Ian had attended two hearing rehabilitation programs, one four years ago at Vancouver Community College and the other two years ago sponsored by CHHA and held at WIDHH. He believed that public awareness of hearing loss should be a priority for the community of people who are hard-of-hearing. Although he was a member of CHHA, he did not actively participate in meetings. He relied on closed captioning for entertainment and had begun a personal campaign to promote and improve closed captioning on his favorite television stations. He believed his hearing aids had had the most value in dealing with his loss.

"Colleen"

Colleen was a 53-year-old female with a bilateral severe sensorineural hearing loss. Her hearing problems began when she was 24 years old and began to experience severe vertigo attacks. At 31 years of age, Colleen was diagnosed with Ménière's disease. She wore hearing aids bilaterally, which she had had for 10 years. She had also used a variety of ALDs.

Colleen attended college 10 years ago to become a health records administrator; she had been unemployed for the last two years. Colleen believed that difficulties in her job were the result of a hostile work environment where co-workers blamed her hearing loss for a variety of problems.

Colleen was a single mother of three sons. By her own account, Colleen had a limited social life outside of her home, although she was involved in various groups and clubs. She was aware of her hearing loss mostly when she was busy, and she believed that her loss affected her decision to go back to school, the program she chose to attend, and her limited social environment. Colleen still struggled to accept her hearing loss and admitted a discrepancy between her intellectual and emotional levels of acceptance of hearing loss. From her own experience, Colleen believed that the greatest problem facing individuals who are hard-of-hearing was the lack of organized

and available information to help them cope with the problem. She believed her involvement in research to have had the most value in helping her cope with her hearing loss; she credited these research experiences as providing her with awareness, knowledge, and a sense of purpose.

Colleen had attended one hearing rehabilitation program two years ago which was sponsored by CHHA and held at WIDHH, and she expressed an interest in attending others. She reported that, through the classes, she gained a greater awareness of hearing loss and had come to adopt a proactive attitude toward her loss.

"Janet"

Janet was a 76-year-old-woman who had been married for 48 years. She was diagnosed with otosclerosis when she was younger and had undergone two stapedectomy operations; one operation was in 1960 and the other in the 1970s. Each operation greatly improved her ability to hear. She had experienced difficulty hearing in recent years and acknowledged that her loss had gradually worsened. At the time of the study, her sensorineural hearing loss was mild dropping to profound above 2000 Hz bilaterally. By her own report, her earlier hearing loss caused her to be more withdrawn; Janet felt she was better able to cope with her present loss than she had been able to when she was younger.

Janet had worn her husband's used hearing aids bilaterally for two years; his hearing loss was much more severe than hers. She believed that her familiarity with hearing aids and the hearing clinic due to her husband's hearing loss had made it easier for her to begin the process of addressing her own loss. Janet was aware of her loss only when having difficulty communicating, and she wore her hearing aids in situations when she anticipated having problems hearing; some of these situations included a lecture, a soft-spoken friend, or British television shows.

Janet had attended two rehabilitation classes with her husband; one class was at the Vancouver Community College and the second was sponsored by CHHA and held at WIDHH. The classes enabled her to cope better with her own hearing loss and also enabled her to help her husband cope with his loss. She felt she had received the most value in dealing with her hearing loss from the stapedectomy operations.

The most obvious common characteristic of this group is that all participants had taken a proactive step to address their hearing problems. None of the participants in

this group were employed at the time of the study: five participants were retired and two were unemployed. All participants in this group were hearing aid users. Men and women were nearly equally represented in this group: four and three, respectively.

No to Rehabilitation Group

This group consisted of four individuals who had no prior experience with a group hearing rehabilitation program and who declined the invitation to participate in such a program: Judy, Grace, Hanna and Ellen.

"Judy"

Judy was a 73-year-old retired female. Judy began to experience symptoms of a hearing problem 10 years ago. Five years ago, she became aware of trouble understanding her husband and problems understanding in groups; it was at this time that she went to WIDHH. She was familiar with this clinic because she had a family history of hearing loss, and her mother was a WIDHH client. She reported that her hearing was 'borderline' though she suspected that it would deteriorate as her mother's had. Hearing test results showed Judy's left-ear sensorineural hearing loss to be mild sloping to moderately severe with slight recovery above 2000 Hz. Results for the right ear showed a conductive hearing loss in the low frequencies, sloping to a moderately-severe sensorineural hearing loss at 1500 Hz. She purchased a BTE hearing aid several years before this study. Two months ago, Judy purchased a second hearing aid and had noticed significant improvement in her hearing abilities with bilateral amplification.

Judy was not conscious of her hearing aids and did not think of her hearing loss much on a daily basis; it had not affected her lifestyle. She was aware of the perceived stigma of hearing loss on the part of others who were hard-of-hearing through the predominant choice of in-the-ear (ITE) hearing aids by her friends. She felt that there was not the same level of stigma attached to hearing loss for seniors as for members of younger generations. Judy was aware of other ALDs because of her mother's experience, but she did not use any devices herself. She claimed her husband had learned better communication habits, and these habits enabled more successful interactions. Judy expressed a concern regarding the problems of hearing loss in nursing homes and the need for more funding in this area. Judy believed that her

second hearing aid and consistent use of both hearing aids had provided the most value to her in dealing with her hearing loss.

Judy expressed an interest in a rehabilitation course that focused solely on lipreading, but not in a comprehensive course on hearing loss. Judy was interested in how her hearing loss would compare to other class participants' losses, and what percentage of the program would be devoted to lipreading exercises. Judy decided not to participate in the rehabilitation program for several reasons: time commitment, conflicting holiday schedule, and the lack of significant problems communicating. She was not interested in interacting with others regarding hearing loss and believed it to be "something you work out on your own".

<u>"Grace"</u>

Grace was a 47-year-old female. She started noticing problems with her hearing 15 years ago; she waited five years to get her first hearing test. At that time, and despite two additional tests a couple of years apart, hearing aids were never recommended. She had recently become aware of how much she was missing because of comments made by a friend. She had also recognized that she was becoming more withdrawn. A hearing test two months prior to the present study indicated a more significant hearing loss, hearing aids were recommended and, at the time of the interview, Grace had been wearing two ITE hearing aids for less than two weeks. Her sensorineural hearing loss was mild sloping to moderate at 2000 Hz. She believed that the cost of amplification had prevented her from addressing the possibility of earlier intervention; she simply could not have afforded to purchase hearing aids.

While cost remained an issue, her priorities changed when she recognized the influence that hearing loss was having on friendships and relationships. She had come to avoid difficult listening situations. With her aids, she reported being more open to new situations. Grace was still adjusting to her hearing aids, but she reported being very satisfied with them. She felt more relaxed and was experiencing less strain in communication. Grace was enjoying hearing things she had not heard for a long time. She reported that the hearing aids had provided the most value to her in dealing with her hearing loss.

Grace was adjusting to the idea of shared responsibility for communication but was not comfortable with the idea of asking others to accommodate her. She believed there

to be a stigma of old age associated with hearing loss. Grace claimed that she was not experiencing the possible shame that could be associated with hearing loss because she had taken action to deal with the loss and was wearing amplification. Grace wondered about the limitations of the aids, but she did not feel the need to use other devices. Although she was not a member of CHHA, she had contacted them for a reference for WIDHH prior to making an appointment.

Grace was interested in attending the hearing rehabilitation course; however, she had a conflicting work schedule and was not able to attend the program offered as part of the present research study.

"Hanna"

Hanna was an 83-year-old retired female. Her hearing loss was discovered during a routine ENT[31] visit to get wax removed from her ears in 1976. She purchased her first hearing aid, an ITE, several years later but was dissatisfied with it. Several years later she was also dissatisfied with a BTE. She was now more satisfied with two BTE hearing aids and was working with her audiologist to make adjustments to improve her performance with the aids. Hanna's hearing was within normal limits in the lower frequencies but sloped to a profound sensorineural loss in the high frequencies.

Hanna was very aware of her hearing loss on a daily basis, and she limited group social activities as a result of her loss. She reported that misunderstandings embarrassed her, and that it "drives her silly" to ask others to repeat themselves. Hanna was unable to describe any strategies that she used when in a difficult listening situation, but she had used a listening device for the television and owned an amplified phone. Hanna did not believe that most people understood the implications of living with a hearing loss. She credited her new digital hearing aid as providing the most value to her in helping her deal with her hearing loss.

Hanna was not interested in participating in the hearing rehabilitation program. She apologized for her decision but acknowledged that she was not a social person and was therefore uncomfortable participating in group situations.

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[31] An Otolaryngologist is commonly referred to as an Ear, Nose, and Throat specialist, or ENT.

"Ellen"

Ellen was an 84-year-old female who had experienced a sudden profound sensorineural hearing loss in her right ear 18 months prior to her interview for the present study. She believed her loss was the result of a middle ear virus. Prior to the sudden loss, Ellen had 'borderline' hearing bilaterally. The sensorineural hearing loss in her left ear was moderate-to-severe. She claimed she was coping but that it was not easy to deal with her hearing loss. She was less comfortable in groups and tended not to try to communicate in difficult situations. She purchased a hearing aid soon after the sudden loss was diagnosed.

Ellen did not dwell on her hearing loss and accepted it. She did not believe there to be a stigma related to hearing loss because "a lot of people have it". Although very accepting of her loss, she imagined that it would be more difficult for younger people to accept being hard-of-hearing. Ellen had many friends with worse problems, and she considered herself to be fortunate. Her lifestyle remained relatively unchanged after the hearing loss was diagnosed.

Ellen reported that she could function without her hearing aid only in ideal conditions; she still considered her hearing aid to be new. She had used closed captioning and was aware of other assistive devices but had not used them. Ellen believed that the cost of devices was a deterrent for seniors living on limited income. She was aware of CHHA and had seen their literature but was not a member.

Ellen was interested in the rehabilitation class and agreed to come to the first class to see if she enjoyed it. Ellen was quite interested in my opinion of whether she "needed to" attend the program and wondered if I had "ever had anyone like {her} before". However, she called on the morning of the first class and said she could not attend. She later reported that the time commitment was too great and that she had decided not to participate.

Each participant in this group was female and a hearing aid user. Three of the four participants were retired; the fourth participant was unable to attend the classes due to her work schedule. The remaining three participants chose not to attend the rehabilitation program for a variety of reasons including time commitment, course content, conflicting travel commitments, and the social nature of the program.

Yes to Rehabilitation Group

This group consisted of seven individuals who accepted the offer to participate in the hearing rehabilitation program and completed the program: Claire, Michelle, Leslie, Hillary, Linda, Tony, and Derek.

"Claire"

Claire was a 52-year-old female. As a child, Claire had serious middle ear infections that were not treated until she was 15 years old. She was born and spent her first 18 years in South America. Claire had several surgeries from the time she was 18 to 22 years old, including removing a cyst on her eardrum and having an artificial eardrum inserted and subsequently removed. At 22, she got her first hearing aid and, seven years ago, she got a second hearing aid to try to achieve more symmetrical hearing. With her hearing aids, Claire realized how much auditory information she had been missing. Claire's hearing loss was largely conductive: moderately severe in the right ear and mild to moderately severe in the left ear. At the time of the first interview, Claire was only wearing her second hearing aid when necessary due to a re-occurring ear infection. An ENT was helping her manage the infection and, at the time of the final interview, Claire reported she was able to wear the second aid for up to eight hours a day. Although she had previously lived in Canada as a young adult, Claire had been back in the country for only 18 months.

Claire was employed as a social worker. She had also worked in the past as an executive director of a South American agency and as a restaurant manager. At the time of the present study, although Claire was in a better work environment, she described past experiences where she had found herself in a hostile environment on the job where co-workers were extremely difficult to work with. She attempted to control her listening environment in order to improve her communication abilities. Claire believed that WIDHH had provided significant value to her in dealing with her hearing loss through hearing testing, hearing aid loans, tubing repair, earmolds, and generally providing a supportive and pleasant atmosphere.

Claire had very high expectations of herself. She spoke many languages. She was comfortable with disclosing her hearing loss but also admitted that it was tiring to always educate others about hearing loss. Claire believed that there was a stigma of reduced intelligence attached to hearing loss. She reported that she was always aware of her

hearing loss and needed to be vigilant about getting enough rest; she believed sufficient rest enabled her to cope better with her loss. Claire admitted that menopause was complicating her ability to deal with her hearing loss. She was an active member of CHHA and was specifically interested in the issues of employability and employment of people who were hard-of-hearing. Claire had applied to attend UBC to study these issues as part of a Master's degree. Claire acknowledged that her perception of her hearing loss was initially quite superficial; she had believed all issues around the loss could be addressed with amplification technology.

Claire admitted to being curious about the group hearing rehabilitation program. She was interested in participating in the program and hoped to meet other people who were hard-of-hearing, to clarify her approach to dealing with a hearing loss, and to learn more about assistive listening technology.

In the final interviews, Claire talked about her satisfaction with the course. She felt that receiving even basic information was a significant improvement to her knowledge base. She was pleased with the topics such as the psychological aspects of hearing loss, speechreading, and ALDs. By the end of the program, she was considering starting to use a personal FM system. She reported that she felt more patient, focused, and relaxed. She had become more interested and involved with CHHA. She believed there to be a fundamental problem of oversimplifying the needs of adults who were hard-of-hearing. Claire had also decided to limit the amount of time spent in noisy environments to one hour when she encountered such a situation. She believed that she was now better at integrating help from other people and from ALDs into her daily routine. Finally, Claire believed this hearing rehabilitation program to be just the beginning, and she was interested in additional classes.

<u>"Michelle"</u>

Michelle was a 73-year-old retired female. As a child, Michelle had scarlet fever and diphtheria, and she had also had two mastoid operations. She reported that her hearing was poor at the time of the operations, but that it later recovered. She was, however, aware of a family history of hearing loss and was tested regularly with the expectation of discovering a hearing loss. Michelle's father had become isolated due to his hearing loss, and she did not want a similar result to affect her life. Michelle had a mild sloping

to moderately severe sensorineural hearing loss in the left ear, and a moderately severe conductive hearing loss sloping to profound sensorineural in the right ear.

Michelle obtained her first hearing aid 10 years ago. Six months prior to the study, she replaced her older hearing aid and purchased a second ITE hearing aid. She believed the bilateral amplification provided sharper, clearer hearing. Michelle did not believe that her hearing loss had any effect on her lifestyle. She accepted her loss and "doesn't dwell on it", though she was aware of her loss when she had to make more effort to communicate. Michelle had difficulty in groups. She had difficulty regulating the volume of her own voice. Michelle was aware of how much she benefited from lipreading, and she had some experience with public FM systems. Michelle believed recognizing her hearing loss and making an effort to attain greater satisfaction with her hearing aids had proved to be the most valuable to her in dealing with her hearing loss.

Michelle initially felt a hearing rehabilitation program would not be much help to her, because she believed she already knew a lot about hearing loss. She felt that such a class would be beneficial for those with greater hearing loss, with a newly diagnosed hearing loss, or "everyone but me!". Nevertheless, Michelle decided to participate in the rehabilitation program because she claimed that she had always been a joiner and that she was always willing to learn something new.

During the final interviews, Michelle reported that she felt the classes had been better than she had expected, and they had dealt with many unexpected topics. She didn't particularly feel much benefit from the speechreading exercises, but she was truly inspired by her classmates. She enjoyed being part of a group who desired improved hearing. This was in contrast to an attitude she experienced often in her social group of seniors; Michelle was more interested in an active approach to creating solutions. Michelle had been thinking about the need to be careful not to use hearing loss as a crutch or as an excuse not to participate. Michelle reported a more realistic attitude about listening in noisy environments and more consistent hearing aid use. She believed that her comparison of her hearing loss to some of her classmates' losses minimized her problems, and she felt more fortunate. Michelle believed that rehabilitation programs and the information they generate are important not only for the population of those who are hard-of-hearing, but also for caregivers. Michelle was interested in some sort of ongoing participation but was unsure if she would prefer another class or a social group. She was actively seeking alternatives whereby she

could remain involved with the movement to educate other seniors about the solutions that could improve the difficulties associated with hearing loss.

<u>"Leslie"</u>

Leslie was a 28-year-old female. Before she started kindergarten, Leslie was diagnosed with a slight unilateral hearing loss. Four years ago, Leslie was in a parking lot and when she did not hear a car behind her, a friend encouraged her to get her hearing tested. She was diagnosed with a more significant hearing loss: a moderate-to-severe sensorineural hearing loss in her right ear and a mild high-frequency sensorineural loss in her right ear. She was fit with a BTE hearing aid for her left ear and was considering a hearing aid in her better ear. When she first tried listening through a hearing aid in the audiologist's office, Leslie couldn't believe what she had been missing. Her doctor and ENT had told her she did not need to wear a hearing aid; she disagreed. Although she was excited about benefits from her hearing aid, Leslie reported that it took a while for her to adjust to listening through the aid. To personalize her aid and make it more noticeable, she bought many styles of EarWear, designer accessories for BTE hearing aids.

Leslie was finding it progressively more difficult to deal with her hearing loss at work. She had recently changed jobs from working in college administration to working as a legal secretary. Leslie believed that others questioned her intelligence as a result of her hearing loss, and that belief had made her begin to second-guess her own ideas and abilities. She had become increasingly confused and uncomfortable at work and faced difficulties both with co-workers' attitudes and specific tasks such as transcriptions. Leslie explained that the decision to disclose at work was complex.

Leslie's hearing loss had affected her lifestyle. Leslie had been involved with music and dance since she was a young girl, and she continued to enjoy dancing. She was a member of both CHHA and the American counterpart, Self Help for Hard-of Hearing People (SHHH). Leslie was just learning about other devices and the possibilities of assistive technology. Leslie identified several issues that she wanted to address: her difficulty with disclosure to authority figures, how to disclose, what specific suggestions to give to others, and her anger regarding the delay in diagnosis of her hearing loss. Leslie was also re-evaluating decisions she had made in the past, before her hearing loss was diagnosed. These decisions were certainly affected by her hearing difficulties;

for example, Leslie attended university courses in linguistics but dropped out of the classes when she had difficulty understanding.

Leslie was interested in participating in the rehabilitation classes. She was hopeful that the classes would help her cope with her loss, and she was excited about the possibilities the program might present. Initially, she caught herself making excuses to not attend but she was now looking forward to connecting with other working people who were hard-of-hearing.

In the last two interviews, Leslie described the program as different from what she expected but she stated that the process "felt right". She enjoyed the general discussions, speechreading exercises and information, explanation of the audiogram of familiar sounds, and the discussions on assertive behaviour. Leslie believed that she was more aware of her own needs and more confident with her hearing aid. She began wearing her hearing aid to her dance classes and enjoyed the benefit that she received from it in that situation; she had never worn her aid to a dance function in the past. Leslie reported that she was more accepting of her hearing loss, more able to share her knowledge from the classes, and that she felt more socially capable. She felt "more comfortable in her own skin". Leslie discussed her belief that she could possibly return to school, a feeling that she hadn't believed possible in the past. Leslie was interested in participating in future rehabilitation classes.

<u>"Hillary"</u>

Hillary was a 37-year-old female. Hillary suspected she had had her hearing loss since childhood. However, her hearing loss was not diagnosed until, at 24 years of age, she was encouraged by her friends to get her hearing tested. Hillary's sensorineural hearing loss was moderately severe in the low frequencies but was mild at frequencies above 2000 Hz bilaterally. She had been wearing amplification for the past 13 years. One year prior to the study, Hillary obtained dual-channel programmable hearing aids fit bilaterally. Although she had been advised to wear her amplification consistently and "incorporate them into her being", she admitted that she only wore the aids when it was absolutely necessary. Hillary wondered if even more expensive hearing aids would make her happy, but she was extremely bothered by the amplification of noise through the hearing aids. This prevented her from wearing her aids more often. She also

suffered from tinnitus. Hillary readily admitted that she hated wearing hearing aids and hated her hearing loss.

Hillary worked for an agency doing temporary office work, but she would have liked a more permanent career outside the realm of secretarial jobs. Hillary graduated in 1999 with a B.A. in Psychology and reported that she was more creative than scientific. The Myers-Briggs personality inventory classified her as an introverted, intuitive, and feeling person. She used to be more shy and quiet but had become more forward and forthright. Hillary worried about her social skills; when tired, she tended to withdraw. She also worried about her abilities to fit into a group at work because, as a temporary worker, she didn't make an effort to interact with others on a regular basis.

Hillary didn't believe that her hearing loss affected her lifestyle. She did, however, become annoyed at repeatedly missing jokes. She believed others were apologetic and accommodating regarding her hearing loss. Although her hearing loss was diagnosed 13 years ago, she was struggling with accepting the reality of it. Hillary believed that her hearing aids and ability to disclose her hearing loss had been the most valuable in helping her to cope with her loss. She was a CHHA member and attended occasional meetings.

Hillary was interested in participating in the rehabilitation group. Ideally, she would rather have had an operation to restore her hearing. Hillary believed that hearing loss was a "boring topic" and that the program "sounds like a lot of work". However, she believed her participation was a proactive step in dealing with something that frustrated her. She believed the classes would provide a new understanding of her loss, support for her difficulties, and the opportunity to meet others.

In the final interview, Hillary described her new job, teaching ESL; she admitted that the job was difficult, but she was enjoying the change from office work. Hillary reported that she enjoyed the rehabilitation class and was able to gain awareness and support through the information and her classmates. She was happy to have found a place within the program where she was able to share her own stories. Hillary admitted that she had "increased her own compassion" for herself. She reported that she was still not wearing her hearing aids consistently, and doubted if she ever would. Hillary had many unresolved work issues such as fear of losing her job, not getting a job, fear of failure, and whether she was professional enough. Hillary would have liked to experience a continuation of the rehabilitation program.

"Linda"

    Linda was a 41-year-old female. Linda was diagnosed five years before this study with a mild hearing loss that was presumed to be the result of childhood meningitis when she was eight years old. She considered that loss to be a nuisance and annoyance. Two months prior to this study, Linda experienced a sudden severe unilateral sensorineural hearing loss in her left ear. Doctors and nurses told her that her difficulties were the result of an ear infection and that the loss would disappear with time. After five requests for an ENT referral and a subsequent appointment, a specialist told Linda that her hearing loss was permanent, although it might have been treatable if he had seen her earlier. The ENT also told her that her symptoms could be the result of an acoustic neuroma or tumour. Linda reported that the last two months had been extremely difficult, "an emotional roller coaster', due to the devastation of the hearing loss, anger about the misdiagnosis, and fear of the tumour. An MRI later confirmed that she did not have a tumour.

    Linda had made major lifestyle adjustments in dealing with the loss. She had been unable to work in her job as a counselor because the effort to concentrate was too difficult and tiring. She claimed her biggest loss to be in her social life insofar as she had stopped going out with friends. She was tired, irritable, and extremely sensitive to sound. She was unsure of how to deal with disclosure of her hearing loss, especially to her clients. Linda didn't think that people understood the complexity of hearing loss; she thought they believed increased volume would solve all her problems. She had experienced the annoyance and frustration of others when she could not hear or understand them. She also felt frustrated when she had to ask for repetitions.

    Linda had tried a hearing aid for her earlier, milder hearing loss. She did not like wearing the hearing aid because she "could not get used to it". Linda reported that there was no comparison between the two experiences of hearing loss. She was having such a difficult time with her loss at the beginning of this study that she was going to try a CROS hearing aid to pick sound from her poor ear and present it to her good ear. She was referred to WIDHH by a co-worker who was also hard-of-hearing. Linda also planned to connect with other individuals who were hard-of-hearing through CHHA.

    Linda claimed she was excited to hear about the possibility of a hearing rehabilitation program and believed it was her "life-line". She admitted that she had unrealistic

expectations regarding speechreading, but she was still very interested and highly motivated to learn.

In the final interview, Linda explained that the timing of the class had been poor for her; she did not function well in the mornings. Although the timing was inconvenient, Linda felt the many of the topics covered throughout the program were helpful, including lipreading, strategies, and assertiveness. By the end of the program, she had obtained her hearing aids, but she was not wearing them consistently because they sometimes made the situation worse by amplifying background noise. Linda planned to see a neurologist to follow up on the "weird sensations" in her head. While she reported that her work and social life remained severely restricted by the hearing loss and that situations were still difficult and depressing, she definitely noticed that she was hearing and understanding more conversations by concentrating on the lips of the talker.

"Tony"

Tony was a 33-year-old male. He was born three months premature and believed the noise from the incubator may have caused a noise-induced hearing loss. Tony's hearing loss was not diagnosed until the age of five; his family doctor first denied there was any hearing impairment. Tony's sensorineural hearing loss was moderately severe sloping to profound in his left ear and severe sloping to profound in his right ear. Tony had worn hearing aids since he was first diagnosed; initially the adjustment was difficult, but Tony had become dependent on his aids and heard little without them. He believed his hearing aids had provided the most value to him in helping him cope with his loss. He was familiar with and had used a variety of ALDs: FM systems, closed captioning, and TTY[32], VCO[33], and MRC[34] for the telephone. Tony expressed an interest in hearing ear dogs.

Tony had relied on reading lips from an early age but had a speech production problem due to his lack of hearing as a child. He attended the "oral" program in a

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[32] TTY (TeleTYpe) or TDD (Telephone Device for the Deaf) is a telephone with a screen and/or printer that transmits typed messages through the telephone line, instead of verbal messages.

[33] VCO or 'voice carry over' service allows an individual who is hard-of-hearing to speak to a person on the telephone and read the other person's response on the VCO phone's display screen. A message relay operator types the other person's response. A VCO phone is a combination of a TTY and a traditional phone.

[34] MRC is "message relay centre", a service provided by telephone companies whereby an operator serves as a translator for those using a VCO phone or TTY. The operator types what is spoken so the person using the TTY or VCO phone can read the conversation and respond verbally.

special school for children with hearing loss. Tony did not become aware of sign language until high school, but he later learned to use some American Sign Language (ASL) with Deaf[35] friends. He found school difficult, and English was the most difficult subject for him. Tony attended the adult education program to attain his GED[36] at Vancouver Community College, but he was dissatisfied with the program. Tony wanted to attend a night school program but was struggling to find an appropriate program.

Tony claimed his hearing aids were expensive, but he was very happy with them; he had owned them for less than a year. His new bilateral hearing aids had dual-channel programs and a remote control. Tony worked at a drug store as a cashier and stock person, and his employer subsidized the purchase of his most recent hearing aids. His co-workers were pleased with his performance with this new technology, and he believed they had noticed an improvement in his communication abilities. Tony worked in a noisy environment, and he felt people were, in general, impatient. He had difficulty on the telephone. Tony felt he had to work harder than his co-workers to prove his abilities.

Tony reported thinking about his hearing loss but accepting it as part of him, since he had never experienced normal hearing. He believed that the general public does not understand hearing loss; from his experience, they believed a person to be either deaf or to have normal hearing. Tony believed that it was important for everyone to understand hearing loss because he was frustrated by the large number of people who yelled when they spoke to him. Tony was interested in participating in the rehabilitation program.

In the final interview, Tony reported that he had enjoyed the classes. Through his participation in the program and comparison to his classmates, Tony had become aware of his advanced ability to read lips but also of his speech production problem and how it likely resulted from the early onset of his hearing loss. He reported enjoying the relaxation exercises. Over the course of the program, Tony also became interested in seeking an employment change from the place he had worked for 10 years. Tony

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[35] A hard-of-hearing person is defined as "an individual who has a hearing loss and whose primary mode of communication is the spoken word" (Laszlo, 1994, p.248). Deaf people "communicate primarily by sign language" (Laszlo, 1994, p.248).

[36] GED is a graduate equivalency degree that provides the equivalent of a high school diploma to those who did not graduate from secondary school.

indicated that he would enjoy a continuation of this program, and he also discussed the importance of co-workers and bosses also attending similar programs.

"Derek"

At the time of the study, Derek was a 68-year-old male. He had grown up in Germany and, as a boy, had begun working in a repair plant. Derek had complained about the noise at the time, but he had been ridiculed and, therefore, he had chosen to continue working in the noisy environment. After moving to Canada, Derek worked in construction. When he noticed he was having difficulty understanding on the job, he had a hearing test and was fitted with a hearing aid, which provided limited help. Derek's sensorineural hearing loss was moderate, sloping to severe, bilaterally. He believed his hearing loss to be noise-induced. At the age of 57, Derek retired early because of increasing difficulty hearing on the job.

Derek was very aware of his hearing loss on a daily basis but admitted that "on a lucky day" he can forget about it. He resisted getting a second hearing aid for some time but finally did so several years ago, because he was having increased difficulty understanding conversations and was embarrassed due to misunderstandings. Derek also believed his hearing loss to be age-related; at first, he felt that disclosing his hearing loss was tantamount to admitting that he was old. By the time of this study, Derek was disclosing his hearing loss so his communication partners would make an effort to be heard. He did not think he was a good communicator, but he believed that this was personality-based rather than the result of his hearing loss. He had remained very socially active; he participated in his strata council, volunteered for the Vancouver Police Department, and enjoyed many outdoor activities such as hiking, biking, and kayaking.

Derek believed that he had made lifestyle changes to accommodate his hearing loss. In addition to retiring early, Derek limited his leadership roles in hobbies and volunteer activities. He used a Clarity phone, which allowed him the ability to adjust the volume and tone of the speaker and ringer. Although he had tried other assistive devices, he had not noticed any significant benefit from them. He sometimes pretended to understand. Derek believed that his hearing aids had provided him the most benefit in coping with his loss; he admitted that he had a love-hate relationship with his aids. The negative aspects of hearing aid use were that he had to deal with moisture problems,

and he worried about the aids causing additional noise damage to his hearing. He also believed that his ability to disclose his hearing loss provided additional benefits over those attributable to the hearing aid.

Derek was interested in participating in the rehabilitation program. He had been unaware of such programs until this project but believed he had "everything to gain and nothing to lose" by participating.

In the final interview, Derek reported that he was "more than satisfied" with the classes. He believed that, through the rehabilitation program, he had attained increased awareness, tools that enabled a better ability to cope with his hearing loss, a sense of community, and a useful diplomatic approach in dealing with others. Derek stressed the importance of the relaxation exercises. Finally, he said he would definitely attend another rehabilitation program.

The participants in this group consisted of a combination of men and women, both working adults and seniors. Each participant who agreed to attend the rehabilitation program was a hearing aid user. Degree of hearing loss varied among this group, and there was a mixture of newly diagnosed and congenital hearing losses. I believe it is also interesting to note that I was unable to predict that these particular participants would agree to attend the rehabilitation program at the time of the initial interview; some of the participants who I felt might decline were enthusiastic participants. Each participant who had completed the rehabilitation program expressed some interest in ongoing rehabilitation through either an organized class or support group.

Dropout Group

This group consists of two individuals who accepted the offer to participate in the hearing rehabilitation program but were unable to complete the program: Cathy and Gina.

"Cathy"

Cathy was a 55-year-old female. Four years prior to the present study, she first recognized symptoms of hearing loss because she was having parallel conversations with her husband. Due to a poor experience with an ENT, she waited four years to address the problem. Two months prior to the present study, she had become aware of difficulties in her job as an administration assistant, and she made an appointment at

WIDHH on the recommendation of a friend. Cathy had a moderate sensorineural hearing loss bilaterally. She had ordered two hearing aids and hoped they would help to improve her performance in difficult listening situations. The improved understanding she experienced from using the infrared system at the Playhouse Theater impressed her. Cathy was also more aware of using more strategies at work to reduce miscommunications. She suffered from tinnitus and migraines.

Cathy had believed that hearing loss was age-related; she didn't want to accept that her hearing loss was a result of aging. She had been shocked by the association between hearing loss and assumption of stupidity and the treatment she had experienced in the form of "cat-and-dog" language; she was insulted by the extremes to which some people simplified their language to 'enable' her to understand.

Cathy believed her recent audiology appointment had provided the most value to her in dealing with her hearing loss. She was relieved to see her hearing test results were as good as they were, because her ENT had implied a more serious degree of loss. At her recent audiology appointment, she also learned hearing loss was not necessarily a result of aging. Her husband had had difficulty understanding the hearing loss and its implications, but his participation in her audiology appointment helped him to understand it; he had become more comfortable with the process of helping his wife cope with her hearing loss.

Cathy was interested in participating in the hearing rehabilitation course and was looking forward to learning strategies from classmates who were also hard-of-hearing. She believed she was participating as a result of her accepting personality, the support of her husband, and the anticipation that her hearing abilities could decease.

In the final interview, Cathy reported being more aware of her hearing loss; her new hearing aids had made her realize how much information she had been missing. Many difficult listening situations had improved, and she was not straining to hear when she wore the aids. Cathy reported that the decision to stop attending the rehabilitation program came only after serious consideration. She had been enjoying the classes and was "extremely sorry to have to back out". Cathy reported benefits in terms of gaining knowledge and social connections through the two classes she had attended; she enjoyed the speechreading exercises. Cathy said that she would recommend the program to others and would enroll in a future program, especially if her hearing decreased and she was not coping well with her loss.

"Gina"

Gina was a 47-year-old female with a congenital hearing loss. Her hearing was normal to 1000 Hz, sloping to a severe sensorineural loss bilaterally above 1000 Hz. Just prior to this study, Gina had moved to BC and, at the time of the first interview she had just been hired in a part-time position as a health literacy coordinator. As a single mother, she reported pressure to remain employed. Her employment over the last 20 years had included employment counseling for those who are hard-of-hearing and advocacy for people with disabilities.

Gina's "ski-slope" hearing loss had prevented her from wearing amplification for many years. Fifteen years prior to the present study, significant life changes had prompted a search for appropriate hearing aids and, since that time, Gina had worn a variety of aids: ITEs, BTEs, and finally, digital BTEs. She had also used a variety of assistive devices, including an FM system, TTY, VCO phone, portable telephone amplifier, and shake-awake alarm. Gina was able to communicate using ASL, which she had learned through employment with people who were Deaf. Gina believed that she had developed a large repertoire of coping skills through her work experience but also by virtue of "trying to get along professionally in the hearing world". A recent car accident had added to usual life stressors.

Gina was very aware of her hearing loss on a regular basis and encountered its effects in every aspect of her life: social, recreational, occupational, and educational. She had made lifestyle changes to accommodate her hearing loss and was very aware of her energy level in relation to her hearing difficulties. Gina was constantly assessing, prioritizing, and asking herself "what's most important right now?". She claimed to be getting better at her new priority: taking care of herself. Gina used disclosure and specific suggestions to her communication partners to better enable them to meet her needs.

Gina had had extensive involvement with the hard-of-hearing community. She was a member of CHHA and planned to join CHHA-BC when her employment issues were resolved. Before moving to BC, Gina had also helped to organize weekly hard-of-hearing groups for hard-of-hearing individuals, and found support for a branch of the Canadian Hearing Society in Ontario. She believed employment issues needed to be a primary focus in helping individuals who are hard-of-hearing and believed that information to help those with hearing loss should be more readily accessible. Gina

believed that the stigma associated with hearing loss was one of aging and reduced cognitive ability. She felt that the general public regarded hearing loss in a very simplified manner: you either have hearing or you don't. Gina felt that self-esteem and advocacy went hand-in-hand, but self-esteem suffered as a result of a hearing loss, and learning to be assertive was a long process. Gina felt she had gained the most value in dealing with her hearing loss from the development of her advocacy skills and the use of technical devices, though she had a love-hate relationship with technology.

Gina was interested in participating in the rehabilitation class. Despite her involvement in the hard-of-hearing community, she had never participated in an organized program. Gina hoped to develop a new network of people, as she was new to the city and the province.

In the final interview, Gina explained her decision to discontinue attending the rehabilitation program. Primarily, the decision was based on a lack of time and energy. Gina had begun a second part-time job, was still dealing with injuries from her car accident and additional health issues. Gina reported that she enjoyed the classes and the different perspectives and experiences of the participants. Although she chose not to invest energy in the speechreading activities, she had gained valuable information from identifying specific environmental factors that affected her abilities to communicate. The class experience, through the three classes she attended, validated her own hearing loss experience and affirmed that she was not alone in her struggle for assertiveness. Gina acknowledged a lifetime of hearing loss had enabled her to develop her skills and coping abilities; however, she also credited a long-time hearing loss as detrimental to positive self-esteem. Gina had re-connected with CHHA and met two women in the class with whom she planned to continue a social relationship. She indicated that she would consider enrolling in another hearing rehabilitation program in the future, once she had settled into her new jobs.

The two participants in the group who did not complete the rehabilitation program were both employed women and hearing aid users. Time and energy were the reasons why they were unable to continue their participation. Both said they would participate in such a program in the future, if their schedules allowed it.

Chapter 5: Theoretical Framework and Results Overview

Overview

This chapter provides an overview of the results for the current study. It presents the theoretical framework, themes, and core category that emerged from the data. In addition to explaining the purpose of the remaining results chapters, it also discusses the rationale for combining the data from the four participant groups into one all-encompassing framework.

Comparison of Group Frameworks

As discussed in the Chapter 3: Methods, participants were placed into one of four groups based on three conditions: prior experience with a hearing rehabilitation program, the decision to participate in a program offered as part of the current study, and completion of the program. The four groups were: 'Experienced', 'Yes to Rehabilitation', 'No to Rehabilitation', and 'Dropout'. The analysis of the data obtained for each of the four groups progressed independently until the final stage of framework development. In the final stage, categories, properties, and dimensions of the interview and journal data were compared and integrated into one comprehensive framework to facilitate group comparisons[37]. A detailed description of each of these items can be found in Chapter 3: Methods.

Comparison of the framework indicated that group differences would not provide a substantial analysis feature, other than the obvious delineation between participants who had experienced a rehabilitation program and those who had not. A discussion of the limited group differences that were observed in the frameworks will be presented in Chapter 11. The questionnaire data were also analyzed by groups to determine if there were quantitative differences and how any such differences related to the interviews (see Chapter 11).

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[37] The framework consists of an organization of the codes into three or four columns, grouped according to their level of abstraction; more abstract codes were identified as categories and were grouped on left of the framework, the different properties of these categories were grouped in the center, and the more concrete codes (dimensions) were grouped on the right.

Theoretical Framework

The complete theoretical framework that emerged from the data is presented in Appendix Q. The framework details the five categories that were identified in the data: **understanding hearing loss, personal experience with hearing loss, interaction between person with hearing loss and society, taking action**, and **reflections on rehabilitative experience**. Each category is described in detail in its own chapter to give a comprehensive view of its properties and dimensions. Chapters 6 to 10 present the categories from the present study, with quotes and descriptions from the participant interviews and journals.

Theme Development

Themes are "recurrent or dominant ideas that do not fit solely in one part of the framework but appear in different parts of the theory" (Grams, 2001, p.44). Three inter-related themes, **identity, challenge**, and **adjustment,** emerged from the interviews to explain why some individuals with hearing loss seek advanced help in the form of group hearing rehabilitation programs, while others do not. These themes will be described, connected, and supported with interview and journal data in Chapter 12.

Core Category

The interconnection of the categories and themes of this study will be presented in the explanation of the core category: **ecological balance**. Figure 5.1 presents an overview of the concept of ecological balance as it pertains to advanced help-seeking for hearing loss and shows the connection between the categories and themes within the core category of ecological balance. A detailed discussion of the core category and more detailed figure demonstrating ecological balance will be presented in Chapter 12.

Figure 5.1. Overview of the model of ecological balance.
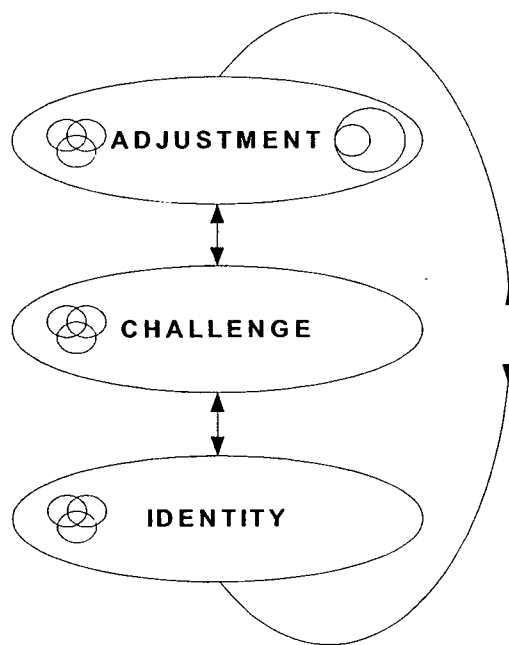
Summary

The present chapter provides an overview of the results section of this study and explains how the findings of this study are to be presented in Chapters 6 through 12. In particular, the theoretical framework, categories, themes, and core category were identified.

Chapter 6:   Understanding Hearing Loss

Table 6.1. Portion of theoretical framework describing theoretical category: Understanding hearing loss

Category	*Property*	*Dimensions*	*Dimensions*
Understanding hearing loss	Hearing loss history	Time with hearing loss	
		Degree of hearing loss	
		First signs	
		Cause	
		Tinnitus/vertigo	
		Improvement in hearing	
		Childhood experiences	
		Testing	
		Prognosis	
	Family history of hearing loss		
	Comparisons with hearing loss	Hearing loss to hearing loss	
	Comparisons with hearing loss and other disabilities	Vision	
		Mobility	
	Comparisons of concepts and experiences	Ages	
		Attitudes	
		Communication	
		Experiences	
	Comparisons involving hearing aids		
	Explaining to others	Explaining hearing loss	
		Explaining hearing aids	
	Awareness of others' hearing losses		
	Technology: general	Psychological	
		Problems	

The purpose of this chapter is to describe how the participants in the present study came to understand their hearing losses and how they, in turn, share that understanding with others. Arriving at this understanding is truly a life-long process that often begins with the realization that hearing abilities have changed, or are not the same as others' abilities. The understanding evolves through personal experiences of testing and diagnoses, and comparing abilities and experiences with past abilities and experiences. It also involves the ability to explain the experience to others. Recognizing similarities and differences in others with hearing loss facilitates understanding the experience of hearing loss. The portion of the framework presenting the first category, *understanding hearing loss*, is shown in Table 6.1.

Hearing Loss History

The participants were asked to talk about their experience of hearing loss. They often began with a description of the first indication of a hearing problem and the steps taken to diagnose it. They described the time that had passed since the loss was diagnosed and the degree of the hearing impairment found. Cause of impairment, experience of tinnitus, possible improvement in hearing, childhood experiences, testing, and prognosis are presented.

Time with Hearing Loss

The time with which the participants had to adjust to their hearing loss was quite varied. Participants whose hearing loss had been diagnosed at birth or during early childhood discussed these factors. Tony's loss was suspected to have been present from birth but was not diagnosed until he was five years old. Hillary's loss was also suspected to have been present since childhood but it was not diagnosed until she was 24 years old, 13 years before the study. Linda had had childhood meningitis that was responsible for a milder loss, but she had experienced a sudden unilateral hearing loss only two months before the study. Ellen also experienced a sudden loss one-and-a-half years prior to the study. Leslie's loss was diagnosed four years before the study, and Kelly's hearing loss had been diagnosed for six or seven years. Although they had sought help only recently, both Cathy and Grace had been experiencing hearing difficulties for four and fifteen years, respectively. Robert and Ian's hearing losses had

been diagnosed 20 and 23 years prior to this study, and these men had been wearing hearing aids and coping with their losses for a similar amount of time.

Degree of Hearing Loss

The degrees of hearing loss of the participants were varied, ranging from moderate to profound, with some unilateral and bilateral, and both sensorineural and conductive types. See 'Chapter 4: Participants' for a complete description of each participant's hearing loss.

First Signs

Participants first recognized that they had a hearing problem for a variety of reasons. Other people were often the catalyst for seeking help for a hearing loss. Robert believed that family members realized that he had a problem before he did himself. Friends of participants encouraged them to get their hearing tested: Grace, Hillary, and Leslie. Tony's sister learned about Deafness and hearing loss as a part of a high school class and recognized the signs in her younger brother. Kelly became aware of her loss when it became difficult for her to participate in groups, and Judy had noticed more difficulty communicating with her husband and in groups. Ian became aware of his own loss when he recognized that he was frequently asking for repetitions and Roger when he started experiencing greater difficulty in high school. Difficulty understanding certain people provided the first clue to Janet that she had a problem. Cathy acknowledged her hearing problem first in her work environment, where she discovered she was "inviting the wrong people to meetings and just not hearing 'do' and 'don't'".

Cause

Not all of the participants were able to pinpoint a cause of their hearing loss. At the beginning of the study, Linda believed her loss might have been the result of a tumor; a subsequent MRI determined this was not the case. Prior to her diagnosis of Ménière's disease, Colleen was told that her loss might be a symptom of multiple sclerosis. Childhood middle ear infections had plagued Claire, and Ian believed his loss was related to his asthma medications. Robert and Derek believed their hearing losses were partly noise-induced, the result of working in high levels of noise.

Tinnitus and Vertigo

Tinnitus is the perception of ringing or buzzing in the ears when no physical stimulus is present (Montgomery & Houston, 2000). Many participants reported having tinnitus. Linda was quite bothered by tinnitus, and Leslie reported that she heard "ringing" in her ears. Cathy described her tinnitus to be "loud but manageable"; she compared her tinnitus to the sound of trains. Certain conditions were reported to exacerbate the problem. Kelly's tinnitus was the worst at bedtime, and stress or a hectic schedule appeared to worsen Leslie's condition. Hillary remembered her tinnitus from childhood when she would stick her finger in her ear to stop the ringing. The most severe case of tinnitus among the participants of this study was reported by Colleen. Her episodes of tinnitus were accompanied by frequent and severe vertigo attacks, which were symptoms of her Ménière's disease.

Improvement in Hearing

Several of the participants described past experiences where their hearing had actually improved. Janet noticed a marked improvement in her hearing after her stapes operations; she wished an operation would correct her current hearing problem. Annual trips to her ENT to have wax removed from her ears had improved Hanna's hearing abilities. Linda experienced instant relief once in the past, when a specialist removed a hairball from her ear canal. Kelly experienced a sudden unilateral loss once after putting oil in her ear; her hearing returned after a couple of days.

Childhood Experiences

Participants with congenital or childhood losses remembered hearing loss experiences from childhood. Gina had her tonsils and adenoids removed as a child, and Linda had meningitis when she was eight and experienced a mild hearing loss as a result. Claire had chronic middle ear infections as a child but received no treatment until she took control of the problem when she was 15 years old. Tony believed that premature birth was likely related to his hearing loss. Leslie received preferential seating in school and remembered favouring one ear as a child without realizing the cause was a unilateral hearing loss. Matt and Roger did not receive treatment for their hearing losses until high school, and Roger recounted childhood as a personal struggle.

<u>Testing</u>

Participants referred little to recent testing. However, Matt and Roger discussed their experiences from the past, and both men recognized there had been improvements in testing protocols over the years. Matt specifically referred to inadequate testing procedures in the 1960s. Repeated testing without a diagnosis was frustrating for Colleen, who had waited years to discover that her hearing loss was the result of Ménière's disease.

<u>Prognosis</u>

One participant reported having been given a prognosis regarding her hearing loss. Colleen was happy that her prognosis of deafness had not been correct; she was told she would likely be deaf by age 40 or 50.

Family History of Hearing Loss

Some participants had a family history of hearing loss. This experience of coping with the difficulties of other family members affected their approach to dealing with their own loss. Participants had watched or helped parents to cope with hearing loss, while others expressed concern over their own children and their children's hearing losses. Judy reported that her mother and grandmother had significant hearing losses. Michelle's grandmother and grandmother's three children, including Michelle's father, also had significant losses. Michelle reported that her father was "quite deaf" at 40, and she had her hearing checked regularly because she had watched her father give up on conversation and wanted to prevent the same reaction to hearing loss in her own life. Claire's mother and brother had hearing losses, as did Judy's brother. Both Hillary's and Derek's fathers had experienced noise-induced hearing loss. Linda's mother had an acoustic neuroma, and Linda described her as disabled in that she was housebound. Leslie was also influenced by her father's hearing loss. His loss was due to childhood meningitis, and Leslie continued to be alternately amazed at what he could, and could not, hear. Michelle discussed her concern for her 55-year-old son who was exhibiting signs of hearing loss without being ready to address the problem.

Comparisons with Hearing Loss

The participants often compared their hearing losses with the losses of others, in an effort to explain or describe their abilities or difficulties in relative terms.

Hearing Loss to Hearing Loss

Participants compared their hearing loss to the hearing losses of others with whom they were close. Leslie acknowledged that her hearing was better than her father's, and Claire considered herself to be lucky, compared to the troubles that her brother had with his hearing. Janet was aware that her husband's hearing loss was much more serious than hers, and Kelly was aware that friends and acquaintances had worse losses. She compared her own abilities to the abilities of other participants in her hearing rehabilitation group. Ellen also compared her hearing abilities to others with worse hearing loss; she believed she was fortunate to have hearing loss, although profound, in one ear rather than two. Judy reported feeling "grateful" for her degree of loss, when compared to others. Kelly discussed the difference between unilateral and bilateral hearing loss, and other participants discussed the benefits and limitations of acquired versus congenital hearing loss. Michelle reported that she felt saddened by those individuals who experienced sudden hearing loss and had to deal with the problems associated with hearing loss all at once.

Participants were also able to compare their own hearing losses at different points in time. Linda had had a mild loss for years and compared that loss to the sudden unilateral loss she experienced two months prior to the study; she believed there was no comparison between the two experiences. Janet compared her experiences with otosclerosis in the past with the more gradual hearing loss she was experiencing at the time of the study. She believed she was better able to cope with the current loss.

Other participants compared hearing loss with the two extremes of hearing abilities: normal hearing and Deafness. Hillary and Roger were able to see that, in certain circumstances, both people with normal hearing and those who are hard-of-hearing have similar struggles. Claire commented on the significant difference between populations of Deaf and hard-of-hearing individuals; Claire struggled to define a hard-of-hearing culture in contrast to the Deaf culture.

Comparisons between Hearing Loss and Other Disabilities

In addition to comparing their hearing losses to other hearing losses, the participants also compared hearing losses with other disabilities, such as visual, mobility, and cognitive impairments. These comparisons served many functions; they explained the understanding or lack of understanding of hearing loss by others and differentiated the perceived difficulties associated with different impairments and the services available for each type of disability.

Vision

Participants made several comparisons between the senses of hearing and vision. Kelly also discussed the comparison of increased volume to enlarged print type, in terms of neither of these strategies providing total relief from the impairments. Kelly quoted Helen Keller as having said, "hearing cuts you off from people, blindness cuts you off from things". Hanna reported that she definitely preferred hearing loss to blindness because she believed that blindness resulted in dependency on others. Robert's comparison of these senses gave him a way to demonstrate the effects of his loss to others; he believed it was much easier to get others to understand blindness, because hearing loss was more complex than just cutting out sound completely.

Mobility

Several participants compared hearing loss to a physical disability. Gina compared congenital hearing loss to a physical disability and recounted that the BC Coalition of People with Disabilities had been developed initially by those people who had lost the use of arms or legs through accidents. She believed these people were initially better able to advocate for their needs, which they had just recently lost. Matt also compared physical and hearing disabilities; he believed that both conditions involved accessibility issues. He wanted to advocate for greater support for people who are hard-of-hearing and believed that there needed to be "ramps for hearing loss".

Comparisons of Beliefs and Experiences

Although the participants were rarely asked to make comparisons to explain their interview statements, comparisons were often made to clarify and exemplify ideas.

Age

Comparisons regarding dealing with hearing loss at different ages were made by the participants and were based on both assumptions and personal experiences. With regard to services and support, Matt believed that there was more support for children with hearing loss than there was for working adults with hearing loss. Other participants felt fortunate that their hearing loss experiences occurred later in life. Kelly believed that elders expected hearing loss, while youth were more embarrassed by it, and Michelle agreed that hearing loss is a different experience for people when they are younger. Ellen suspected that disclosure of a hearing loss is more difficult for younger people, and Kelly believed that seniors found it easier to ask for help.

Attitude

The participants compared attitudes of the general public, as well as those who were hard-of-hearing. Matt compared the attitudes of people who lived in rural versus urban areas; he believed that urbanites were less tolerant of the difficulties resulting from hearing loss. In terms of comparing attitudes amongst individuals with hearing loss, Claire had been told that there were other people who were more troubled by hearing loss than she was, and Roger observed that the attitudes of people who are hard-of-hearing often depended on whether they were satisfied to just get by or whether they were seeking more fulfillment in their lives. Robert compared assertive and aggressive behaviors. On a personal level, Leslie wondered about her own attitudes and her decisions about whether or not to give up on a goal and whether she was avoiding a situation because of difficulties associated with hearing loss or simply because she was not interested in that activity. Gina described decisions she had to make in certain situations regarding whether to get the information she needed from someone (e.g., a store clerk) or to use the experience to educate them about hearing loss. Michelle described a journey in changing her belief that hearing loss was a personal problem to the attitude that shared responsibility was the best solution.

Communication

The participants compared different aspects of communication abilities and views on communication. Claire considered the approach to communication of the hard-of-hearing to be sloppy compared to the concrete approach of the Deaf. Kelly described

the difference between volume and clarity, while Colleen and Ian explained the difference between hearing and understanding. Language comprehension and production were compared; Colleen reported that she was often questioned about her hearing loss because of her unaffected ability to speak well. Derek talked about his ability to communicate one-on-one but not in a group, and he happily reported that he understood everyone at WIDHH. Hillary compared her comprehension ability to others' when she expressed her belief that no one in a class she took could understand a soft-spoken ESL speaker. Robert reported that many of his social efforts to communicate left him feeling "alone in a crowd".

Experiences

The participants compared experiences of hearing loss in an effort to better explain them. Matt struggled to find support and services to enable him to cope more effectively with his hearing loss; he believed social and government assistance was much greater for visual and physical disabilities than for hearing loss. Kelly agreed that there was less sympathy for those with hearing loss. When she compared her own experience to others', Janet believed that the experience of hearing loss was much worse for those who were also dealing with family responsibilities, employment issues, and tinnitus. Claire compared the group rehabilitation program to a "training" workshop. Hillary questioned whether her difficult experiences in a social environment were due to a lack of social skills and experiences or due to her hearing loss, and Roger believed that he had been required to make more effort to achieve the same accomplishments as his coworkers who had normal hearing. He believed that people could not understand the implications of hearing loss by reading information; some level of personal experience was necessary to truly understand.

Comparisons Involving Hearing Aids

In an effort to explain the purpose and benefit received from amplification, participants compared hearing aids to a variety of objects. Kelly compared hearing aids to glasses; this is a frequent comparison since sight is often compared to hearing. Judy pointed out one significant difference between hearing aids and eyeglasses: there is no stigma with glasses since they are so common. While many people are aware of the benefit of ALDs over hearing aids, Ian noted that his hearing aids could be

individualized to suit his specific hearing loss, while ALDs increased all frequencies equally. Hearing aids were also compared to assistive devices that accommodated disabilities of mobility. Roger compared hearing aids to walking canes. Matt compared the development of hearing aid technology to the improvement of "clunky straight wheel, weigh-a-million-pounds" wheelchairs of the past to the slim-line titanium-framed wheelchairs of today. Finally, Cathy made a financial comparison; she believed some people might have to choose a hearing aid over spending money on rent and food.

Explaining to Others

Participants had developed a variety of methods to explain their experiences to others, in an effort to obtain greater compassion and assistance with their needs. Participants also described their efforts to explain hearing loss and hearing aids to others. Some participants, by virtue of having spent more time coping with hearing loss, were more sophisticated in their explanations; those participants with newly diagnosed hearing losses still struggled to find successful ways to explain their experiences.

<u>Explaining Hearing Loss</u>

Grace described her hearing loss simply as a "problem". Kelly made efforts to explain that dealing with a hearing loss was more than simply increasing volume, and Hillary distinguished between volume and enunciation for her communication partners by telling them she needed them to speak more clearly, not necessarily more loudly. Ian told others hearing loss was "part of aging", whereas Roger believed it was important to teach others that hearing loss could happen to anyone, at any age. Roger wanted people to understand that hearing loss was different from not hearing anything.

Matt used the experience of speaking with people who had an accent as an opportunity to educate them. In a difficult listening situation resulting from a speaker with an accent, Matt said "you have a wonderful accent, but between your accent and my hearing, it's not working". In an effort to describe being bothered by noise, Kelly said, "if you've got a sore knee and somebody bumps it, it hurts more than if they bumped a good knee and hearing tissue is damaged -- it's more sensitive".

When Robert is questioned by friends because he hears but doesn't understand speech, he compares listening with a hearing loss to listening to someone speaking another language: "I can hear you but you might as well be talking Italian, German,

French because I don't know what you're saying". In a further attempt to explain his hearing loss to others he would:

> "sometimes tell people it's like being in a phone booth with glass walls all around. And I said you had a family reunion but you are in this glass booth, and you can see everybody and you can see their mouth going but you have no idea what they're saying".

Colleen also described feeling that "there's a glass wall between me and others".

<u>Explaining Hearing Aids</u>

The degree of experience with hearing aids seemed to mediate the way that certain participants explained their hearing aids to others. Kelly, who had several years of experience with amplification, wanted others to be aware that hearing aids did not solve all the problems of hearing loss; she told people that "hearing aids are not new ears". At the time of this study, Grace had been wearing her aids for less than two weeks. In an effort to explain the benefit she received from her aids, she compared amplification to a "restoration". However, she also admitted to not yet knowing the limitations of the hearing aids.

<div align="center">Awareness of Others' Hearing Losses</div>

For the participants of this study, the awareness of the similarities and differences of their experiences to the experiences of others who also had hearing loss added to their overall understanding of their own problem. Leslie admitted that she used to believe that she was the only one having trouble with hearing loss. Hillary had become aware of different degrees of hearing loss, and Kelly had learned about, and met, people with greater hearing losses than her own. Kelly believed that a person's response in conversation demonstrated whether they heard or not and possibly whether or not they had a hearing loss. As a result of his own loss, Derek believed he was more sensitive to whether others were understanding during a conversation. While Michelle encouraged hearing aid use by others, Claire was aware that others did not do well with amplification. Claire worried that there were a lot of 'lost' individuals with hearing loss who were unaware of learning opportunities. Claire had spent time observing other people who were hard-of-hearing and believed some individuals with hearing loss wanted quick answers, while others were happy to stay as they were in isolated

environments. She identified maladaptive behaviors in others and analyzed her own behaviors in an effort to better understand her hearing loss.

<div align="center">Technology: General</div>

In addition to utilizing appropriate amplification devices (see Chapter 9: Taking Action), the participants displayed an understanding of hearing loss through a discussion of the implications of using technical devices. They identified such implications as the psychological effects of technical devices on the user and others in the environment and an acknowledgement of the problems associated with technology. Understanding the consequences of using technology seemed to go hand-in-hand with understanding hearing loss.

<u>Personal Observations</u>

Participants identified some of the psychological consequences of using technology in an effort to improve the difficulties associated with hearing loss. Colleen acknowledged that in order to use the devices, an individual must admit to having a problem and choose to overcome the stigma associated with using the devices. Claire admitted that she became more interested in the devices, and accepting of them, after the rehabilitation session that dealt with a variety of assistive technologies. Grace believed that her hearing loss was not bad enough to warrant using additional devices, and Derek doubted that he would realize any personal benefit from them.

<u>Problems</u>

Through understanding the problems associated with technology, the participants displayed a deeper understanding of the consequences of hearing loss. The expense of technology was certainly a deterrent to its use. Maintenance of devices was identified as a problem, and Matt specifically identified maintenance of the community-based devices at theaters to be a problem. Compatibility between hearing aids and ALDs was identified as an issue that often had to be resolved for proper functioning of all devices. Participants appreciated the benefit they obtained from the technology but struggled with the problems in a "love-hate" relationship. Roger addressed the limited capabilities of the available technology, and he stressed that those interested in

providing hearing services needed to focus on interventions beyond technical help, such as services to help integrate the person into their own environment.

This chapter discussed the variety of means used by the participants to gain a more comprehensive understanding of their own hearing loss. To understand hearing loss, participants considered many aspects of their own losses as well as those of others. Participants compared hearing losses to other health conditions and compared beliefs and experiences related to hearing loss. Participants also described how they explained hearing loss and hearing aids to others, demonstrating their own degree of understanding.

Chapter 7:   Personal Experience with Hearing Loss

Table 7.1. Portion of theoretical framework describing theoretical category: Personal experience with hearing loss

Categories	Properties	Dimensions
Personal experience with hearing loss	Self-perceptions	Acceptance
		Denial
		Assertiveness
		Awareness of own hearing loss
		Lifestyle
		Abilities
		General positive self-perceptions
		General negative self-perceptions
	Disclosure	Purpose
		Method
		Process
		Reasons for not disclosing
		Of hearing aid
	Emotional reactions	Hearing loss
		Communication difficulties
		Possible solutions: positive
		Possible solutions: negative
	Effect on communication	Desire to communicate
		Inability to communicate
	Underlying personal concerns	Voice
		Safety
		Humor
		Function in social situations
		Work
	Identification of specific problems from personal experience	Environment: noise
		Environment: other factors
		Speaker
		Listener
		Message

The purpose of this chapter is to describe the significance of hearing loss for the participants. Throughout the present study, participants discussed the extent to which their hearing losses affected them on a personal level. The consequences of personal hearing loss discussed in this chapter include: altered self-perceptions, decision-making related to disclosure of hearing loss, emotional reactions, and effects on communication. Hearing loss affected the concerns of the participants, and this chapter discusses those concerns. This chapter will also discuss factors identified by the participants as affecting their ability to communicate. The portion of the framework presenting the second category, *personal experience with hearing loss*, is shown in Table 7.1.

Self-perceptions

The existence of a hearing loss influences how a person feels about himself or herself. The participants in this study discussed many aspects of their self-perceptions; they described their acceptance and awareness of their hearing loss, how they reacted to the loss, and how it affected their abilities and life choices.

Acceptance

The participants in this study spoke of their acceptance of their hearing loss, hearing aids, and the consequences of hearing loss. Participants stated that they accepted their hearing loss, but that the acceptance had been a gradual process. Although Michelle had been determined to accept her loss, she admitted it still took time. She believed hearing loss was "reality". Tony readily acknowledged acceptance of hearing loss, but as his loss was congenital, he had never known life without hearing loss. Ellen "just accepts it" because she believed her situation "could be worse". Kelly believed her acceptance was aided by the prevalence of hearing loss in the elderly, and she believed she had also become more accepting of incomplete information during her typical conversations with others, as a result of her loss. Grace accepted her loss as a part of who she was, and she was also accepting of how she looked when wearing hearing aids. Claire believed that her age and experiences affected her attitude, which was to focus on a problem and deal with it. She also believed that accepting her loss meant she was ready to be helped. Leslie's acceptance was also growing. She was becoming more accepting of herself, and because of increased knowledge about

hearing loss, she admitted she was more comfortable with herself and was feeling good about using compensatory strategies. Roger believed that accepting hearing loss led to success in work and married life.

Other participants struggled more to accept their losses. Linda admitted her hearing loss would have been easier to accept if it had been caused by an acoustic neuroma insofar as identifying a cause often aids the process of acceptance. Colleen resisted accepting her loss, as she believed that acceptance lead to reliance on others, and she admitted an incongruence between her acceptance on an intellectual versus on an emotional level; she accepted that her impairment existed, but she had difficulty accepting the consequences of being a person who was hard-of-hearing. A discussion of acceptance is better appreciated when accompanied by a discussion of denial, which follows below.

Denial

Colleen also believed that there was a positive effect of not accepting, but rather denying, her hearing loss; she felt she was a stronger, more independent person. Colleen resented being hard-of-hearing and believed she would have to become deaf in order to accept her hearing loss; until that time came, she planned to continue to "act like a hearing person". Hillary was struggling with the reality of her hearing loss and was resisting a "lifelong association" with hearing aids. Cathy believed that she had denied her hearing loss for years because she was "resisting aging". Roger discussed denial as avoidance of the problem, and Michelle admitted that she believed she could "cover up" her hearing loss. She believed that pride inhibited acceptance of the loss, and that she continued to deny her hearing loss for a time because of the "pride thing". Linda sometimes forgot about the consequences of her loss, indicating that she had not fully accepted her loss; for example, she would agree to meet friends at a restaurant and not remember that she would have difficulty communicating until she was sitting at the table. Leslie had struggled with her loss; she discovered that she had developed an ambivalent attitude to cover her difficulties due to the loss. When she discovered that she was unable to do something, she would exhibit the attitude that she "didn't want it anyway". Realization of this pattern of reactions helped her to become more accepting of her hearing loss.

<u>Assertiveness</u>

Assertive behavior can be contrasted with passive or aggressive behavior; quite simply, assertiveness is putting yourself and your needs first but also acknowledging the needs and feelings of others. Roger acknowledged that being assertive was a personal choice, and skill in being assertive was learned over time. He also believed it was a necessary skill and felt it was important to encourage assertiveness in children who were hard-of-hearing. Gina believed she was more assertive than she had been in earlier years, as did Linda, Hillary, and Claire. Participants reported benefits from being assertive. Michelle "feels good about her assertiveness", and Leslie believed that it was becoming easier for her to be assertive. Leslie was enjoying this new behavior and was now going into situations more aware of her needs and feeling okay about trying to fulfill those needs.

<u>Awareness of Own Hearing Loss</u>

For many participants, awareness of their own hearing loss developed gradually, and they discussed this process. The participants also described their awareness of their loss on a daily basis. Michelle and Roger claimed to "always" be aware of their hearing losses, while Hillary and Claire described their awareness as "constant". For others, their environment determined their awareness; Ian was aware when he was with other people. Janet was aware of her loss only when she was with certain people, and Colleen was more aware when she was busy. Derek reported being aware of his hearing loss daily, especially when he was with other people, but he admitted that "on a lucky day" he could forget his hearing loss. Derek said awareness of his loss made him feel older. Cathy's hearing abilities were improved by her hearing aids, and she had not realized the extent of her hearing loss until she obtained her aids. Hillary was conscious of the need to exert more energy to understand certain people, and she also reported a heightened awareness that her hearing loss alienated her, because in certain situations she didn't feel she was "part of the group". Her father's hearing loss helped Michelle to be more aware of her own loss, and she reported being more aware of it when participating in groups. Leslie was aware that she was working hard to hear and that she was "hyper-aware" of her difficulties due to her hearing loss. She felt her hearing loss was worse on a "bad day". In the past, however, she had not made the connection between feeling incapable of dealing adequately with life events and her

hearing loss, and she often believed her behavior was due to her personality, rather than her hearing loss. Leslie's awareness of hearing loss helped her to come to terms with decisions and events from the past when, 10 years later, she was able to understand previously unexplained difficulties in her marriage and at university.

Lifestyle

Some of the participants talked about their perceptions of their lifestyle and how these perceptions affected their lives. Janet believed that becoming familiar with WIDHH because of her husband's hearing loss had been a catalyst for her acceptance of her own loss and the possible benefit of amplification. Matt believed that his technology-oriented lifestyle predisposed him to embrace the technological solutions that helped him deal with his loss; however, he also believed his addiction to smoking was detrimental to his remaining auditory ability. Leslie was tired after work. Claire thrived on stimulation, whereas Derek admitted that he never liked small talk. Linda felt that she couldn't really afford to look after herself properly, and Claire believed she was vulnerable as a mental health worker. Michelle acknowledged that she mainly socialized with older people, but she considered this to be positive in that she was aware of the prevalence of hearing loss. She also believed that many older people had a "defeated acceptance" regarding hearing loss; she looked for an approach that was more positive and proactive.

Hearing loss also affected lifestyle decisions. Kelly considered her hearing loss in her decisions about whether or not to participate in groups, and Claire described her need to accommodate her hearing loss in setting personal goals. Derek and Roger had retired early, and Roger also went through counseling with his bride-to-be to ensure they could deal with the anticipated effects of his hearing loss in their marriage. Each of these lifestyle factors affected how the participants viewed themselves and their hearing losses.

Abilities

The participants in this study discussed their views on their abilities both in light of, and in spite of, their hearing losses. Ian was shy, but wanted to contribute; he found it hard to be aggressive. Matt was highly confident of his knowledge and abilities, and he had a positive self-image. Roger felt he was goal-oriented, determined, and patient.

Both Roger and Tony believed they were intelligent. Derek believed his hearing loss made him feel "useless" but also believed he was "good with his hands". Claire and Tony believed they were very observant. Claire admitted that it was depressing to acknowledge that she didn't always hear well with two hearing aids, and Kelly noticed that it was difficult for her to listen and take notes simultaneously. Gina recognized her need for increased focus and concentration in order to understand, and Linda had more difficulties on the phone when she was tired.

Leslie believed her good communication habits were automatic, and she was creative. She recognized she was being more social and feeling like less of an outsider than she had been prior to the rehabilitation program. She believed she could successfully attend university, if she chose to return for further education. Michelle felt she was handling her hearing loss "capably", and Grace believed she was aware of her personal strengths and was expressive in her style of communication. Gina believed she had good speech discrimination abilities, had developed useful advocacy skills during her years in the workforce, and had made improvements in her ability to care for herself.

Roger prided himself on being able to analyze a situation to determine his needs and abilities. Claire liked to systematically solve problems, while Leslie admitted having difficulties in analyzing problems and explaining her hearing loss to others. Throughout the course of the study, her efforts to improve these abilities had been successful.

General Positive Self-perceptions

In addition to the self-perceptions discussed above, the participants also discussed general self-perceptions that were sometimes positive and sometimes negative. Kelly believed that even a little bit of hearing was important, and she felt very fortunate to hear. Claire and Roger claimed that their realistic expectations helped them maintain a positive attitude. Kelly believed that more devices for hearing loss were being used and that increased visibility would lead to a greater understanding of hearing loss, and Claire wanted to write about her hearing loss experience. Matt focused on positive thinking, Leslie felt "empowered" with her new knowledge, Gina was meeting new people, and Michelle was not afraid of new experiences. Ellen believed she was coping well, and Grace felt more relaxed with her hearing aids and admitted she felt "full of herself" and her newfound ability to communicate with her hearing aids.

<u>General Negative Self-perceptions</u>

The participants also experienced a variety of negative self-perceptions. Hillary reported that she found the topic of hearing loss overwhelming and there were times when she experienced a sense of paranoia when she was unable to communicate well. Tony sometimes blamed himself for not listening carefully enough when he misunderstood. Robert reported that, in certain situations, he felt like an "idiot", Judy felt "stupid" when she couldn't understand the remote for her hearing aid, and Kelly felt "conspicuous" when she used strategies to help her cope with her loss. Robert reported that it was easy to become depressed, and Leslie found that when she focused on the negative, she experienced reduced confidence, poor self-esteem, and fear of new environments. Hanna admitted she was not a social person and was uncomfortable in groups; she felt like a nuisance for complaining about not being able to hear. Claire reported that she felt "vulnerable", and she was scared of possible dependence as a result of her hearing loss. While in many ways, they appreciated the understanding of others, Grace felt uncomfortable with accommodating behavior, and Colleen felt "victimized" when she was being helped.

<div align="center">Disclosure</div>

The process of disclosing, or telling others they have a hearing loss, represented an important decision for the participants in this study. The properties of disclosing a hearing loss, as experienced by these participants, are presented below. These properties include how and why they disclosed, the process of learning to disclose, and reasons for choosing not to tell others about their hearing loss.

<u>Purpose</u>

The participants reported a variety of reasons for disclosing their hearing losses to others. Participants disclosed their hearing losses after a miscommunication, in order to explain the problem of understanding. Robert disclosed to provide an explanation of his behavior, to prevent a misunderstanding, or as a request for help. He believed that his choice was either to disclose his loss or have others believe that he was less intelligent than he was. Colleen had trouble with disclosure and had decided to disclose only in special situations. Her disclosure was dependent on the people involved, though she admitted that disclosure was important for an ongoing relationship and the building of a

trusting relationship. Gina admitted that disclosure was not the perfect strategy, but it helped others be more comfortable and helped her to get what she needed. Roger was compelled to disclose when he was missing information, and Judy disclosed if she deemed the situation to be important, such as in an emergency. Grace also believed that disclosure was situation-dependent, and her decision to disclose was often influenced by the importance of the speaker to her.

Many people had encouraged Derek not to hide his hearing loss, and this encouraged him to be upfront about it. He believed his hearing loss was obvious, so it was easier to acknowledge it earlier rather than later, and he disclosed so that others would make the effort to be heard. Leslie felt relief when she disclosed, especially if she felt she had already proven her competency to the person to whom she was disclosing. Claire believed that honesty was paramount. She also reported that in certain situations, like doctors' appointments, disclosure was a priority for her. Hillary often disclosed, and she felt it was necessary because, as a speechreader, she didn't want others to think that she was staring or being rude.

Method

Certain participants reported how they told others about their hearing losses. Robert used disclosure as his primary strategy for dealing with his loss, and he included the fact that he had a hearing loss in a typical introduction. Robert also had a "communi-card" that listed strategies for talking to a person who is hard-of-hearing that he used in difficult situations. Derek disclosed by acknowledging when he didn't hear, and Leslie wore a CHHA pin as a way to disclose her loss. Claire made a list of her coworkers and systematically told each of them about her loss when she started her job. Other participants had standard lines that they used to tell others that they were hearing-impaired: "I can't hear you", "I have a hearing loss", I have "difficulty hearing", I have "hearing problems", and "I'm a little bit hard-of-hearing". Gina decided that stating that she was hard-of-hearing was not sufficient; in addition to telling people she was hard-of-hearing, she also told them where to sit and to face her.

Process

Most participants in this study reported an ease with disclosure. Kelly reported that for her, disclosure was a conscious decision and that, after an initial struggle, she was

now more comfortable doing it. Cathy first disclosed six months prior to the present study during a meeting at work and found that it was not difficult, but Derek struggled with disclosure at first because he felt it was the same as announcing "I'm old". Grace reported no problem in telling others about her hearing loss but admitted that it was not a common occurrence. She believed that in the past she would only disclose when communication broke down, but that since she got her hearing aids, she found it easier to disclose because she was not having as many problems. Hillary reported that she was more outspoken about her loss than she used to be. Colleen reported a dilemma regarding disclosure; disclosing meant choosing to have her needs met but also drawing attention to herself. Gina had come to realize that in addition to disclosing, it was important to give people suggestions and directions to promote helpful behavior because people simply did not know what to do.

Reasons for Not Disclosing

In addition to the participants who had difficulty disclosing, the participants who regularly did disclose their hearing losses described situations they believed prevented disclosure. In situations where she could hear well enough, Leslie would decide not to disclose. Michelle believed she could sometimes cover up her hearing loss, and Judy believed in the 'don't ask, don't tell' philosophy. Linda hadn't been working since her sudden hearing loss, and she believed that she hadn't dealt with disclosure since she hadn't been at work. Leslie believed that sometimes disclosure held no meaning for acquaintances and coworkers. Robert feared being perceived as lacking intelligence, and Colleen had been treated as if she were stupid in the past when she disclosed her hearing loss. Grace reported that she resisted disclosing her hearing loss because she felt that it put the responsibility, or burden of dealing with her hearing problems, on those she told. Robert and Colleen experienced indignation on the part of others when they disclosed, and Ian and Janet believed that the effort to disclose was wasted because people with normal hearing forgot how to communicate effectively within minutes of being told. Disclosure of hearing loss seemed to be inhibited in work environments. Roger had feared losing his job, and other participants believed that the stigma of having a hearing loss could prevent disclosure at work. When Leslie disclosed at work, she struggled when her coworkers laughed as she walked past; she believed they were laughing at her hearing aid.

<u>Disclosure about Hearing Aid</u>

Some participants reported that, in addition to disclosing their hearing losses, they also disclosed their hearing aids. When choosing the style of her hearing aids, Grace decided that she didn't want a BTE because she believed they were too big and ugly. While she hadn't predicted that she would disclose her hearing aids, she found that she was telling others about them. While Judy admitted that she kept her hair longer, she reported that she didn't mind having a more visible BTE hearing aid. Though Matt criticized women for keeping their hair long to hide their hearing aids, he also admitted that in the past, he had kept his hair longer for the same reason. Finally, Cathy and Roger believed that wearing a hearing aid had the same effect as disclosing a hearing loss.

Emotional reactions

The participants described their reactions to the hearing loss and the resulting communication difficulties they experienced. Emotional reactions in response to interventions including amplification, devices, and surgical options were also discussed.

<u>Hearing Loss</u>

The study participants reported a variety of emotional reactions to their hearing losses. Cathy was initially "upset for weeks" and was later bothered by the reactions she received from others when she disclosed her hearing loss; she was treated as though she was slow. Linda discussed that she was "terrified" of becoming deaf. Participants were angry, nervous, and depressed as a result of their hearing losses. Grace had initially felt shame regarding her loss, and Matt was worried about his ability to provide for his family.

<u>Communication Difficulties</u>

Participants reported many emotions in response to the communication difficulties they were experiencing. Gina reported that she was worried, but she tried not to dwell on her difficulties, and Robert reported a "reluctant acceptance". Leslie and Robert both admitted a "downward spiral" of emotions regarding their inability to communicate. Robert described how feeling good can quickly turn to feeling down and depressed, and Grace admitted that it was "painful" to not understand conversations happening around

her. The most common emotional labels were: frustration, stress, isolation, depression, and embarrassment. Participants described that they felt angry, regretful, ineffective, overwhelmed, sad, and useless. They were annoyed and discouraged to have to miss information and felt short-tempered and out of control. Linda was annoyed and uncomfortable making repeated requests for repetition, and she felt angry and sad. Overwhelmed by emotion with no end in sight, Linda wondered in her journal writing, "Will I ever not care?".

Possible Solutions: Positive

Participants reported positive emotional reactions to solutions they tried, and they hoped to deal better with hearing loss in the future. Taking the ultimate positive position, Matt optimistically anticipated a cure for hearing loss, and Robert hoped that he would fulfill a more useful role within his family when he obtained his cochlear implant. Robert was excited about his implantation, as Grace was about her hearing aids. Linda expressed gratitude for her friends' efforts to help her hear and cope better, and she reported feeling optimism, relief, and hope for possible solutions to her problems. Janet reported she had not been worried about her stapes operations, and Janet was pleased that she did not experience the nervousness while wearing hearing aids that her mother predicted. Leslie felt "empowered" by her new knowledge about hearing loss and strategies. Linda had decided to think of communication situations, even if difficult, as opportunities to practice her speechreading.

Possible Solutions: Negative

Participants discussed negative emotional reactions to possible solutions to help them cope with their hearing losses. Kelly described her discouragement at having to repeat suggestions to her communication partners, and Robert described a similar feeling about the inadequacy of talking to people about the problem. Hillary felt guilty for not wearing her hearing aids more often, and Matt described the shock he felt the first time he heard a loud noise while wearing his hearing aids. Matt described the world as quiet and frightening without his hearing aids. Robert described feelings of doubt and hopelessness in response to several of the solutions he had tried to help him cope with his loss.

Effect on Communication

The participants in this study were asked how their hearing losses affected their daily experiences. Hearing loss renders communication effortful. The participants described their desire to communicate with those around them and the consequences of their frequent inability to communicate.

Desire to Communicate

Participants described a desire to communicate with others. Gina reported that she loved communicating and wanted to be involved in conversations. Robert said "I love to talk, I love discussions...I just love being involved". Claire believed that communicating was important at work, and Roger reported "communication is very important and that's the thing -- that's what this whole hearing problem is about, it's communication". Colleen agreed that communication was important but also said "this business of communication is more than just language". The reason for the yearning to communicate was varied; Matt wanted to make a personal contribution to the world, Colleen wanted to "be part of the general population", and Linda didn't want to be alone. Gina admitted that her love of communication motivated her to learn coping strategies.

Inability to Communicate

Throughout the study, the participants reported details and repercussions of being unable to communicate better. Quite simply, Robert said, "I have trouble communicating. I miss most of what's being said.". Many of the participants identified environments where they were better able to communicate, such as during one-to-one conversations in a quiet place, and they were able to describe factors that affected this ability, including both environment and personal factors, level of concentration, and identification of topic shifts. Despite acknowledgement of these factors, the inability to communicate was reportedly detrimental to the participants. Ian avoided social situations where he had difficulty communicating, and Hillary was aware that she withdrew from communicating when she was tired. Hillary described sometimes feeling that investing energy in listening was a waste of time and that it was stressful. Matt and Claire admitted that their response time was greater when speaking to someone due to their with a hearing losses. Derek asked for repetition less often when he was in a

social environment, and Leslie admitted that she "swallowed her pride" when she asked for clarification in certain situations.

Matt believed that his inability to keep up with the fast pace of conversation isolated him from his family, and Robert described often feeling "alone in a crowd". Robert believed that, as a result of his difficulties communicating, his conversational partners "would prefer to talk to someone who can hear them without them having to make the effort required to speak to me". Regarding expectation of others regarding his communication difficulties, Derek said:

> "you can expect a reasonable effort but you cannot expect the whole world stops because you have a hearing loss...and unless they have a vested interest to make sure that I'm part of their conversation, I just have to hear what I hear and do without what I can't hear".

Underlying Personal Concerns

The participants in this study often shared concerns about personal characteristics for which they perceived their hearing loss was an intervening variable. These concerns included their voice quality and level, sense of humor, and ability to function in a social environment.

Voice

The participants in this study expressed concern over the volume and tone of their own voices. Grace had several concerns regarding her voice, since she had worn hearing aids less than two weeks at the time of her interview. She felt that she was speaking louder and that her voice had a nasal quality that she was not used to. She reported feeling a sense of separation because of the sound of her own voice was unfamiliar. Tony reported that he had a speech production problem; due to his congenital hearing loss, there were sounds that he had never heard and, therefore, had difficulty producing. Matt reported that he "felt" his voice without hearing it, and he was troubled that his daughter sometimes felt that he was yelling at her when that was not his intention. Both Michelle and Leslie believed that they were speaking too loudly, but others complained they weren't speaking loudly enough.

Safety

Some of the female participants voiced concerns over their safety as a result of their hearing difficulties. Kelly had confused the sound of her tinnitus with the fire alarm in

her building, and she worried about habituating to the 'head sounds' and not being aware of a potential fire. Claire had requested an apartment in her building next to the fire escape, due to a concern about her own safety, but she still had difficulty sleeping when alone. She avoided going out at night and was interested in getting a dog as a companion. Claire went to work quite early in the morning while it was still dark, and she experienced a "strong reaction" when she realized someone was close that she had been unable to hear. Michelle had also been surprised several times to discover someone walking behind her.

Humor

Participants expressed sadness at being unable to appreciate humor. Grace and Hillary were aware of missing jokes in social situations, and Hillary described that missing out on that aspect of socialization often made her doubt her own intelligence. Matt found it difficult to tell a joke, and Kelly identified her difficulty with punch lines. Kelly and Colleen also recognized that they missed out on nuances, which made them feel disconnected from others.

Function in Social Situations

Social situations and their many complexities were identified as difficulties for the participants. Gina specifically identified intimate situations as difficult since hearing problems were difficult to address at the time. Grace strongly believed hearing loss altered relationships. She believed it caused confusing parallel conversations, caused her to miss information she did not feel she could ask to have repeated, and caused her to miss opportunities to begin and nurture relationships. Ellen didn't like to be shouted at, which was a common response to a person with hearing loss, and Hanna wished people would make an effort to communicate face-to-face, instead of talking from another room or from a distance. Although she was a social person, Leslie reported that in certain situations, and due to her hearing problems, she "would have been alone had I gone by myself or with a friend", because communication was often prohibitive in social environments.

Work

Some participants expressed concerns over work issues. Matt described a worry over the responsibility he had to bring money home to pay the bills. Gina addressed the difficulties she had in an interview situation where she should be selling herself but was conflicted by the need to disclose her hearing loss. Hillary was worried that she would be "eliminated" from a group interview situation due to her hearing loss and constantly wondered if she was "professional enough" for the temporary position she was filling at the time. Matt had been let go from his job as a result of difficulties with a manager, and Colleen believed her hearing loss had been used as a scapegoat for problems her co-workers were facing on the job. Participants struggled in their work environments or struggled to find a work environment when they were unemployed.

Identification of Specific Problems from Personal Experience

The participants in this study often identified particular factors that affected their ability to hear, speechread, and comprehend. These factors involved the environment, the speaker, the listener, and the message.

Environment: Noise

Noise was a ready complaint for the participants in this study when they were asked to describe a difficult listening situation. Certain participants were vague with complaints of "background noise", while others were more specific regarding sources of noise in their complaints: spray paint compressor, car horns, running water, loud music, and background music on television programs. Derek described difficulty with increased noise at parties, and Grace specifically reported trouble picking a voice out of a noisy background. Leslie described a difficult situation with poor acoustics and a lot of noise, and Matt had experience with reduced comprehension under a tin roof when it was raining and also when there was a fan in the room.

Environment: Other Factors

Many environments were described as less than perfect listening conditions. The most difficult situations were: meetings, classrooms, and telephone conversations. Other specific difficult listening situations included: banks, stores, luncheons, job interviews, cars, movies, plays, restaurants, and parties.

Roger reported having had great difficulty with sports when he was a boy, because he could never hear the signals and plays being called. Colleen reported she was unable to play "party games", and Michelle reported having difficulty communicating during dinner in a crowed room and at church socials in the gymnasium. Judy had difficulty with multiple speakers, and Ellen couldn't understand a speaker if she was in the back of the room. Unlike many of the other participants, Hillary reported great difficulty in "quiet" rooms; she found that when a room was too quiet, speakers reduced the volume of their voices accordingly, and this prevented her from understanding.

Adequate lighting was also an issue. Comprehension was compromised by reduced light, talking by the firelight, and parties where the light is low and the music is loud.

Speaker

There were many factors related to the speaker that participants identified as affecting their ability to understand. Difficulty understanding accents was a problem shared by most of the participants. Speed of speech, or fast speech, was a reported problem. Volume of voice was also a problem; specific complaints included whispers, mumbles, reduced volume, but also uncomfortably loud voices. Derek had specific trouble understanding women on the phone, while Ellen found it more difficult to understand men. Visual distractions or obstacles were also reported to be a problem: beards and moustaches, heads pointing down, moving heads, hands over mouths, blocked faces, and people turning away while speaking made comprehension difficult.

Hanna was frustrated with people who talked to her from another room, and Cathy had problems with "walk-thru" conversations, as coworkers walked in one door of her office and out the other door without stopping for a proper conversation. Linda reported that without seeing the lips of the speaker, her comprehension was less than 50%; for this reason, she was no longer able to enjoy documentary movies. Ian reported that he could not understand a doctor who spoke to him with a mask on. Shopping clerks were reported to be difficult to communicate with, as were people who were drinking alcohol.

Listener

Participants discussed factors pertaining to themselves as listeners that affected their ability to communicate. Matt acknowledged that without glasses, he was unable to

speechread. Robert recognized that his stress level affected his abilities, and Leslie reported than comprehension was more difficult for her when she was tired.

<u>Message</u>

The participants identified a number of factors related to the message itself that affected their ability to comprehend what was being said. As part of her job as a legal secretary, Leslie found transcription tapes difficult due to the quality of the tape; abbreviations and clichés were also difficult to understand. Leslie also reported that she had more difficulty understanding when she was not aware of the topic. Linda and Colleen mentioned jokes as being particularly difficult, and Roger remembered oral French as especially difficult in school. Grace and Kelly believed that when certain discussions were of a personal nature, reduced volume, and less eye contact made it difficult to understand what was being said. Ian and Matt reported difficulty with names, and Hillary specified unfamiliar names as a source of problems. Derek reported great difficulty with daily specials in a restaurant setting. Janet complained of difficulty with complicated instructions on the phone, and Kelly often had trouble with messages on her answering machine. Gina noticed that she had difficulty understanding multi-step verbal instructions.

This chapter discussed many of the factors relating to the personal experience of hearing loss, as perceived by the participants. These factors included self-perceptions, disclosure decisions, emotional reactions, effect on communication, personal concerns, and specific features that caused difficulty communicating. The negative effect of hearing loss on these factors was stressed, and the extensive and intense impact of the repercussions on the individual was described.

Chapter 8:   Interaction Between the Person with Hearing Loss and Society

Table 8.1. Portion of theoretical framework describing theoretical category: Interaction between the person with hearing loss and society

Category	Property	Dimensions	Dimensions
Interaction between person with hearing loss and society	Effect of hearing loss on personal relationships	Wife	Positive
			Negative
		Husband	Positive
			Negative
		Family and friends	Positive
			Negative
		Exceptions	Positive
			Negative
	Influence of hearing loss on lifestyle	Change of activity	People
			Events
		No change of activity	People
			Events
		Removal from situation	
	Relationships with professionals	Doctor	
		ENT	
		Audiologist	
	Social concerns	Work issues	
		Socialization issues	
		Advocacy issues	
		Funding issues	
		Service issues	
		Age-related issues	
		Understanding hearing loss	
	Misunderstandings by others	Regarding not hearing	
		Regarding technology	
	Stereotypes	Towards hearing loss	
		Towards hearing aid	
		Towards person with hearing loss	
	Work and school environments	Work	Details
			Difficulties
		School	
		Volunteering	

The purpose of this chapter is to describe the effect of hearing loss on the person's interaction with his or her world. All participants in this study reported that their hearing loss did affect how they communicated with others, the level at which they chose to participate, concerns regarding social relationships, and beliefs they assumed their communication partners held regarding hearing loss. The portion of the framework presenting the third category, *interaction between the person with hearing loss and society*, is shown in Table 8.1.

<div align="center">Effect of Hearing Loss on Personal Relationships</div>

The participants identified many instances when hearing loss affected their close relationships with spouses, friends, and family members. In some cases, these frequent, familiar communication partners were more supportive and accommodating than were members of the general public. However, the opposite was also often true; those closest to the individuals who were hard-of-hearing did not necessarily understand hearing loss, nor the consequences of it.

<u>Wife</u>

Several of the male participants talked about the effect of their hearing loss on their relationships with their wives. Before marrying, Roger and his wife-to-be met with a counselor to discuss the potential effect of his hearing loss on their relationship. Roger reported that she was aware of the implications of his loss and was helpful in ensuring that he understood conversations in which they were both involved. She was supportive, encouraging, and had attended his hearing rehabilitation program to support him. Ian believed that his wife was also aware of his problems, and she often 'interpreted' for him. Robert and his wife made compromises regarding their social activities, and she handled most of their arrangements for activities and holidays. Robert believed their communication was easier because he could "usually anticipate what she is going to say so things go pretty smoothly". Derek believed his wife was a "wonderful communicator". She answered the phone at home, alerted him when his hearing aid whistled, and was considerate of his needs when they watched TV.

The wives of the participants were not, however, always supportive. Robert's wife spoke quickly and needed constant reminders to speak slower. Robert reported that he was uncomfortable with his dependency on her and with the amount of responsibility

she had to take on. Matt believed his wife was frustrated and stressed by his hearing loss. Her lack of understanding led to her impatience with verbal communication. Matt admitted that their reduced communication was partially responsible for a lack of intimacy.

Husband

Participants discussed the effect of their hearing losses on relationships with their husbands. The effects of hearing loss on Janet's relationship with her husband seemed to be more the result of his more profound hearing loss than a result of her hearing loss, and she believed they socialized less as a couple because of his hearing loss. Claire was divorced, but experienced some discomfort when her new partner questioned her participation in CHHA and the hearing rehabilitation program. Ellen reported that her husband occasionally shouted in an effort to get her to understand. Judy believed that in the past, her husband hadn't been "sympathetic" to her hearing loss and had been frustrated when she couldn't hear. Their relationship was less affected by the hearing loss at the time of the study, because he had learned better communication behaviors and her second hearing aid had improved her hearing and made communication less frustrating. Cathy believed that her husband had doubted her hearing loss, and he was initially afraid that her ears would get "lazy" if she wore hearing aids. She believed that his participation in her audiology appointment increased his understanding and reduced his fears. She believed she needed to continue to work with him in an effort to teach him better communication behaviors, so he didn't do things like talk to her while looking in the fridge.

Family and Friends

Relationships with family and friends were also reportedly affected by the participants' hearing losses. Many participants reported positive experiences with friends and family. Hillary had friends who spoke clearly and were patient, Linda described friends as conscious and respectful, and Leslie had positive experiences with friends who were good communicators. Michelle believed many people were helpful if they were aware of her loss, and Kelly's friends often checked to ensure that she heard something if it was important. Ian believed that people's efforts depended on their experience with hearing loss and their personality. Claire and Gina reported good

relationships with their adult children, and Michelle found her church group very co-operative regarding accommodation of her hearing loss. Michelle had adopted an assertive approach with her family, and they now seated her in a place at the dinner table that best suited her hearing abilities. Other friends were apologetic about the participants' losses, saying that they were sorry when the person with hearing loss didn't understand.

Participants reported that a major frustration with their close relationships was the necessity to constantly remind those around them of their loss and ways to improve communication. Robert made a comparison between his expectations of friends and family members and his expectations of other people when he expressed his exasperation:

> "I mean even the people closest to you, you have to constantly remind. And that's the part that I find most frustrating. Like I can almost deal with strangers because I've told them once and they don't realize, it's not something you can see. So they forget. But sons, daughters, wives, you know they've been living with it for years now, they should know. And yet they forget".

Linda believed that when her family forgot to use appropriate strategies, they were showing that they did not care and were, in essence, rejecting her. Robert went to bed tired and frustrated when he was visiting family, because there always seemed to be more than one speaker at a time. Matt believed that his teenage daughter had difficulty accepting that her father had a disability, and she had little patience or tolerance with his inability to "handle the pace". Linda's teenage daughter often snapped when Linda asked for a repetition or responded with "never mind". Gina's family denied her loss, Leslie's mother was dismissive regarding Leslie's loss, and Colleen often experienced difficulties because her younger children did not recognize that she didn't hear and thought she wasn't interested or paying attention to what they said.

Roger believed relationships could suffer as a result of hearing loss, while Grace believed that hearing loss affected the development of friendships and resulted in missed opportunities. Hillary wondered during one interview if hearing loss was a turn-off romantically, and Leslie reported that when she didn't understand, she could feel abandoned and jealous. Robert believed that in many situations, people were simply unsure how to help.

Exceptions

Some of the participants discussed exceptions to their typical communication experiences. Robert talked about his sister who was constantly helpful by using strategies, accommodating his needs, and advocating for him. He was incredulous at the consistency of her positive behaviors and the fact that she never forgot to consider his hearing loss. Linda also recognized that certain environments provided exceptions; she believed it was nice to talk to people at WIDHH, where it was "a treat to be able to communicate without difficulty since they are very conscious of the needs of hard-of-hearing people". There was also an example of a negative exception. Roger found many people to be helpful and supportive, but he believed that his sister had never understood his hearing loss and its significance in his life.

Influence of Hearing Loss on Lifestyle

The communication difficulties that result from a hearing loss affected how the participants chose to spend their time or even with whom they chose to spend it. Some hard-of-hearing individuals were adamant about not allowing their hearing loss to interfere in their social activities. More severe difficulties as a result of a hearing loss prevented other participants from participating, and avoidance of social interaction was the result.

Change of Activity

Participants reported that hearing loss had affected their lifestyle to the extent that they had changed the people with whom they spent time and the things they liked to do.

People

Participants consciously considered who they spent time with. Robert admitted that he had made social changes as a result of his hearing loss, and he now didn't converse with others as often. While he used to talk with other fishermen when he was on fishing trips in the past, he no longer made small talk. Colleen was spending more time with her kids rather than with other adults, because they "aren't chatting to me", and she believed her social life had become "pretty narrow". Leslie discussed that she changed the people in her life, and that she was also meeting many new friends who were hard-of-hearing. Gina admitted that she limited time with others who didn't consider the

needs associated with her hearing loss. Matt also consciously chose communication partners who had a desire to communicate; he believed that:

> "if the perception is on somebody's part that it's a struggle to communicate with me, well then fine...you want to spend time with people who want to spend time with you...that's one of the greatest things about the support group here is that we share a disability and so we all have a solid footing and so we're all very very tolerant of one another".

<u>Events</u>

Participants changed the things they did to accommodate their hearing loss. Ellen recognized that she was more uncomfortable in groups since her sudden hearing loss; she reported that she still attended some activities but had to deal with more difficulty communicating. Colleen could no longer listen to the radio; she changed from participating in group activities to restricting her socializing to one-on-one encounters. Colleen chose to return to school as the result of her hearing loss and trained as a health records professional; she chose this field as she believed she could still perform the job if her hearing were to decline further. Colleen also believed that "I've changed what I do to accommodate others as much as myself" insofar as she tried to prevent others from feeling uncomfortable around her. Roger's decision to return to school forced him to make a decision to obtain a hearing aid, and his hearing loss also made him decide to attend counseling sessions before he got married to address concerns about marital communication issues. Kelly considered her hearing loss in deciding whether or not to participate in groups.

Participants reported spending more time reading, Robert played more chess, and Leslie and Claire acknowledged a preference for quiet activities. Derek stopped going to dances because the music was too loud, and although he still attended plays, he admitted that he faked his understanding. Derek still participated in sports, but he chose to focus on low-risk sports like hiking, where his hearing loss would be less of a problem. Ian, Kelly, and Derek acknowledged that they changed their level of participation in many activities by limiting and avoiding leadership roles. Gina often chose not to socialize and instead to sit back and relax rather than struggle to be involved. Claire believed she used to be more social, and Linda reported that she could only tolerate about two hours in public since her hearing had worsened. Linda had taken time off work, was sleeping more, and could no longer watch documentary movies, which had been her favorite.

Cathy experienced a positive change in her level of participation; she discovered the benefit of the ALDs at the Vancouver Playhouse and planned to attend the theatre more often.

No Change of Activity

Other participants did not believe their hearing losses had affected their lifestyle.

People

Many of the participants believed that they had not changed the people they spent time with as a result of their hearing loss. Although Ellen did not see her friends as often as she used to, she talked with them on the phone. While Tony has Deaf friends and plays on a baseball team with people who are Deaf or hard-of-hearing, Gina reported that her friends did not necessarily have hearing loss. Derek did not believe that he had changed the people with whom he spent time. However, he believed that "we could turn that around. Have some people told us that they're too busy because they find our conversation a bit funny?", implying that the change might not be by his choice.

Events

Certain participants reported no change in the things they spent their time doing. Cathy and Judy believed that they had made no significant decisions where hearing loss was a factor. Judy believed that because she was retired, "life is easy", and she did not feel that she needed to consider her hearing loss when making decisions. Hanna believed she did things mostly as usual, and Ellen reported that she did everything she wanted to do. Matt remained involved in many activities such as outdoor sports, squash, and motorcycling, and he continued to enjoy being in public situations, such as Toastmaster meetings. However, he did note that some of his activities had resulted in hearing aid casualties and, therefore, he had learned to keep a spare hearing aid close-at-hand. Matt believed you needed to live in the moment, so he continued to do the things he loved to do. Ian continued to enjoy musicals and the symphony with the help of ALDs, Kelly participated in her church board, and Michelle didn't believe that her hearing loss prevented her participation in anything she wanted to do. Leslie had always been involved in dance and music and continued to be active. Derek had never liked parties and had not attended them, and Roger believed that there

were things that he had never chosen to become involved with due to his congenital hearing loss; for these individuals, not participating in certain activities was considered by them to be the status quo.

Removal From Situation

Many of the participants admitted to avoiding certain situations when they deemed them to be too difficult for communication. Hanna admitted that she often declined invitations as a result of her hearing loss. Gina avoided bars, parties, and movies and admitted that she would often sit alone at lunch and read. Grace recognized that she had been avoiding social situations and withdrawing before she got her hearing aids. Ian avoided plays, Leslie would not attend concerts, and Claire tried to stay away from noisy places. Robert admitted that he often left a social scene to get a break from communicating, and Colleen recognized that she made a choice between resting and socializing. When Linda first experienced her sudden hearing loss, she stopped socializing and began calling in sick at work.

Leslie hadn't realized the reason she avoided certain situations. Robert believed it was a subconscious choice, and Colleen thought of her behavior as an unconscious retreating. Roger considered some avoidance to be a self-protection mechanism. Regardless of the purpose, several of the participants referred to the danger of isolation as a result of withdrawal.

Relationships with Professionals

When facing the possibility of a diagnosed hearing loss, people seek help from hearing professionals, namely a family physician or general practitioner, an otolaryngologist, and/or an audiologist. Clients have been taught to trust and value the opinion and diagnoses of these professionals. The participants in this study recounted positive and negative interactions with these professionals and addressed the implications of these relationships.

Doctor

The family physician was often the first person from whom the participants sought help for hearing loss. Leslie's doctor told her repeatedly that nothing was wrong; Leslie also admitted that she tended to avoid her doctor because she could not hear him and

was uncomfortable asking him to speak up or repeat. Tony's doctor did a crude test when he was five-years-old, in which the pages of a phone book were flipped behind his head to test his hearing. The doctor claimed Tony had a cognitive impairment, which would explain a developmental delay when Tony responded positively to the 'hearing' test; Tony believed he had been cued by the air that was displaced when the doctor flipped the book. Linda went to a walk-in clinic and then to her regular doctor when she experienced a sudden hearing loss. She was told her complete loss of hearing in one ear was the result of an ear infection and that it would go away without treatment. Although Linda requested an ENT referral, she was denied one by the referring physician for two months.

ENT

The ENT is a physician and surgeon who is the medical 'ear specialist' and many of the participants had experience with an ENT. Hanna had regular ENT visits to remove wax from her ears. Cathy disliked her specialist; he suggested that her hearing loss was progressive and worse than it was actually diagnosed. Although her ENT referred her to an audiologist, she was disappointed that he provided no opportunity for questions. Ellen's ENT diagnosed a virus in her middle ear as the cause of her sudden unilateral hearing loss, and Claire's ENT advised her against wearing her second hearing aid until he had treated her fungal problem. Leslie's "specialist" told her she did not need a hearing aid; however, she relies on her hearing aid daily. Linda's experience with an ENT was perhaps the most notable. Regarding her sudden hearing loss, her ENT told her:

> "it's permanent, no cure, no treatment, nothing you can do, no devices, that's it. He said don't worry you'll get used to it and besides there's a lot of people with worse hearing problems than you. I've got someone waiting".

She was distressed by the appointment but did not have the opportunity to discuss the problem before he left the room.

Audiologist

The audiologist is the health care professional who tests hearing, prescribes hearing aids and assistive devices, and provides rehabilitation. Participants in this study reported that they were happy with the audiological service they received from WIDHH.

Judy reported that it was not a difficult decision to first see an audiologist. Claire reportedly received "significant" help from her three or four audiology appointments per year. Hillary reported that her audiologist encouraged her to attend a CHHA meeting and to wear her hearing aids more consistently so that she would adjust to the amplified sound. Cathy's husband was invited to participate in her audiology appointment, and Cathy reported that he was better able to help her and understand her loss once his questions had been answered. Judy believed that it was vital to be comfortable with your audiologist, and Roger believed that his previous audiologist both accepted and helped him to accept his hearing loss. Roger believed that it only took "one person" to promote acceptance of hearing loss; he believed his audiologist was that person for him. Derek remembered that his audiologist spent a lot of time choosing his hearing aids, and Kelly was encouraged to return to her audiologist for hearing aid adjustments.

While the majority of comments were positive, Claire also believed that there were voids in audiology services. Issues were over-simplified and there was an apparent lack of knowledge concerning counseling individuals who are hard-of-hearing.

<div align="center">Social Concerns</div>

The participants discussed a variety of social concerns resulting from their hearing loss. In the early stages of coping with a hearing loss, the emphasis is most often placed on the personal significance of the loss. Later, the concerns of a person who is hard-of-hearing broaden to include the social difficulties shared by other people who are hard-of-hearing. The participants identified several issues that were significant in their lives, as people who are hard-of-hearing. These issues related to work, socialization, advocacy, funding, and hearing health care services, as well as age-related concerns, and how others understand hearing loss.

<u>Work Issues</u>

Participants discussed concerns regarding hearing loss and employment, including challenges in interviews, work environments, and unemployment. Grace reported a reluctance to go for an interview without her hearing aids, and Gina discussed that disclosing during an interview was a conflicting experience, because in an interview you try to sell yourself, not focus on your limitations. Participants acknowledged the competitive job market and government funding cuts, but they also reported that hearing

loss affected their chance to be employed. Claire worried about failing her probationary period, and other participants had encountered socially hostile work environments as a result of their hearing losses.

Even in a positive work environment, issues resulted from hearing loss; adapting to a new job was exhausting, and a new job meant educating a new group of people about helpful strategies and the consequences of hearing loss. Matt believed that industry needed to address hearing loss, and he called for employer education and employer support services. Matt believed that 80% of people who are hard-of-hearing were unemployed. Gina reported that unemployment was devastating, and Linda and Hillary acknowledged the associated financial stress of unemployment. Participants agreed that in addition to the regular stresses of employment, people who are hard-of-hearing faced additional challenges.

Socialization Issues

Participants discussed several issues regarding socializing as a person who is hard-of-hearing. Participants reported their feelings on personal responsibility versus their expectations of others to ensure a positive communication environment. Kelly believed in personal responsibility, Grace reported that it was not the responsibility of others to make her hear, and Roger could see how others could be responsible. Participants seemed to distinguish between people with normal hearing and those who are hard-of-hearing in the social environment; participants referred to a "hearing world" or "auditory" people. Claire expressed a need to find a hard-of-hearing culture.

Hearing loss affected the development of friendships, and there were many factors that played a part in this difficulty. Humor was important when socializing, and participants reported difficulty with jokes and nuances. Gina reported difficulty when something was heard but not understood or remembered, and Matt admitted that many individuals who are hard-of-hearing have difficulty in new environments and like to control the situation. Matt also reported that hearing loss affects development of reading and writing skills, and this deficiency often affected communication skills. Claire believed withdrawal to be a problem for many people who are hard-of-hearing, and Michelle agreed that it was possible to use hearing loss as an excuse to not participate. Linda acknowledged the global effect of her hearing loss on her life plan:

> "My goals for when I finished school were to get out and have a life, make new friends, do fun things for a change. Now it feels like there is a huge obstacle in the way."

Advocacy Issues

Participants voiced concerns regarding advocacy by people who are hard-of-hearing. Michelle believed it was important to share experiences with other people who are hard-of-hearing, and Tony agreed that it was important for others to know about hearing loss. Michelle believed that in order to improve the situation for people who are hard-of-hearing, they needed to educate others. Other participants agreed that there needed to be greater awareness of hearing loss on the part of the general public and specifically in the school system. Gina recognized a connection between self-esteem and advocacy and believed people who are hard-of-hearing first need to address their own self-esteem issues in order to be able to advocate.

Obstacles to more effective advocacy were seen as: lack of focus on the part of people who are hard-of-hearing, difficulty organizing people who are hard-of-hearing who are often isolated, lack of media attention, and lack of government involvement. Matt believed that CHHA needed a more passionate leader, such as a "Rick Hansen" of hearing loss. Professional marketing, promotion of the symbol for hearing loss, public demonstration campaigns, and an up-to-date demographic study would assist the advocacy efforts of some consumer groups. Matt believed that advocacy efforts needed to be more effective, with better organization and direction:

> "I think what is really required is a unification of the resources being directed towards the hard-of-hearing people...there's probably hundreds of people involved in some respect but I swear if there's 150 people involved, there's 148 different directions that they're moving in".

Participants felt that, in addition to greater awareness, the benefit of increased advocacy would include more accessibility options such as closed captioning, as well as health prevention measures, such as an awareness of the dangers associated with noise-induced hearing loss.

Funding Issues

The participants raised a variety of issues regarding funding concerns. Cathy was saddened by the inability of some people who are hard-of-hearing to afford appropriate amplification. Cathy recognized that she had good extended health benefits; however,

she also believed there was very poor coverage specific to hearing health care. Ellen expressed concern for those on a limited senior's income, and she believed that there should be financial help for those who couldn't afford to help themselves. Claire believed that ALDs should be available to everyone. Matt felt strongly about the need for appropriate technology to help people cope and function well with a hearing loss; he acknowledged that resources were needed to fund appropriate technology. Matt believed society should provide these technological aids, since the resulting increase in productivity would benefit society and reduce demands on the social system.

<u>Service Issues</u>

While most were pleased with their current level of service, participants were able to identify areas that needed improvement. Roger believed programs like that at WIDHH needed to expand. He believed that support services for people with hearing loss were lacking, and service needed to focus beyond mechanical and technical help and toward helping the person to incorporate hearing loss into his or her life. Participants reported a need for family counseling and improved employment counseling. From the experience of having a congenital hearing loss, both Roger and Tony believed there needed to be better speech services, so individuals could be taught pronunciations that they could not hear. Roger and Colleen explained that there was a general lack of assistance in knowing where to go to get information on dealing with a hearing loss and its consequences. Colleen believed an information system needed to be developed, and Claire agreed that knowing where to find help opened the door to accepting and coping with hearing loss. Michelle believed that this information system also needed to be available for the care-givers of those with hearing loss. Participants believed that service should include preventing hearing loss as a result of noise exposure. Matt believed there was a general disparity in services depending on geographical location; he lived in an urban area in order to obtain better hearing aid service. He believed there should be spare hearing aids provided by the hearing aid manufacturer/dispenser during repair times, and he suggested that "maybe there should be a 'McEar' to satisfy the needs of the hard-of-hearing".

Claire expressed several concerns with service for people who are hard-of-hearing. On one hand, she believed that the hearing aid was more than just a device; she felt people needed more assistance when they first received their amplification, because

people needed to learn how to use the tools they were given. Claire believed there was a lack of knowledge on the part of hearing health care professionals on how to counsel people who are hard-of-hearing. Secondly, she believed there were voids in service for those who had begun to accept their losses. Claire perceived an oversimplification of issues in some areas; she felt services often provided the ability to function, but not to excel, and she hoped for an expansion and extension of available services.

Age-related Issues

Participants discussed issues relating to hearing loss and age. Roger and Kelly believed that support for hearing loss needed to begin in the schools; Roger had not been aware of other people who also had hearing loss when he was a child. Matt believed that children with hearing loss were well taken care of, but that support was typically cut off at 18 years of age. Because he believed children and seniors were supported by the provincial health care system, Matt felt that the focus needed to shift to working adults.

Several participants expressed concerns regarding dealing with hearing loss as a senior. Michelle believed that many seniors accept hearing loss as a part of getting old, are set in their habits, and don't try to think creatively about solutions; they don't try to improve their hearing beyond buying hearing aids. Judy acknowledged a problem with how hearing loss was handled in nursing homes and believed that many staff members were unaware of how to solve hearing aid problems. Derek believed that learning was more difficult when you were older.

Understanding Hearing Loss

The participants described their concerns regarding how others understood the meaning of hearing loss. Participants believed there was a general lack of understanding of hearing loss, and they reported that this lack of understanding was often exemplified by communication partners who forgot to use helpful strategies that had been suggested many times. The participants believed that this lack of understanding resulted, in part, from the invisibility of hearing loss and the lack of awareness as to the seriousness and complexity of hearing loss. Matt and Tony believed people were uncomfortable with situations they did not understand, and such

discomforts lead to a lack of patience and tolerance toward individuals with hearing loss.

Misunderstandings by Others

The participants in this study were aware that other people did not understand the implications of living with a hearing loss. These misunderstandings ranged from assumed personality characteristics, to mistaking the function of ALDs as providing normal hearing, to false assumptions that ALDs were being used to audiotape private conversations.

Regarding Not Hearing

Participants reported that people often mistook their hearing loss for other personality traits. A common complaint was that others seemed to believe that a hearing loss implied reduced intelligence. Several participants reported that because they had a hearing loss, people expected poor language skills. Hanna found that others believed that if she did not understand, the problem would be solved if they shouted. Hearing loss was also reported to be mistaken for inattentiveness, disinterest, snobbery, or ignorance. Participants had also been accused of having "selective hearing".

Regarding Technology

Participants reported disappointment with other people's misunderstandings about technology, including both hearing aids and assistive listening technologies. Cathy reported that people did not understand that there was a difference between normal hearing and aided, or amplified, hearing; people had suggested that they believed a person with a hearing impairment regained essentially normal hearing by wearing a hearing aid. Michelle had also been told that hearing aids solved all the problems of hearing loss. Conversely, she also believed that others were unaware of the possible benefits of hearing aids. Colleen had been accused of taping a meeting, when in actuality she had been using an FM system[38] to hear better. Claire had also run into this problem with the remote microphone accessory of her hearing aid; her

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[38] An FM system is an assistive listening device that uses frequency-modulated radio waves to send sound from a transmitter to a receiver. This type of device provides benefit to a listener who is hard-of-hearing by effectively eliminating the distance between speaker and listener and reducing the amount of interference from background noise.

conversational partner believed he was being taped when she turned up the volume on her aid. Colleen experienced this misunderstanding in an educational setting, when her college instructor refused to wear an FM transmitter during class, which would have enabled her to hear him during the classroom lectures.

<div align="center">Stereotypes</div>

The participants were aware of stereotypes or negative attitudes that existed regarding difficulty in hearing and understanding spoken conversations or auditory messages. Some of these stereotypes were ingrained in their own beliefs, and some were discovered through their interactions with others. The attitudes these participants discussed included attitudes towards the hearing loss, hearing aids, and the person who was hard-of-hearing.

<u>Towards Hearing Loss</u>

Many of the participants agreed that hearing loss engenders negative attitudes, and Roger believed that hearing loss could be a "taboo" subject. Many people believed that hearing loss was synonymous with "old age". Cathy admitted that she first denied having a hearing loss because she was resisting aging, and Judy reported that many people deny hearing loss because they want to remain "young". Judy believed that the stigma associated with hearing loss decreased as you aged. Leslie reported that hearing loss was normal for seniors. A second stereotype related to hearing was that of reduced intelligence. Cathy experienced this attitude when she told a receptionist at her doctor's office that she had a hearing loss. The receptionist responded by shouting very simple sentences. The third stereotype identified by these participants was that hearing loss was simply a problem with the amplitude of sound. Linda reported that many people believed that the solution to a hearing loss was just to increase the volume, but the participants agreed that merely increasing the volume is only a partial solution. The final stereotype was the lack of distinction between the problems of the Deaf and those of the community of hard-of-hearing individuals. Both Gina and Tony reported that many people believed that hearing ability was an 'all or none' experience, and Leslie reported that people did not seem to distinguish between the Deaf and the hard-of-hearing. In spite of these stereotypes, Janet believed that the general public didn't think

about hearing loss at all. Hanna agreed that there were people who ignored the facts and talked as though you didn't have a hearing loss.

Towards Hearing Aids

Participants reported their own stereotypes regarding hearing aids, as well as their opinions about the stereotypical views held by others. Grace refused to purchase a BTE hearing aid because she believed it was ugly and too visible. Judy reported that many of her friends were resisting the purchase of visible hearing aids; her friends preferred hearing aids that fit in the ear (ITE) or completely in the ear canal (CIC). Judy believed vanity was the reason for this preference.

Towards Person with Hearing Loss

Participants also reported an awareness of stereotypes towards the person who is hard-of-hearing. Having a hearing loss might mean you are not a worthwhile communication partner or that communication with you is too much of a bother. Leslie reported an assumption that she knew American Sign Language (ASL) simply because she was hard-of-hearing, and Hillary was aware that others seemed to feel that they needed to speak slowly, because they thought she was dumb. Colleen had had her hearing loss blamed for problems at work, Derek believed he had been "tolerated" by others, and in high school, Roger had even been voted least likely to succeed. Colleen believed that whether or not someone promoted a stereotype was more dependent on their ability to empathize than on their intelligence; she had encountered rude behavior from a person with a brother who was hard-of-hearing, who she expected to be more tolerant and understanding. Gina had been asked, "What's your problem?", and Hanna recounted a "sad joke" of "Are you deaf?".

Not all the participants had experienced behaviors driven by stereotypes. Judy did not believe she was treated differently, and Ellen believed she was treated well. Kelly believed that those who were aware of her hearing loss were helpful. Janet felt that there was a change in attitude of the general public, as more people seemed to have a hearing loss.

Work and School Environments

Work and school environments represent important everyday settings where the ability to communicate was felt to be vital. The participants discussed their work and school environments and described the difficulties encountered in these settings as a result of hearing loss. These situations were discussed as they existed in the present, as well as how they were remembered from the past. The effect of hearing loss on volunteer environments was also described.

Work: Details

The participants in this study worked in a variety of environments and in a variety of jobs. Several of the participants were retired from building construction, and one had been a social worker. Other participants were unemployed at the time of the study; one was a business analyst, and another was a health information professional. Hillary worked part-time as an office worker and, later during the study, as an ESL teacher. Linda was a counselor, Claire was a social worker, and Leslie had recently changed jobs to become a legal secretary. Tony worked as a cashier and stock person, and Grace was a photographer. At the time of the study, Gina had just begun a job as a literacy coordinator.

Work: Difficulties

The variety of environments provided a myriad of difficulties for the participants. While some problems were situation-specific and more idiosyncratic, other problems were common across many of the participants' experiences. A noisy work environment was detrimental to job performance, and many of the participants reported that noise was an issue in their workplaces; Derek reported that he "suffered" with the noise of the repair plant where he worked as a boy; he had "looked forward to coffee time when, for ten minutes, all the equipment stopped". Communicating on the telephone represented a challenge for the participants; Hillary noted that in her jobs, which involved working as a receptionist for small companies, frequent callers spoke very quickly, and she had great difficulty understanding them. Time constraints were a problem, as were hostile or unsympathetic co-workers. The inability to socialize with co-workers as a result of the hearing loss was also a concern for participants.

Participants also reported more idiosyncratic problems. Gina found that adapting to two new work environments had been exhausting; she was also concerned that her many meetings and conferences occurred in new and unpredictable environments. As a legal secretary, Leslie found the lawyer "ego" difficult to deal with, the quality of her transcription tapes poor, and the implications of potential mistakes to be costly. Tony had experienced discrimination from managers at his store who did not believe he was capable of working at the cash register. Tony also cited busy and impatient customers as a difficulty of his job. Hillary reported "information overload" when she was being trained to cover for someone as temporary office support; Hillary cited work as her most important concern, and she admitted a fear of letting her employer down. Linda was experiencing difficulty counseling couples and was becoming irritated with clients since her hearing loss worsened. She had decided to take time off work to deal with her recent hearing loss.

In contrast, other participants reported positive working conditions. Gina believed she worked in a hearing accessible environment, and Claire was hoping to gain access to an FM system to use at work. Claire had also given a CHHA information package concerning hearing loss and employment to her supervisor, and she believed it had been positively received and shared with co-workers. The office where Cathy worked had installed a new sound field listening system that improved the meeting environment, and Cathy also believed that she was experiencing fewer misunderstandings with her new hearing aids. Tony's workplace had purchased walkie-talkie devices, which enabled staff to easily contact him when he was needed. Leslie had been invited to use an empty office instead of her cubicle at work, which provided a more controlled acoustical environment.

School

Participants described their earlier school experiences. Gina had gone through public school and also studied nursing. Hillary had completed a B.A. three years prior to this study and had found that she liked English. She had also attended computer courses at UBC just prior to this study; Hillary reported that she had been disappointed with the group dynamics, as she felt progressively more alienated when she was unable to adequately socialize with the other students. Hillary also admitted that, in some ways, being a student was "safe" when compared to the world of employment.

Roger reported that he had received no help to deal with his hearing loss while in secondary school. His performance had been inconsistent, and he remembered having particular difficulty with oral French. Roger believed his hearing loss became more obvious at university. He also believed that his decision to return to school pushed him towards his decision to wear a hearing aid and that he learned more in the educational setting as a result of wearing his hearing aids. He reported that his hearing loss had not been a deterrent to attending school; he found his university experience to have been fulfilling. Colleen also admitted that she had become more aware of her hearing loss when she was a college student. She attempted to compensate for her loss by sitting in front, paying close attention, and obtaining a note-taker.

Leslie believed that she had been a good student; she had attended linguistics classes at university. Unfortunately, she found her professor unapproachable, and when she could not hear the subtle linguistic differences in the languages being discussed in class, she dropped the course. She was unaware at the time that she had a significant hearing loss. After the hearing rehabilitation program was complete, Leslie expressed a possible interest in returning to school.

Tony had attended an elementary school with a special oral program for children with hearing loss, and he later attended an integrated high school. He reported that English was a difficult subject for him, while math and physical education were better. Tony had used an FM system throughout his schooling; he reported that the device was not a perfect solution to his hearing difficulties in the classroom, because he was unable to hear discussion amongst the other students, and the teacher often forgot to repeat questions from the other students before answering them. When he did not complete high school, he briefly attended the adult education program for people with hearing loss at Vancouver Community College. He was dissatisfied with the program but reported a strong desire to find a suitable program and complete his high school education.

Claire had attended post-secondary school and had also completed a management training program. She stated she always sat in front and believed she was a good student. During the first interview, Claire expressed a desire to continue her studies but felt that she might be too old to return to school; however, by the end of this study, Claire had decided that she would return to school. She was aware that FM systems were available for students, and she was looking forward to a school experience where

she would be able to hear better. Claire had applied to do a Master's degree at UBC on the topic of hearing loss and its effects on employment.

<u>Volunteering</u>

While participants volunteered for a variety of organizations, two of the participants, Derek and Gina, discussed their volunteer situations in detail. Derek reported feeling a personal responsibility to volunteer, and he did so at a community Vancouver Police office. He admitted that he was often placed in a difficult situation when he was unable to hear, and he worried about his need to answer the phone when he was volunteering. He had been told he was doing a great job, but he believed the truth may have been that no one else was available. Although he thought about quitting, he decided that he would continue to volunteer.

Gina had volunteered for many years with the Deaf and hard-of-hearing communities and admitted that she had learned a lot from her volunteer experience. She had initiated a self-help group for people who are hard-of hearing, developed weekly hard-of-hearing group meetings, done advocacy work, and received funding to begin a new branch of the Canadian Hearing Society. Gina had decided that she now wanted to volunteer in different areas and would initiate that in the future. She believed, however, that life decisions took priority over volunteering, and she first needed to adjust to her new job situation.

This chapter demonstrated the interaction of the participants, their hearing losses, and society. It discussed the effect of hearing loss on their personal and professional relationships, their social concerns relative to hearing loss, and the misunderstanding and stereotypes that they believed existed towards hearing loss. Participants discussed the positive and negative aspects of their interactions, and many of them stressed the impact of these interactions on their beliefs, actions, and concerns. Details throughout the chapter demonstrated the similarity of the participants' experiences, and idiosyncratic experiences were also captured through the interviews.

Chapter 9:   Taking Action

Table 9.1. Portion of theoretical framework describing theoretical category: Taking action

Category	Property	Dimensions	Dimensions
Taking action	Technology: use and awareness	Hearing aids	History
			Positive comments
			Negative comments
			About two hearing aids
			Expectations
			Cost
			Amount of hearing aid use
		Infrared	
		FM	
			Conference microphone
		Loop system	
		Sound Wizard	
		Phone	
			VCO and MRC
		Closed captioning	
		Real-time captioning	
		Rear-window captioning	
		Computer/internet	
		Fax	
		Alerting	
		Cochlear implant	
		Other/general	
	Conversational strategies	Request for repetition	
		Identification of topic	
		Anticipating	
		Bluffing	
		Guessing	
		Repeat what was heard	
		Specific suggestions	
		Giving up	
	Strategies and support	Environment	
		Written material	
		Speechreading	
		Sign language	
		Vision	
		People	
		Dogs	
		Humor	
		CHHA	
		Earwear	

The purpose of this chapter is to describe the category of *taking action* and the efforts that the participants made in an attempt to cope better with hearing loss. These efforts include: use of available technology, conversational strategies, communication strategies, and other forms of support. The portion of the framework presenting the fourth category, *taking action*, is shown in Table 9.1.

Technology: Use and Awareness

All participants in this study utilized some form of technology in an effort to cope better with hearing loss. The technology took many forms but the most common and widely used was amplification by conventional hearing aids. All participants in this study used hearing aids to some extent and discussed a variety of topics relating to amplification. The participants also discussed additional forms of technology that helped to improve listening conditions (assistive listening devices) and provided visual displays as alternatives to auditory signals (alerting devices).

Hearing Aids

Hearing aids are the technology used most widely to reduce difficulties associated with hearing loss. All participants in this study owned hearing aids and discussed their positive and negative experiences with their amplification; they recounted personal opinions about and experiences with this type of technology.

History

The participants had been hearing aid users for varied amounts of time; some had obtained a hearing aid during the course of the study, while others had worn hearing aids for over 30 years. There were a combination of ITEs and BTEs and also a variety of analogue, advanced programmable, and digital hearing aids. While some participants were experiencing their first hearing aid, other participants had used at least four sets of aids over the years and had personally experienced the technological advancements of the hearing aid industry. Some hearing aids were purchased because of significant life changes at the time, while others were purchased to deal with problems at work. Grace purchased her aids because she became aware that she was missing opportunities, avoiding meeting people, and not developing new friendships. Many of the participants reported that a hearing aid was rarely a perfect solution and

that perseverance, determination, and a helpful audiologist helped to improve the experience.

Positive Comments

The participants reported many benefits from wearing hearing aids. Tony described himself as happy with his hearing aids. Grace believed that ordering and wearing her aids represented an important first step in acknowledging and accepting her hearing loss. Grace and Leslie reported that they socialized more when they wore their hearing aids, and Grace described feeling more "connected". Roger believed that, as a result of wearing hearing aids, he was more responsive to those communicating with him and that the aids enabled him to appreciate and enjoy music. Increased productivity was a benefit of wearing good hearing aids reported by Matt; he also believed that his aids helped him to cope with his tinnitus. The hearing aids worn by the participants helped to improve their participation in dinner conversations, committee meetings, and family discussions. Gina was able to hear birds chirping.

Some participants also identified specific improvements in amplification technology as positive. Gina was able to obtain a hearing aid customized to her hearing loss; she needed amplification which would increase the high frequencies without increasing the lower frequencies where her hearing was better[39]. Linda, though having difficulty adjusting to her CROS hearing aid[40], reported success in being able to identify that someone was speaking to her on her deaf side; her aid sent the sound from her "deaf side" to her better ear.

Negative Comments

Even newer and more sophisticated hearing aids are not able to replace or restore normal hearing, and the comments from participants supported that fact. Matt and Derek had problems with moisture build-up inside the hearing aid during sports activities that caused their aids to malfunction. Matt found wearing amplification cumbersome with the tubing, molds, and batteries that were necessary accessories. Derek found

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[39] Newer hearing aid technology allows for greater control over the frequency response of the amplification; in this case, the higher frequencies could be amplified without amplifying the lower frequencies, where hearing thresholds were within normal range. Newer amplification technology is more successful in reaching high frequency targets without the risk of feedback.

[40] A CROS hearing aid features contralateral routing of the signal; a CROS aid places a microphone on the ear that cannot benefit from amplification and sends the signal to the ear with good hearing (Mueller & Carter, 2002).

feedback to be frustrating, and Michelle was concerned that her aid whistled because of feedback every time she hugged someone[41]. Hillary was distressed by the amplification of noise, and she felt "overloaded" whenever she wore her aids in public. Linda worried that her aid might exacerbate the problem that she was having coping with noise. Linda also reported being distraught by the size of her BTE; it made her "feel old". Judy believed her remote control was too complicated, and Grace noticed interference from florescent lights. Although she claimed it was a minor concern, Michelle thought it was inconvenient to have to remember to put her hearing aids in and take them out.

About Two Hearing Aids

For some participants, the decision to wear two hearing aids represented a significantly difficult decision; for others, the decision was easier. Matt reported that he benefited from the more balanced hearing provided by his second hearing aid; he believed that functioning in the real world required bilateral amplification[42]. Judy believed that obtaining her second hearing aid had provided the most benefit in her effort to cope with her hearing loss. Michelle and Derek had initially resisted purchasing second hearing aids; Derek believed a second aid would cause him to lose contact with the outside world. He only purchased the second aid once he acknowledged that he was missing too much information without it. Michelle didn't want the bother of a second hearing aid, but she reported a sharper and clearer signal with two. Judy reported no personal issues related to the difference between wearing one and two hearing aids. Roger, however, found the decision to use two hearing aids was a difficult one. He believed his hearing loss would be much more noticeable with two aids, and that the need for bilateral amplification represented an indisputable inability to hear.

Expectations

For many participants, wearing their hearing aids had become an ingrained part of their daily routine. For newer hearing aid wearers, the expectations were still fresh, and these participants were able to describe what they expected from their new devices.

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[41] Feedback occurs when the microphone picks up amplified sound, and it produces a squealing sound (Palmer & Mueller, 2000).

[42] A more balanced hearing experience is likely the result of localization abilities and binaural advantage. Localization, or the ability to recognize directionality, is a "binaural phenomenon, the result of interaural time and intensity differences" (Bentler, 2000, p.108). Bilaterally fit hearing aids "allow for the summing of two signals, resulting in binaural thresholds that are approximately 3 dB better than monaural" (Palmer & Mueller, 2000, p.349).

Before she received her new hearing aids, Cathy hoped they would decrease her effort to understand, help her at work meetings, and improve conversations with her husband. Although Grace had previously doubted benefit from amplification, she was now appreciating novel sounds, experiencing improved communication when not face-to-face, and when talking with a quiet speaker. Grace also admitted that she had not yet had time to discover the limitations of her hearing aids.

Cost

Hearing aids can range in price from approximately $700 to $2500 per unit, and the participants in this study talked about the expense of obtaining and maintaining amplification. Several of the participants had received funding for their hearing aids through WIDHH due to limited income. Hillary wondered if she had more money to spend on aids, whether they would provide greater benefit. In some cases, the prohibitive cost of hearing aids had prevented participants from acknowledging and addressing hearing loss earlier. Regardless of the cost, Ellen believed that the hearing aid she wore was worth the money she had spent on it. Hearing aid batteries and maintenance were also costly; Michelle resented frequently having to change batteries. Digital technology is more expensive than analogue or advanced programmable hearing aids; however, neither Gina nor Michelle believed the increased cost of a digital hearing aid corresponded to a significant improvement in hearing ability.

Amount of Hearing Aid Use

Participants represented the full gamut of hearing aid use from almost never to absolutely always. Linda was having difficulty adjusting to her new aid, and more often than not, she chose not to wear it. Some participants made the decision whether to wear their aids depending on their activities for the day, and Hillary admitted that she wore her hearing aids only when she could not function adequately without them. Hillary doubted she would ever adapt to the idea of wearing hearing aids full-time. Nevertheless, participants had grown to accept that they were better able to adapt to listening through the aids when they wore them constantly. Derek, Claire, Tony, and Matt did not believe they could function well without their aids. Leslie continued to try her hearing aid in new environments; she had worn her hearing aid fairly consistently for four years, but during the course of this study, she started to wear her aid to dancing class and commented on the benefit.

Infrared

In addition to hearing aids, a variety of additional devices, referred to as ALDs, provided benefit to the participants in this study. Infrared is one type of ALD. Infrared (IR) listening systems transmit sound by invisible light beams; an IR system converts an acoustic signal into infrared light and carries or emits it by special light emitting diodes (LED) to the infrared receiver. The receiver converts the light energy back into an acoustic signal. There is no spillover from room to room, as the IR signal is limited to line-of-sight transmission. The personal IR system is quite flexible and may be used in various modes with or without a hearing aid. (HAC Hearing Aid Centers of America Inc., 2002) Group IR systems are also available, and such systems are often used in theatres. The benefit of this type of device is that the distance between the listener and speaker is irrelevant; it provides a clear signal uncontaminated by room noise and unaffected by room echoes.

Cathy reported using the IR system at the Playhouse Theatre and, instead of struggling to follow the flow of the play, she was able to understand the plot from the beginning of the show. Janet, however, reported that she became frustrated when her husband, who was hard-of-hearing, wore an IR headset at the theatre, because it prevented him from understanding when she spoke to him. Ian used an IR system to listen to the television but had noticed a gradual decrease in benefit.

FM

Similar to an IR system that uses light transmission, an FM system uses frequency-modulated radio waves to send a signal from a transmitter to a receiver. This type of device also provides benefit to a listener by effectively eliminating the distance between speaker and listener and reducing the amount of interference from background noise. Participants had experience with sound field FM systems in public places and also with personal systems used for one-to-one communication. Claire loved participating in groups when a soundfield system was used, because she heard "everything", and Cathy reported that she benefited at work meetings where a soundfield system was used. Michelle enjoyed the system in her church. Gina had used a personal FM at school and at work, and Tony had used an FM extensively in school. While providing benefit, the FM system was also reported to be expensive and to make small talk difficult.

Conference Mic

A conference mic is a small, lightweight, unobtrusive accessory for an FM system. When placed on a table, it picks up speakers' voices within a ten-foot radius and eliminates the need to pass a microphone to each speaker. Colleen had used, and been happy with, her conference mic, as it had decreased her level of stress when listening in meeting situations. However, due to a change to her hearing aids, her FM system was no longer compatible with her amplification.

Loop System

Induction loop systems consist of a 'loop' wire, a special amplifier, and a microphone for use by the primary speaker.

> "The 'loop' wire is placed around the listening area, and speech signals are amplified and circulated through the loop wire. The resulting electro-magnetic energy field is picked up by the telecoil found in many individuals' hearing aids, cochlear implants, and tactile devices or by portable induction loop receivers which are able to deliver a customized amplified signal" (Oval Window Audio Assistive Listening Devices2002).

Robert enjoyed the experience of listening through a loop; he struggled less to understand, and he believed it was a good solution for difficult environments. Matt reported amazement that castles and cabs in Scotland were looped; he wondered why his environment closer to home was not as accessible.

Sound Wizard

The Sound Wizard is a portable amplifier with a directional microphone. It is lightweight and portable and can enable high-frequency gain. It is compatible with telecoil couplers and direct audio input hearing aids (WIDHH, 2000). Robert was interested in the Sound Wizard but was unsure if it would work with his anticipated cochlear implant and did not want to invest the money until he was sure. Matt reported great benefit and ease using the device in situations where he anticipated having problems understanding.

Phone

Telephone use is pervasive in today's society. While some participants were able to function normally on the phone, most participants had some difficulty. The degree of

difficulty ranged from the need to use an amplified phone, or an amplified phone with tone control, to using a hearing aid telecoil. Tony described severe difficulty on the telephone; he understood only familiar speakers.

Difficulty understanding on the telephone can become more than a social inconvenience; telephone difficulties can result in problems at work. Phone difficulties were one factor in Derek's early retirement and represented a constant source of difficulty for Hillary in her temporary office clerk positions. Both Derek and Hillary used some assistive telephone technology in an attempt to improve their abilities to communicate on the phone.

TTY, VCO, and MRC

Tony and Gina had experience with TTY and VCO phones. Gina received benefit from the text phones and used them primarily to communicate with Deaf friends and co-workers. Gina complained, however, that it interfered with her regular phones and did not support telephone banking. Robert reported great frustration with his reliance on his VCO phone and the Message Relay Centre.

Closed Captioning

A closed caption function on the television provides a text transcription of the spoken conversations and allows both audio and captions to be available at the same time. Although a separate device was necessary in the past, new television sets have closed captioning decoder chips installed within the television (WIDHH, 2000). While certain participants were merely aware of captioning, or planned to used closed captioning in the future, other participants had become reliant on the service. Tony used closed captioning for TV programs and was happy that most movies were now closed-captioned. Ian relied on closed captioning to understand any television program, but he noticed that many stations and programs did not provide captioning. Ian reported that he copied a CHHA article on closed captioning and sent it to his favorite television station to promote more consistent captioning. Matt also used captioning but reported disappointment with television captioning due to lagging captions and missing punch lines once commercials began.

Real-time Captioning

Real-time captioning, similar to court stenography, is the simultaneous process through which an auditory signal is rendered by a specially trained person as readable text. A trained captionist, using specialized computer software, listens and takes down all spoken communication in steno shorthand on a dedicated machine. The computer then reinterprets the captionist's entries into readable text, which it displays on a computer monitor, television screen, video, or overhead projector (Accommodating Ideas Inc., 1998). The display can be presented to an individual or to a group. The participants who attended CHHA meetings had experienced real-time captioning. Robert no longer attended meetings that did not offer captioning; he claimed the pleasure he experienced at the meetings was primarily due to the reduced effort and reduced stress resulting from his ability to read and "understand everything that is being said". Claire was not as dependent on the captioning but admitted that she would read the screen if she missed a part of what was said. Although she appreciated the benefit of increased understanding, Claire also believed that reliance on the captioning was detrimental, as it was unrealistic for the "real world".

Rear-window Captioning

> "Rear-window captioning "displays reversed captions on a light-emitting
> diode (LED) text display, which is mounted in the rear of a theater.
> Patrons use transparent acrylic panels attached to their seats to reflect the
> captions so that they appear superimposed on or beneath the movie
> screen. The reflective panels are portable and adjustable, enabling the
> caption-user to sit anywhere in the theater" (National Center for
> Accessible Media, 2002).

This system enables the individual to understand the movie dialogue while eliminating the distraction for other movie-watchers. Matt and Robert were aware that this type of captioning system was used in theatres in the United States and were disappointed that they were not able to use this type of support and enjoy a movie on the big screen in local theatres[43].

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[43] Several months after these interviews, rear-window captioning became available in several Vancouver theatres.

Computer/Internet

The computer has enhanced communication for many individuals who are hard-of-hearing, through the Internet and email correspondence. Many of the participants used email to schedule our initial meeting times, and several of them continue to keep in touch with me through email. Derek used the internet to communicate, and Ian relied on the internet for correspondence, managing his investments, and developing newsletters for his committee work.

Fax

Facsimiles provided an alternate mode of communication for many participants, and faxing was occasionally preferred over telephone communication. For Robert, faxed messages often provided his only method of communication, as he did not use a computer and could not understand conversations on the telephone. While faxing provides a method of gathering information, it also limits control over interactions. For example, Robert reported great frustration in the uncertainty of whether a message was received and the occasional lengthy delay in obtaining a response.

Alerting Devices

In addition to devices that provided an improved acoustic signal, many devices can provide a visual or tactile signal in addition to, or instead of, an acoustic one. Gina and Tony have alarms which shake the bed or pillow, in addition to emitting a audible signal. Judy was familiar with a door knocker alert, which would cause a light to flash when a visitor knocked, and Kelly expressed an interest in a visual fire alarm to prevent confusion between the fire alarm and her tinnitus.

Cochlear Implant

A cochlear implant is:

> "an electronic device that provides a sensation of hearing for profoundly
> deaf persons who are unable to obtain significant benefit from
> conventional hearing aids. Cochlear implantation involves surgical
> installation of a receiver/stimulator package into the mastoid bone and the
> insertion of an electrode array into the defective cochlea. This gives the
> user an 'artificial' form of hearing." (Pijl, 1995).

Robert was on the waiting list for a cochlear implant and had expectations of improved hearing and communication ability once he received the implant.

Conversational Strategies

In addition to the technological devices, the participants in this study also used a variety of conversational strategies to better enable them to understand and participate in conversations. These strategies ranged from verbally altering the conversation to making the decision not to participate.

Request for Repetition

Requesting a repetition when part of an utterance is misperceived is perhaps the most common conversation strategy, and one used by the participants. Ian believed that his need for repetition was the first noticeable symptom of his hearing loss. Derek reported self-imposed limits on the number of repetition requests he would make and acknowledged he made fewer requests when in some social situations; however, he also recognized that he would keep asking if it was important. Kelly had decided that, in some circumstances, asking a person to repeat was not appropriate, and she decided to "just let it go". Although typically helpful, Matt had discovered that asking for a repetition could be detrimental in a job interview.

Identification of Topic

Awareness of the topic enhances comprehension for a person who is hard-of-hearing. Robert and Kelly acknowledged greater understanding when they knew the topic of conversation, and Kelly admitted that when she knew the topic, there were fewer negative consequences if she missed some of the words.

Anticipating

Anticipating what will be said next is another strategy used by participants. Robert admitted that when he was with friends whom he saw quite often, he would anticipate what they were going to say. He also admitted that "sometimes it works and sometimes it doesn't". Anticipatory strategies could also be used on a broader scope; Robert reported that he often planned ahead and had "some sort of scheme where he could figure out what was going on".

Bluffing

Bluffing or pretending to understand conversation can be harmless in many situations but harmful in others. Derek admitted to bluffing in a variety of situations where the result was irrelevant; he pretended not to want the specials in a restaurant when he didn't understand the waiter, and he pretended to understand when he didn't understand the dialogue at a play. He believed it was:

> "only a short term solution, and in long-term it's negative cause unless I force the issue and make sure I can communicate, I'm really doing neither myself of the other party a favor".

Robert learned that bluffing didn't always provide a good result and he often responded inappropriately. Pretending to understand can become automatic. As Hillary described, she often would "just kind of let it go", and she "wondered sometimes how much I'm doing that".

Guessing

Participants reported that guessing what was said often provided insight into difficult conversations. Robert described that he "guesstimated", and Gina reported that she sometimes "filled-in-the-blanks". Colleen claimed that she might rely on the gist, but her decision to guess depended on if she was in a social environment or one where she was attempting to get information.

Repeat What Was Heard

Repeating what was heard while requesting a repetition often lessened the demand on the conversational partner. Leslie and Michelle wrote about using this strategy in their journals.

Specific Suggestions

Certain study participants were aware that announcing that they have a hearing loss was not enough to trigger the desired behaviors from communication partners. Specific suggestions were more effective. Examples of these suggestions included: "I need to see your mouth", "stop, face me", and "close the door and sit down".

<u>Giving Up</u>

When all other attempts to understand the conversation failed, some study participants reported that they would simply stop trying to be an active participant. When in a noisy restaurant and conversation was impossible, Linda would tune out and look around. Because it was difficult to communicate in the car, Michelle decided she would sit in the back seat, read a book, and not try to understand the discussions of other passengers. Tony also had a strategy for difficult situations at work; if he didn't understand what a customer was trying to say after two attempts, he asked a co-worker for help.

<div align="center">Strategies and Support</div>

The participants in this study reported many strategies and supports they used in order to be better able to communicate. These strategies and supports are described below and include controlling their environment, using alternate modes of communication, and garnering support and ideas from other individuals who are hard-of-hearing.

<u>Environment</u>

Awareness of environmental factors associated with hearing, and the control of these factors, provided a powerful foundation in compensating for hearing loss. The participants in this study reported many examples of controlling the environment, especially in terms of selecting the most advantageous seating and reducing or avoiding background noise. Cathy usually arrived early for a meeting to ensure she got the best seat and, when Leslie was unsure which seat was best, she tried all available seats before deciding which one would be best. Ian, Janet, and Michelle reported that they also consciously considered their seating position. Ellen usually tried to sit in a corner seat in a restaurant, while Derek identified the most important speaker at a meeting and chose a seat based on where that person sat.

Noise was always detrimental to communication, and participants reported a variety of strategies to control or eliminate noise from their environments. Kelly knew that carpeting improved her ability to hear, and as a general strategy, Grace tried to eliminate most background noise. In an attempt to restrict the limitations imposed by background noise, Gina tried to choose one individual in a noisy environment who she

could ask to move with her to a quieter area, where conversation would be more pleasant and less difficult. An awareness of the detrimental effects of noise on her mood and energy level had led Claire to consciously limit the amount of time she spent in a noisy environment to one hour, when she encountered such a situation.

Written Material

Several of the participants acknowledged the use of written material to supplement or replace auditory messages. Hillary used a note-taker at UBC, and Matt credited reading text books as the reason for his high school success. Derek read the special's board at restaurants so he would be aware of specials and not have to rely on a server's rushed monologue. Matt used the printed meeting agenda to aid the comprehension of a business meeting, and Kelly credited meeting minutes as a way to gain more complete understanding of committee meetings.

Speechreading

Many of the participants reported an awareness of the benefit of seeing the speaker's face while trying to understand a conversation. The participants who had attended a rehabilitation class had some formal instruction in this process; other participants were aware of this advantage through personal trial and error. The study participants who had congenital hearing losses recognized their highly developed ability to speechread[44]. Other participants were aware that they concentrated on others' mouths to understand conversations. Linda had been making a significant effort to speechread after her sudden hearing loss; however, she had become aware of her reliance on visual cues before the loss, while trying to talk to a Spanish friend on the phone, or while she was driving. Linda believed that her increased concentration on the speaker enabled her to understand more of her conversations with friends.

The effort to speechread was greater for some participants. Robert reported much difficulty in his attempts to speechread. Both Robert and Matt described feeling self-conscious when speechreading because speakers often thought they were staring.

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[44] The term speechreading represents a more comprehensive name for lipreading; it includes facial expressions, gestures, and other information gained from more than just the 'lips'.

<u>Sign Language</u>

The ability to communicate through ASL was identified as an important support. Tony used ASL to communicate with Deaf friends and wanted to learn more about signing. ASL was also seen as a tool that might become more useful in the future; Matt knew some ASL and saw it as a coping tool that would become necessary for communication if he experienced additional hearing loss.

<u>Vision</u>

The study participants used vision to compensate for their loss of hearing; ensuring optimum vision promoted general use of visual cues and better speechreading ability. Ian described better understanding when he could see and hear the speaker. For Matt, the potential loss of both hearing and vision became reality when, during a motor vehicle accident, his hearing aids and eyeglasses were thrown out of his reach. As a result of this experience, Matt decided to have laser eye surgery so he would be less likely to feel unable to communicate if such a situation was to reoccur.

<u>People</u>

Study participants reported that other individuals often provided support in dealing with hearing loss. Hillary found support in the tips she received from other individuals with hearing loss, and Gina had received useful information from a WIDHH employment counselor. Matt received social support through a Toastmasters' group, and a co-worker learned good communication skills to help Cathy at work. Sometimes, certain individuals provided an alternative to a difficult situation; for example, Derek was often able to speak directly with his building supervisor and avoid conversations with workers he had trouble understanding. Spouses were also considered major sources of support, especially by Roger and Derek.

<u>Dogs</u>

Dogs can provide a reliable service to a person who is hard-of-hearing. PADS, the Pacific Assistance Dogs Society, is a non-profit society that trains dogs to assist individuals with disabilities. Hearing ear dogs can alert their owners to a variety of sounds, for example a doorbell, fire alarm, and telephone. Tony, Leslie, and Claire expressed interest in getting a dog, either through PADS, or one that they could train

themselves. Matt's "furry little white dog" provided great support by alerting him to situations he was unable to hear.

Humor

Participants in this study displayed their senses of humor throughout the interviews and rehabilitation classes. The ability to laugh often diffused a tense encounter and made communication partners more at ease with a difficult situation, where tempers could flare and misunderstandings could ensue. Humor provided a method of dealing with depression, and participants felt it was an important factor in healthy coping: "you keep your sense of humor and you keep going". Robert shared many of the funny sayings he had come to rely on in difficult situations. He told people to "throw a rock at me" if he wasn't responding, and he'd say "I'm a what!?!" or "I'll take two if they're red!" if he discovered that people were waiting for a response from him, but he had been unable to follow the conversation and didn't know what to say.

CHHA

The Canadian Hard of Hearing Association is a consumer group of individuals who are hard-of-hearing. This advocacy group is a national organization with provincial representation and various local chapters; the chapters provide support through regular meetings and newsletters. Participants in this study were aware of CHHA, and many were active members. Participants received CHHA literature; Gina was interesting in reconnecting with the association after an absence since moving. Participants reported that the quarterly CHHA magazine, Listen/Ecoute, was interesting and informative.

The CHHA meetings provided support for participants. Claire was able to help and relate to others at the meetings. Robert benefited from the variety of ideas and felt the meetings provided one of the few experiences where he could partake in "normal" socialization. Participants described a relaxed environment, with social support for others who experienced similar difficulties. Her first CHHA experience left Gina with a great feeling of relief and a sense of community.

Not all the participants embraced the CHHA experience. After she attended a meeting, Linda wrote "I don't belong here", and other participants found the meetings to have a negative focus and be crisis-oriented. The prevalence of parents of children with

hearing loss and seniors in the CHHA network had others wondering if there was room to address the needs of working individuals who had hearing loss.

<u>EarWear</u>

EarWear, designer accessories for BTE hearing aids, was used by one study participant. Leslie purchased several types of EarWear prior to participating in the study and shared her experiences with the various designs[45]. Leslie was quite excited when she ordered the designs, and though she knew the dimensions of the items, when she first tried them on her hearing aid, she "felt like a clown with big shoes". She convinced herself that exaggeration was the point of her purchase and soon discovered that the attention and questions were the best part of wearing the accessories. Leslie used the explanation of EarWear as a strategy to assist in her disclosure of her hearing loss with co-workers.

This chapter described the technology, conversational strategies, and other supports used by the participants in this study as a means of taking action for difficulties resulting from hearing loss. Participants demonstrated that the options for handling communication difficulties resulting from hearing loss were numerous and complex, ranging from technological devices, to communication and conversational strategies, to various support systems. The support gained from group hearing rehabilitation programs will be discussed in a following chapter.

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[45] Leslie's EarWear designs include a fish (herring), lightning bolt, cat with moving tail, ear of corn, and colored plates with rhinestones.

Chapter 10: Reflections on Rehabilitation Experience

Table 10.1. Portion of theoretical framework describing theoretical category: Reflections on rehabilitative experience

Category	Property	Dimensions	Dimensions
Reflections of rehabilitation experience	Rehabilitation experience	Expectations	
		Positive comments	
		Negative comments	
		Description	General
			Ear anatomy
			Audiogram & audiogram of familiar sounds
			Factors affecting abilities
			Hearing aids & assistive listening devices
			Pacific Assistance Dog Society
			Working with hearing loss
			Assertiveness
			Speechreading
			Relaxation exercises
		Comparisons	
	Observations	Of self	
		Of others	
	Participation in the hearing rehabilitation program	About own decision	
		To encourage others	
		What's next?	
	Positive change resulting from rehabilitation experience		
	Dropping out of the rehabilitation classes		
	Factors affecting participation of people who are hard-of-hearing	Preventing participation	
		Promoting participation	
	Study reflections	Journal	
		Positive effect	
		Negative effect	

Rehabilitation Experience

Participants discussed their rehabilitation experience by reporting what they expected before taking the program, how they described the program, how they made the decision to participate, how they felt about the decision-making process, their future plans regarding further rehabilitation and action-taking related to hearing loss, and what factors they felt prevented or promoted participation in a program. The portion of the framework presenting the fifth category, *reflections on rehabilitation experience*, is shown in Table 10.1.

Expectations

Participants who agreed to attend the hearing rehabilitation program discussed their expectations for the program, prior to its commencement. Participants were interested in interacting with classmates, learning from others with hearing loss, and sharing experiences. More specifically, Leslie wanted to meet others who were working and of a similar age, and Claire wanted to determine if her own behavior was similar to that of other people with hearing loss. Gina believed that time for social interaction in the group would be important, and she hoped to develop a social and employment support network. Leslie also wanted to see other people who were hard-of-hearing who functioned in a group environment, and Linda was hoping to find empathetic support through the classes and her classmates.

Derek hoped to learn new and "all-enlightening" information. Other expectations included: speech discrimination exercises, instruction regarding such topics as coping skills, advocacy skills, day-to-day strategies, telephone and work strategies, and restaurant strategies. Tony wanted to improve his vocabulary, Claire hoped to learn about technology, and Linda expected to be able to learn to lipread. Leslie and Hillary identified an expectation that the program would improve their understanding of their own hearing losses. Leslie and Linda wanted to learn how to tell others about their hearing loss, and Tony wanted to be able to teach others about hearing loss.

Several of the participants in the "No to rehabilitation" group also reported expectations of the program. Ellen guessed that the rehabilitation program would have helped her to hear or understand better, Hanna suspected it would have involved talking about her problems, and Grace expected the classes would provide tips on "how to

improve their hearing beyond what the hearing aids are able to give them". Kelly, who was in the experienced group, remembered that she had been surprised by the younger people in her class because she had expected everyone to be a senior.

<u>Positive Comments</u>

Participants reported a variety of positive comments regarding their rehabilitation programs. They reported finding companionship, learning from others, and enjoying discussions. Participants made positive comments about various features of the programs, such as the quality of the instructors/instruction, the fact that the agendas were structured but flexible, and that the plans included discussion and exchange of ideas. Robert reported a sense of instant belonging. Gina acknowledged that the variety of experiences described by classmates validated her own experience, and she was pleased to discover that she was not the only one engaged in advocating for rights as a person with hearing loss and asserting her rights. Robert experienced an increase in self-worth, Hillary gained emotional support, and Derek reported feeling positive about the class environment. Participants reported being comfortable with other people who were hard-of-hearing, developing trust amongst classmates, and becoming comfortable in the group environment. Roger acknowledged the benefit of seeing "people who have more serious hearing problems than you do and they're doing well". Leslie described the program as a "treasured source of support".

Participants also made positive comments about various aspects of the program logistics: two-hour classes, length of program, number of participants, and the variety of topics that were covered.

<u>Negative Comments</u>

Some participants had negative comments or suggestions for improving future group rehabilitation programs. Cathy reported that she would change the original table set-up, as it was difficult to sit on the long side of a table when trying to see everyone. Derek believed that a greater emphasis on relaxation exercises would be beneficial. Michelle didn't feel that she benefited from the speechreading sessions, and she didn't feel that the office problems that her classmates discussed related particularly to her issues. Robert was unaware of an improvement in his speechreading ability; he also remembered being nervous during his first rehabilitation course. Robert had taken

several courses at the Vancouver Community College and had been disappointed to discover that each course seemed to be an exact repetition of the previous ones. Hillary reported that the session on ALDs was irrelevant for her and went over her head. Claire reported that she did not think the class was as challenging as she wanted it to be. Saturday morning was not the ideal class time for a few participants. Leslie sometimes wished it was later in the day, Linda felt that the morning class was difficult for her because she found it difficult to sleep when she had a commitment in the morning, and Hillary initially felt that attending the classes meant "sacrificing sleep". Unlike many of the other participants in this study, Colleen (an 'experienced' participant) reported that she felt uncomfortable with other people who had hearing loss.

Description

Participants described the group hearing rehabilitation programs in which they had participated. 'Experienced' group participants' recollections of the programs were more vague, because they had been completed at least two years prior to the present study. 'Yes to rehabilitation' group participants described their program in greater detail, and they readily elaborated on topics that they had found most and least helpful.

General

Participants in the 'Experienced' group identified several topics covered in their classes, in particular skills and knowledge that they continued to use, and issues they continued to contemplate. Kelly remembered things she had learned about how to respond to people when she didn't hear, how to speechread, how to identify difficulty with particular sounds, and how to recognize possible factors affecting her ability to hear. Participants commented on speechreading exercises, strategies for selecting seating positions, and strategies for use at restaurants. Participants also recalled discussions involving assertiveness and ways to use facial expressions to support comprehension.

Ear Anatomy

Leslie, Michelle, and Hillary reported the session that described the anatomy of the ear and discussion of 'how we hear' to be very useful.

Audiograms and Audiogram of Familiar Sounds

An audiogram is a graph of hearing thresholds plotted by frequency and sound pressure level, and the audiogram of familiar sounds is a graph with speech sounds and common everyday sounds plotted according to their typical frequency and sound pressure level, so that it is apparent what sounds may be inaudible given a particular audiometric hearing loss. Hillary wanted to understand her audiogram and the details of her specific hearing loss better, and she suggested that a full class should be dedicated to understanding the audiogram. Leslie plotted her own hearing thresholds on the audiogram of familiar sounds, and she showed it to co-workers after the class on this topic. She reported that she used the audiogram when she had a difficult listening situation at work; Leslie reported that the audiogram gave others insight into, and help in understanding, her hearing problems.

Factors Affecting Participants' Abilities

Leslie, Gina, and Claire identified the series of classes on 'factors affecting abilities to hear and speechread' as helpful. In the program conducted as part of the current study, brainstorming sessions were organized around each of four components of the communication situation: environment, speaker, listener, and message (Erber, 1988). Leslie believed this series provided a foundation for understanding the difficulties associated with hearing loss. Although she reported that much of the information was not new to her, it allowed her to analyze communication situations as a whole system, whereas in the past she would have focused on only one isolated component of the problem. Gina acknowledged that she benefited from the discussion on environmental factors and had used the class handout in work situations to explain difficulties communicating. She requested the handouts distributed in the weeks after she dropped out of the class. Claire also reported benefiting from this series; she believed that an analysis of the factors could change her view of a situation and that a small change in understanding might have a big impact.

Hearing Aids and Assistive Listening Devices (ALDs)

Leslie reported sessions on both hearing aids and ALDs to be beneficial, and she particularly enjoyed the hands-on time with the devices. Michelle was interested in the session on the assistive devices, but she did not believe that they were relevant for her. Linda also reported that the ALDs session was not useful to her. Tony enjoyed seeing

some of the newer ALDs, and he appreciated receiving the WIDHH catalogue of available devices. Claire admitted that at the beginning of the study she knew little about ALDs; after the session on the devices, she admitted that the FM system was a big discovery for her, and she was going to use one at work as well as at UBC, if she was accepted in graduate school. Claire learned about a variety of phones, and she concluded that she needed a phone with a volume and a tone control.

Pacific Assistance Dog Society (PADS)

PADS is a non-profit society that trains dogs to assist people with disabilities, including people with hearing loss. Tony, Leslie, and Claire were glad to learn about this society and expressed an interest in getting a dog, either from PADS or one that they would train on their own.

Working with Hearing Loss

Tony identified the topic of 'working with a hearing loss' as significant to him. He reported that he learned new information concerning employees, employers, and the rights of a person with hearing loss in the work environment. Tony reported that he made an appointment with an employment counselor at WIDHH after the class discussion. He was interested in looking for a new job. Leslie acknowledged that it was helpful to talk in the class about difficulties at work.

Speechreading

The hearing rehabilitation program included formal speechreading exercises that identified groups of homophonous sounds, or sounds that looked the same on the lips but sounded different from one another (e.g., /p, b, m/). Leslie reported that she enjoyed phonetics, and she found the speechreading exercises helpful. As a result of his congenital loss and delayed diagnosis, Tony reported that he had always read lips. He believed that people didn't understand the importance of reading lips; he was surprised by the struggle some of his classmates had reading lips. Derek reported that he did not believe he was speechreading well; he believed he did not have enough experience, nor did he feel that he was able to focus enough effort on the activity. Michelle also reported that she did not believe she benefited from the speechreading exercises, though she admitted that the exercises probably helped more than she realized. Cathy reported that she enjoyed learning about the different speech sounds

and about visual speech shapes on the lips; she had tried to test her knowledge by watching TV without the sound. Claire believed she needed more speechreading practice. Gina had chosen not to invest much energy in speechreading, because she believed it was one more detail that might lead to information overload. Linda reported that the speechreading sessions had been very helpful for her, and she had been surprised by how much help she had gained from the first couple of sessions. She had been making a concentrated effort to speechread and believed that she was functioning better in group meetings and in one-to-one situations, as a result of her improved speechreading abilities.

Assertiveness

Claire and Leslie identified the discussions on assertive behavior as being a very important topic in the rehabilitation program. Participants commented on personal observations of their own increased assertive efforts throughout the program.

Relaxation Exercises

Leslie reported she was using several of the relaxation exercises at work; she was self-conscious of using certain exercises in public but recognized the benefit of certain exercises when she experienced eye strain while working on the computer for a long period of time. Tony reported that he really enjoyed the relaxation exercises; he believed that if people were too "tight", it was difficult for them to focus attention on the conversation, and that the exercises were effective in relieving stress. Derek believed relaxation was a skill that had to be learned, and it was important to include such exercises in the hearing rehabilitation program.

Comparisons

In an effort to gain insight into the participants' expectations of and experiences during the program, participants were asked to what they would compare the hearing rehabilitation program. Robert, who had the most experience with various rehabilitation programs, compared them to companionship programs for seniors and Alcoholics Anonymous. Matt compared the hearing rehabilitation program to programs to train people to work with seeing-eye dogs, wheelchairs, or assistance dogs; Roger compared the program to training with a cane or some other assistive device. Roger also compared the program to a learning environment such as an investment seminar, and

Colleen believed it was similar to public speaking. Leslie, Claire, and Hillary compared the rehabilitation classes to CHHA meetings. Hillary admitted that she attended the rehabilitation classes instead of attending CHHA meetings; she liked the positive focus of the classes on beneficial strategies. Leslie also commented that the rehabilitation classes were more hopeful, helpful, and better addressed her needs than any efforts she had made in the past.

<div align="center">Observations</div>

<u>Self</u>

Participants discussed observations of themselves in light of the hearing rehabilitation program, including personal expectations. While Robert reported having high expectations of himself, Linda and Claire reported unrealistic expectations. Leslie and Michelle believed they had realistic expectations of themselves before the program. Participants reported being hopeful, excited, and looking forward to the classes, in addition to being eager and motivated to learn.

Participants in the 'Experienced' group commented on their self-observations. Robert evaluated his own speechreading abilities, and he admitted that he often played the devil's advocate with classmates in the rehabilitation classes. Robert also believed that without the rehabilitation classes, he would be angry, depressed, and isolated. Matt acknowledged that he had known most of the information that was presented in the program; he felt he needed more advanced support. Kelly believed that she needed more speechreading practice, but she had gained a greater understanding of her hearing loss. Colleen wanted to attend more classes. Ian recognized that he was more comfortable with other people who were hard-of-hearing than with groups of people who had normal hearing, and Robert, Matt, and Roger confirmed their approach to dealing with their losses by comparing themselves with their classmates.

Participants from the rehabilitation program, conducted as a part of this study, also made observations. Hillary reported that she was frustrated with her hearing loss, and she needed to force herself to make an effort to understand her hearing loss. She enjoyed sharing her story in the class but also believed she was a "lazy" participant. Derek reported it was good not to feel alone. Tony had been aware that, at times, he was the only male in the class, and Michelle also believed she was the only senior when

Derek was not present. While Tony reported that he felt lucky with his ability to speechread, Michelle reported that her effort to understand speechreading was inconsistent. Leslie was used to being the only person who was hard-of-hearing in her activities outside of class; she believed she gained a better perspective from the class and her classmates. Although Leslie reported that she needed time to adjust to certain personalities, she felt good within the group. She believed that she left each class "processing" a lot of information, but also believed the class also gave her energy to deal with the remainder of her day. Claire reported that she wanted to be, but was not, challenged by the class; however, she also came to recognize many issues that she wanted to work on.

Others

Participants reported observations they made of their classmates. Participants from the "Experienced" group reported being surprised by their classmates' difficulties in their work environments and by their degree of anger regarding their hearing loss. Janet remembered that the hearing loss experience had been more difficult for some classmates, and she also acknowledged the disparity in lipreading abilities. Kelly had assumed the class would be comprised of retired people and was surprised by younger participants. Robert had compared classmates' abilities, and he commented on their self-evaluations of their speechreading abilities.

Participants who attended the rehabilitation program as part of this study also made observations of others. Tony acknowledged his classmates to have better speech production abilities, but they also had more difficulty reading lips; he recognized that everyone's abilities were different. Derek reported that some of his classmates were coping "wonderfully"; he acknowledged that some had similar problems to him, while others had worse problems. Michelle was impressed by the variety of problems and was inspired by her classmates. She reported that she gained an immediate awareness of younger people with "real" problems and felt that when she compared her own difficulties to theirs, she thought more positively about her own issues. Michelle was pleased by the desire expressed by other participants to improve their experiences. Leslie recognized that each of her classmates was participating by choice, and Claire reported a high level of comfort among the participants. Derek acknowledged the participation of all his classmates in the discussions and the positive group support.

Hillary recognized that some participants were struggling with their hearing losses and subsequent lifestyle changes, and Gina felt empathy for the participant with sudden hearing loss because "you could just see the pain". Participants commented on the variety of perspectives and experiences of the group, and several participants made plans to continue to meet on an informal basis.

Participation in the Hearing Rehabilitation Program

The Decision to Participate in a Program

All participants who had prior experience with a hearing rehabilitation program, or who gained experience through the present study, discussed the process of deciding to participate. Ian believed his decision was an easy one; he reported that he had been ready to participate in such a program since his hearing loss was diagnosed. Robert had seen his first program advertised in a brochure, and Kelly had received encouragement from WIDHH staff.

Gina wondered whether she would participate; she questioned what benefit she would gain due to her prior extensive use of strategies. Linda's decision to participate was easy; she was motivated to learn and believed the program was a "lifeline" when her audiologist told her about it. Tony participated because he was interested in new ideas. While Derek was doubtful of the potential personal benefit and whether he needed such a program, he participated because he believed he had "everything to gain and nothing to lose". In spite of the fact that Hillary believed that the rehabilitation program sounded like "a lot of work", she participated because it sounded useful; her participation signified a "proactive step" in dealing with her hearing loss. Michelle reported that she had always been an eager participant in various groups and clubs. She also reported her deliberations about participating; she didn't believe the program would be much help, that it was probably better suited to "people who have very great hearing loss so that it's getting to be a problem or for people who are just starting to be aware of it – or everything but me!", and she believed she already knew everything she needed to know about hearing loss. During her mid-rehabilitation interview, Michelle reported that she was embarrassed by her earlier comments, and that the program had proven her wrong. She was glad she had decided to participate even though she hadn't been aware that she had wanted or needed more information on hearing loss. Leslie

also detailed her decision-making process. Leslie described the program as a possible "salvation", but she was also aware of past expectations of solutions and her subsequent disappointments. She reported that she had not been sure how she'd fit or what relevance the program would have for her. She acknowledged that she had focused on why it wouldn't help, instead of why it would, and the fact that she believed she was such a "special case", rather than considering herself to be like others. Leslie also had to seriously consider whether or not to participate in a process termed "rehab". She thought about each of these factors and decided, "anything is better than nothing". Deliberations were quite varied, but nine participants agreed to participate in the hearing rehabilitation program.

Encouraging Others

Participants were asked if they would recommend a similar group hearing rehabilitation program to others who were hard-of-hearing. Many participants reported that they would recommend and encourage other people with hearing loss to attend hearing rehabilitation programs. Claire and Michelle believed that everyone with hearing loss should participate. Claire also believed that the classes would even help those people who didn't believe they needed help. Janet believed that people with hearing loss needed to explore all avenues and learn more about possible solutions. Kelly believed that the classes made people more aware of issues and solutions, and of the factors that affect abilities in difficult situations. Matt acknowledged that you need confidence to manipulate the environment, and Robert believed the reason people should attend was simple: more meetings, more tools.

Michelle wanted to help promote the program and was thinking about the best way to do that; she believed that she could encourage others by sharing her experiences in the classes. Kelly believed that community centres and church groups would be good places to promote such programs.

What's Next?

Participants were asked if they would consider participating in future hearing rehabilitation programs. Hillary believed that WIDHH should have a regular rehabilitation program; she believed if there were more classes, she would attend more and learn more. Both Hillary and Leslie reported that they would be sad when the

program was completed; they wanted a second phase of the program. Leslie wrote about "separation anxiety" over the end of the program in her journal. Michelle reported an interest in some sort of ongoing participation, in the form of either classes or a support group. She wondered if a program could be organized as part of a hearing aid purchase. Derek reported that he would "definitely" consider taking another course and would also re-take the course he had just completed. Tony wished the program wasn't over and also wanted another course. Claire wanted to continue with classes, because she was interested in learning more and in working on a "deeper" level.

Participants in the "Experienced" group reported their future plans regarding hearing rehabilitation. Robert was experiencing renewed interest in a fifth rehabilitation program, while Janet was not interested in a future class. Kelly believed that her participation in the future depended on scheduling considerations.

The two participants in the "Dropout" group were also asked about future participation. Gina believed she would consider it if the time was convenient, and Claire reported that future participation would depend on her hearing loss; if her hearing loss increased, she would be more likely to participate.

Dropping Out of the Rehabilitation Classes

The two participants who dropped out of the rehabilitation program discussed their reasons for not completing the entire program. Both Cathy and Gina reported that it was a difficult decision to quit. Cathy was sorry to have backed out, but she had become very busy at work. She reported that her decision was based purely on time constraints. Gina reported that her decision was based on lack of time and energy. She reported experiencing a busy time at work with a second part-time job, which started after the beginning of the rehabilitation program. She had wanted to attend but found that adapting to two new jobs was exhausting, and she found she had no energy at the end of the work week. She cited continuing health problems due to a car accident she had just prior to this study and peri-menopausal symptoms as adding to her decision to discontinue her participation. She acknowledged that self-care was her first priority, and she suggested that Saturday afternoon might have been a better time for her, since she could have "rested and rejuvenated" on Saturday morning.

Positive Change Resulting From Rehabilitation Experience

Participants in the group hearing rehabilitation programs described personal positive changes resulting from their participation. Participants reported a greater awareness and knowledge of hearing loss. Participants reported increased knowledge and use of a variety of strategies; more specifically, participants reported improved experiences in restaurants. Gina reported that she was a better advocate for herself; she believed this improvement was due, in part, to a better understanding of her difficulties. Kelly and Ian were better able to educate others about hearing loss, Linda learned how to ask for what she needed, and Michelle acknowledged that she was no longer apologizing for her needs. Participants reported increased assertiveness, more confidence, increased self-worth, a better perspective, and an increased awareness of things they were able to control. Derek and Michelle believed they were observing more positive responses from their communication partners when they used a diplomatic, or positive reinforcement, approach to proper communication behaviors. Linda believed she was better able to speechread, which enabled her to go out more socially. Michelle had started putting her hearing aids in automatically every morning, and Leslie wore her hearing aid in new environments.

Claire believed that her participation in the rehabilitation program had helped her arrive at a point where she could accept help from others. Claire believed she was more patient, more relaxed, and less anxious. She acknowledged that she was using humor as a strategy more often, and she had also decided to return to university to complete a Master's degree. Leslie also reported a variety of positive effects of her participation. She was more comfortable with disclosure of her loss and was disclosing and explaining the implications of her hearing loss to others more often than she had before the program. Leslie was thinking of more "salvaging" factors in difficult environments, instead of giving up or "suffering" through them. Leslie also reported that she was feeling "empowered" by her new knowledge. She was able to participate more socially, because she felt more accepted, more normal, and "part of the human population". She reported that she was "more comfortable in her own skin". Leslie was also considering a return to post-secondary education.

Factors Affecting Participation of People with Hearing Loss

All participants in this study were asked what factors they believed would prevent or promote participation in a hearing rehabilitation program. Participants reported answers based on what they believed at the time of the study, as well as what they had believed in the past. In addition to their own beliefs, participants also reported their assumptions regarding others' beliefs.

Factors Preventing Participation

The participants in this study were able to share ideas that gave insight into factors that might prevent individuals who are hard-of-hearing from participating in a group hearing rehabilitation program. Participants in this study identified these factors as including denial of hearing loss, stigma associated with hearing loss, fear of ridicule, shame, anger, and embarrassment. Kelly believed some people might assume the groups were only for older people, and younger individuals might resist help or wrongly see their hearing loss as age-related. Matt believed the "male ego" would prevent the participation of some men. Participants reported that certain individuals might be in the stage of bluffing when they encountered misunderstandings, waiting for a greater severity of hearing loss, or not realizing they had a problem. Michelle believed seniors might be prevented from participating by a fear of change, since she thought many of them were rarely exposed to new experiences. Claire and Gina agreed that energy level was affected by hearing loss and could affect the decision to participate. Roger identified social isolation as preventing participation, and Gina agreed that when a person is withdrawn and depressed, it could be difficult to make an effort to seek help. Claire believed individuals needed to be secure before they were open to help, and some individuals didn't feel they deserved help. Michelle reported that some individuals "won't allow themselves to be helped". Lack of self-esteem and lack of personal support were also seen as factors preventing participation.

The group aspect of the program might also prevent participation; people might be afraid they won't "mix", dislike group events, have an inability to speak in groups, or be inexperienced and fearful of a 'school' environment. Practical considerations might also affect participation: availability, conflicting work commitments, or transportation concerns. Participation was prevented if individuals were not aware that the opportunity existed, and some might believe they already knew everything about hearing loss.

Finally, participation might be prevented due to an actual lack of need. Participants might already have the ability to cope and function, or they might not be aware of having a disability.

<u>Factors Promoting Participation</u>

The participants in this study were also able to describe factors that might promote individuals who were hard-of-hearing to participate in a group hearing rehabilitation program; these factors were both positive and negative. The negative factors included desperation and a sense of being alone. Robert believed he had been forced to participate by absolute necessity and an inability to communicate with his family. Roger participated because his difficulties were being observed by others, and Colleen was experiencing problems at work. Colleen also believed that the alternative to not participating was worse. Kelly believed a profound hearing loss would motivate a person to participate in a program, and Grace and Cathy agreed that a decline in hearing might promote participation.

The participants also discussed positive factors that could promote participation. A willingness to try new experiences, and an innate nature as a "joiner" promoted participation. Participation was also promoted by a desire to learn strategies, find alternatives, learn from others, and share knowledge with others. A rehabilitation program would provide the opportunity for making personal comparisons, understanding the social significance of hearing loss, and improving lipreading ability. Participation could be promoted by the desire to live a full life, an identified purpose in life, and the belief in one's own ability to seek help. Participation was promoted by the knowledge that the opportunity existed, through advertising and word-of-mouth encouragement from prior participants. Support from family, participation of family members in the program and the desire to improve communication environments for spouses and friends also promoted participation. Self-esteem, confidence, as well as financial ability were also seen as factors that encouraged help-seeking and promoted participation.

<div align="center">Study Reflections</div>

Participants were asked to reflect on their participation in this study and on whether being a research participant affected their experience. Participants discussed the

journal writing exercise and the positive and negative aspects of their research experience.

<u>Journal</u>

Several participants were apologetic for not making journal entries over the course of the study. Derek apologized that he was not a writer. He reported that he:

> "Didn't want to just produce something and when I have the problem, I'm usually too involved to mark it down and once it's over, it's not important enough".

Claire was puzzled by her lack of journaling and wished she had written more. She had read some of her early entries and believed it would have been better if she had emailed her journal entries. Cathy had never written in a journal prior to the study and did not remember to write in her book; she also wished she had emailed her journal entries.

Hillary declared in her journal that she would try to be honest. She apologized for not writing more, but she reported that the journal increased her awareness of her personal experiences with hearing loss. Leslie kept a journal throughout the rehabilitation classes and often wrote after each class. She reported that she tried to separate the hearing journal from her personal journal.

Robert decided not to write in his journal after 12 entries, because he found that when he wrote about his dealings with the public, he was too focused on the negative; he found this negativity depressing. Kelly did write in a journal but not during a month in which she was busy.

<u>Positive Effects</u>

Participants reported positive effects of being in a research study. Cathy reported that she had learned from the initial interview; she believed it had been very helpful insofar as it focused her thinking on issues that she hadn't previously considered. Gina also enjoyed the initial interview and believed that it provided a more thorough session compared to a typical health care encounter; she enjoyed the reflective aspect of the interview process, and she particularly enjoyed that the direction of her reflection came from someone other than herself. Tony also enjoyed the interviews.

Leslie reported that friends and acquaintances were interested in the study, or "important class", that she was participating in, and she believed that the research aspect of the study made her feel "more accountable" for her participation. She reported that she benefited from the experience and hadn't felt like a "lab rat". Hillary acknowledged that she had felt she would gain from the experience and had decided to participate after she applied her "WIFM principle" (what's in it for me?). She did believe that she benefited. Matt had wanted to help with the study as soon as he heard about it, and Claire also wanted the study to be successful. Claire was "thrilled" with the focus of the research and believed there should be more research done to study the experiences of people who are hard-of-hearing.

Negative Effects

Linda believed that for some participants there might have been a negative effect from taping the interview sessions, and the cameras might have changed the dynamics and restricted the interview. However, she added that she always forgot that the cameras were present.

This chapter reviewed the reflections on the study participants on the hearing rehabilitation program. This study captured and reported these reflections retrospectively, prospectively, and also from participants as they experienced their first hearing rehabilitation program. This chapter summarized expectations, descriptions, and evaluations of the program. The degree of benefit reported from different aspects of the program was idiosyncratic; certain participants preferred particular topics. Participants discussed how they came to decide to participate and provided insight into factors that might prevent or promote participation. Individuals reported benefiting from their participation in the hearing rehabilitation program, and they reflected on their involvement as research participants.

Chapter 11: Contrasting Groups and Comparing Data Sources

Overview

The purpose of this chapter is to contrast groups and compare the data sources used for this study. The group differences found in the interview data will be described, and the questionnaire results will be presented. Finally, this chapter will compare the data sources of interviews, journals, and questionnaire results as they contribute to triangulation[46].

Contrasting Group Frameworks

The theoretical frameworks for the groups were compared to ascertain if group differences existed. However, it was readily apparent that the individuals in the four groups presented greater similarities than differences. With the exception of the groups who chose to participate in the hearing rehabilitation program ('Yes to Rehabilitation' and 'Dropout') and the group that did not ('No to rehabilitation'), differences between the groups do not seem to be significant. As a result, the final theoretical framework consolidates findings for all the groups. The similarities were both specified and implied throughout Chapters 6 to 10, which described the categories, properties, and dimensions of the theoretical framework.

Despite the number of similarities, several contrasting trends were observed. The most obvious difference in the composition of the groups was that the 'No to rehabilitation' group was the only group that included individuals who had no experience with a group hearing rehabilitation program. The individuals who declined the invitation to participate in a rehabilitation program appeared less aware of negative consequences of their own hearing losses, and they reported that hearing loss had less of an impact on their lifestyles than did the other participants. None of these individuals reported a problem with tinnitus.

Participants in the 'Experienced' group reported using a greater variety of conversational strategies, such as anticipating what was going to be said and identifying the topic of the discussion, than did participants in the other groups. Participants in this group also reported more awareness and use of a greater variety of technological

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[46] Triangulation is "using interviewing in tandem with another method to see how well they corroborate with each other" (Mason, 1996, p.42).

services and devices, such as rear-window captioning, conference microphones, and induction loop systems. Individuals with prior experience with a program described the more sophisticated explanations they used in an effort to help others understand the implications of living with a hearing loss. Typical explanations of hearing loss and hearing aids were presented in Chapter 6: Understanding Hearing Loss. Participants in neither the 'Experienced' group nor the 'Drop-out' group reported any family history of hearing loss.

<div align="center">Questionnaire Results</div>

Three questionnaires were administered as a part of the current study. See Chapter 3: Methods for a description of each questionnaire. All participants were given the questionnaires at the time of the initial interview session and asked to mail the completed questionnaires, at their convenience, in the stamped envelope that was provided to them. Those individuals who participated in the rehabilitation program were given a second administration of each questionnaire during their final interview session. The COSI was discussed within this interview context, and a stamped envelope was provided for the return of the other two questionnaires.

<u>Client-oriented Scale of Improvement (COSI)</u>

The purpose of the COSI (Dillon et al., 1997) was to obtain a list of difficult listening situations from each participant in which he or she would like to cope better. This questionnaire was obtained for 16 of the 20 participants. Tables 11.1 to 11.4 summarize the items identified by each group in the study. All participants who chose to participate in the group hearing rehabilitative program were asked to re-evaluate their responses from the first administration during their final interview session; in addition to being presented below, these comments were incorporated into the interview codes and analyses in developing the framework.

The COSI was helpful in identifying the difficult situations considered by the participants to warrant remediation. The identified difficulties did not differentiate the groups. The second administration of the COSI to those individuals who participated in the rehabilitation program provided an opportunity to evaluate the efficacy of the program, to observe changes in the goals of the participants, and observe changes in their perceptions of difficult circumstances.

Table 11.5 summarizes all of the situations identified by the participants and indicates the number of participants who included each situation. These data identify the most common difficult situations identified by the participants to be: groups, telephone, television, restaurants, accents, feeling left out, work, and one-to-one conversations.

Table 11.1. 'Experienced' group responses to COSI

Participant	Difficult Listening Situations
Robert	- Not part of dinner conversations - Phone - Understanding at miscellaneous courses - Dim lighting at night and speechreading
Matt	COSI questionnaire not returned
Roger	- Phone clarity - People with beards or accents - Tuning in to people and tuning out noise - Clarity of speech and realistic expectations of limitations - People calling from distance- direction of sound
Kelly	- Discussions during meetings or church service - Missing part of conversations in group, e.g., jokes - Conversations in restaurant, women's voices difficult - Missing interesting conversations - Unfamiliar speaker on phone
Ian	- Conversing in group social situations - Listening to a speaker at a meeting - TV with no closed captioning, accents, and background music - Exercise class with background music - Attending plays
Colleen	- Talk with children without them getting annoyed - Be able to watch TV without it being too loud for everyone else - Be in social situation without missing most of what's being said - Talk one-to-one without worrying if hearing all she needs to hear - Be able to go to party without having to explain hearing difficulties
Janet	- Hearing exercise teacher over music - TV shows with no closed captioning and background music - Background noise with hearing aids - Noisy social situations

Table 11.2. 'No to rehabilitation' group responses to COSI

Participant	Difficult Listening Situations
Judy	COSI questionnaire not returned
Grace	COSI questionnaire not returned
Hanna	COSI questionnaire returned blank
Ellen	- Large crowds with background noise - Meeting when speakers don't use microphones - Speakers with accents - Men's voices sound garbled

Table 11.3. 'Yes to rehabilitation' group responses to COSI

Participant	Difficult Listening Situations	
	Pre-rehabilitation Program	**Post-rehabilitation Program**
Claire	▪ Informal talk at work ▪ Lack of social contact ▪ Intimacy ▪ Phone ▪ Restaurants	No comment No comment No comment ⌘[47] Now believes humor and jokes more important than phone
Michelle	▪ Chatting in 'hall' after church ▪ Understand grandchildren ▪ Accents on TV ▪ Hear better in car ▪ Know people walking behind her	⇧[48] More relaxed, more realistic expectations ⇧ Improving ⇨[49] Accents more of a problem than grandchildren ☒[50] Doesn't try to understand anymore ⇨ Tries to be more careful and observant
Leslie	▪ Dancing group ▪ Work ▪ Group meetings	⇧ Much better, wearing hearing aid ⇧ More comfortable disclosing ⇧ Easier to do something about problems ⌘ Level of own voice ⌘ Localization of sound
Hillary	▪ Telephone at work ▪ Quiet speakers in quiet rooms ▪ "Dropping out" of quiet conversations ▪ Small talk with strangers ▪ Speakers with accents	⇨ Still a problem ⇨ Still a problem, too much effort No comment No comment ⇨ Still a problem: New job teaching ESL
Linda	▪ Social setting (e.g., party, dinner) ▪ Restaurant ▪ Group meeting/workshop ▪ Conversation ▪ Movies/TV	⇧ Little better ⇧ Better for 1:1 ⇧ Little better ⇧ Little better No comment
Tony	▪ In park, talking and listening to nature ▪ At home, chatting with people ▪ At work, with noise, music and phone	No comment No comment ⇧ Improved due to walkie-talkie
Derek	▪ Board meeting ▪ Communication with staff ▪ Listening environment in restaurant ▪ Talking on 3rd party phone ▪ Listening to news on TV	⇧ Improved, has more control ⇧ Found man to act as go-between-loud voice ⇨ Strategies help but still a problem ⇨ Still a problem, will bring own "Clarity' phone (moves to #2 position) ⇨ TV not perfect but okay

[47] '⌘' identifies a new situation introduced in the second administration. Post-program observations refer to the initial situation listed on the same line.

[48] '⇧' identifies a situation which has improved since the first administration.

[49] '⇨' identifies a situation which has remained the same since the first administration.

[50] '☒' identifies a situation which has been dropped as a goal since the first administration.

Table 11.4. 'Dropout' group responses to COSI

Difficult Listening Situations		
Participant	Pre-rehabilitation Program	Post-rehabilitation Program
Cathy	■ One-on-one with family	⇨ Still a problem because removes hearing aid at home
	■ When taking minutes at meetings	⇧ No problem due to hearing aid
	■ One-on-one with work colleagues	⇧ HAs help with 1:1 conversations
	■ At restaurants when noisy	No comment
	■ At small social groups, e.g., sewing class	No comment
Gina	■ Job interview	⇨ Still difficult
	■ Meetings at work	No comment
	■ Lunch room at work	No comment
	■ Intimate situations	⇧ Able to advocate for self before situation occurs
	■ Movies	☒ Doesn't go to movies anymore
	■ Social group talking at work	No comment

Table 11.5. Summary COSI data listing difficult listening situations

Difficult Listening Situation	Number of Participants Who Identified Situation N = 16
Group in noise	11
Group in quiet	6
Telephone	6
Television	5
Restaurant	5
Accents	5
Feeling left out	5
Work	4
One-to-one conversations	4
Humor	2
Movies	2
Intimate situations	2
Understanding from a distance	2
Clarity of speech	2
In the car	1
Dim lighting	1
People walking behind	1
Plays/theatre	1
Small talk with strangers	1
Attitudes of others	1
Understanding grandchildren	1
Understanding quiet speakers in quiet rooms	1

Communication Profile for the Hearing Impaired (CPHI)

The CPHI (Demorest & Erdmann, 1987) was developed as a comprehensive assessment and intervention tool for audiological rehabilitation. CPHI questionnaire

data were obtained for 19 of 20 participants at the initial administration and for eight of nine participants at the time of the second administration. Average scores for each individual for each of the 22 sub-scales, three importance ratings, and four average scores for the summary areas (Communication Performance, Communication Environment, Communication Strategies, and Personal Adjustment) are presented in Appendix R. Response scales for all questions of the CPHI range from one to five, and low scores indicate a need for attention whereas high scores do not[51].

Figures 11.1 to 11.3 present a variety of findings from the CHPI questionnaire data obtained in this study. Figure 11.1 shows the group averages for each of the four major summary areas and the average importance rating. A visual inspection suggests that the 'No to rehabilitation' group may have rated its communication environment and personal adjustment as more favorable compared to the other groups. The 'No to rehabilitation' group also seems to use fewer communication strategies. Nevertheless, a Kruskal-Wallis H-test failed to reject the null hypothesis that there were no differences between groups[52].

Figure 11.2 shows group averages for the post-rehabilitation administration of the CPHI. When the post-rehabilitation data are compared to the pre-rehabilitation data of Figure 11.1, it is apparent that the participants in the 'Yes to rehabilitation' and 'Drop-out' groups indicated an improvement in communication strategies, a decrease in 'personal adjustment', and a decrease in the importance of communication rating. The average score for the 'Yes to rehabilitation' group increased for communication performance and communication environment, while these average scores decreased for the 'Dropout' group.

Figure 11.3 shows the researcher's estimates of the CPHI scores for those who participated in the present hearing rehabilitation program. A comparison of this figure to Figure 11.1 indicates that the researcher estimated a lower importance rating and a greater need for communication strategies than did the participants in the two groups. The researcher also estimated a more favourable environment and personal adjustment score for both 'Yes to rehabilitation' and 'Dropout' groups. Average communication

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[51] The CPHI manual (Erdman & Demorest, 1990) indicates that a score of 3 or below is indicative of potential difficulty.

[52] A nonparametric test was used due to the small sample size and non-normal distribution of the scores. The insignificant finding may be the result of the small sample size.

performance of the 'Dropout' group was over-estimated, while the communication performance of the 'Yes to rehabilitation' group was estimated correctly.

Figure 11.1. CPHI group averages for major category areas and importance ratings at the pre-rehabilitation administration of the questionnaire.

CPHI Group Averages
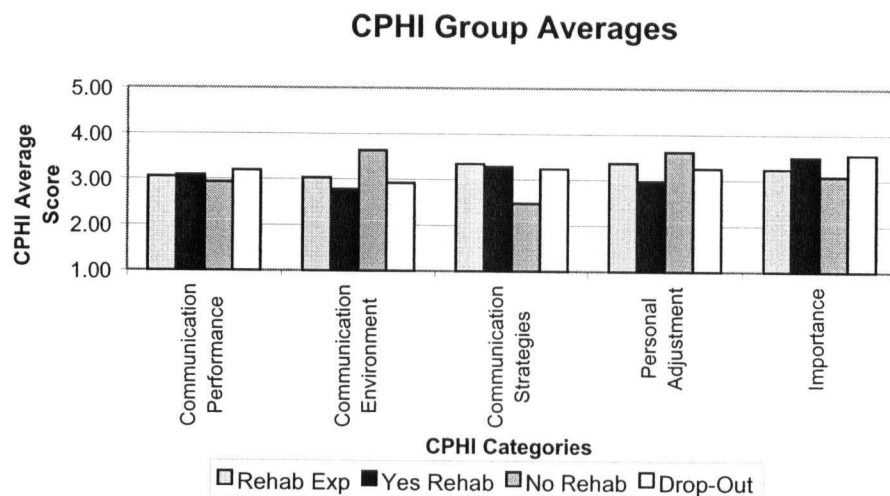
Figure 11.2. CPHI group averages for major category areas and importance ratings for post-rehabilitation administration.

CPHI 2nd Administration Averages
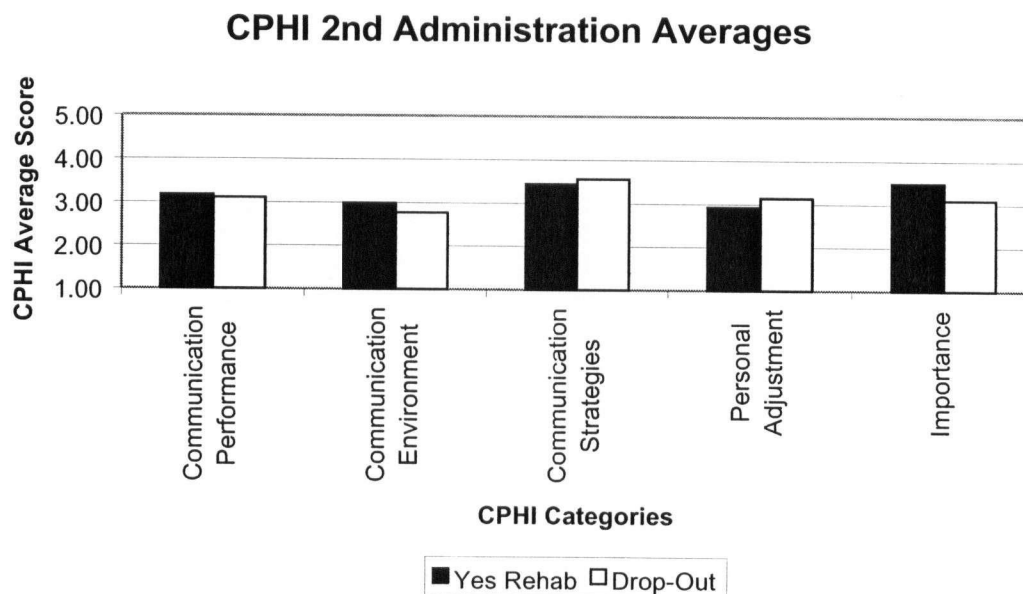
Figure 11.3. CPHI group average estimates by the researcher for major category areas and importance ratings.

Researcher CPHI Estimate
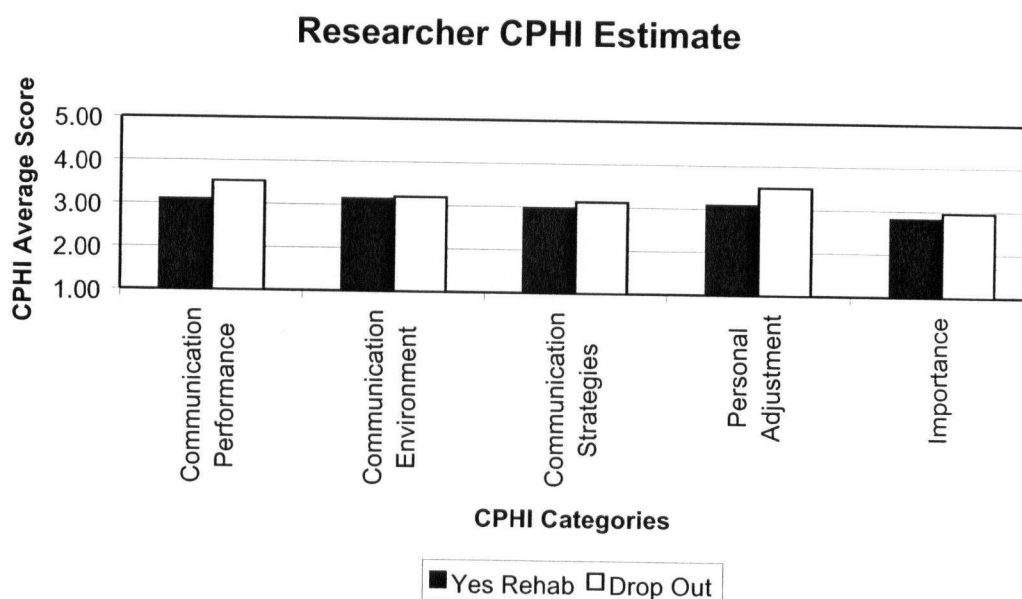
It is interesting to note that, even though the CPHI questionnaire has 145 items and specific questions such as "If someone repeats what they've said and I still don't understand, I ask them to repeat again" (#20) and "You're talking with a friend or family member in a quiet room" (#17), many participants were compelled to 'qualitatively' alter the items. For instance, regarding #20 above, Gina added, "or say it in another way". Regarding # 17, Hillary indicated that she could frequently communicate effectively but specified, "if they're speaking up, otherwise quiet spaces are often times problematic". Hillary qualified the entire questionnaire scale of "frequently often" regarding communicating effectively with "it takes work, mind you". Gina wrote that she experienced difficulty with the wording of "communicating effectively", and Matt commented that it was "very difficult to answer some of the questions out of context". However, certain participants were also pleased with the focus of the questions; Leslie wrote, "This is a very important questionnaire".

Readiness to Change Questionnaire for Hearing (RTCQ-H)

The RTCQ-H (see Appendix N) was adapted for the present study from the RTCQ developed for use with excessive drinkers (Rollnick et al., 1992). This questionnaire attempted to identify participants as corresponding to one of three stages of change in

Prochaska and DiClemente's stages of change model (1986): precontemplation, contemplation, or action (see Chapter 2). The questionnaire was administered to all participants and a second administration was given for all individuals who participated in the group hearing rehabilitation program. RTCQ-H data was obtained for 19 of the 20 participants for the first administration and eight of nine participants for the second administration. Questionnaire responses can be found in Appendix S. Table 11.6 presents the average scores for each group for each of the three stages[53]. The average response for each of the groups presented the same pattern for the stages; all groups were negative for the precontemplation scale and positive for both the contemplation and action scales. This questionnaire was not successful in distinguishing between groups in this study[54]. The questions in the exploratory version of the RTCQ were not specific enough to distinguish between these groups of individuals. The usefulness of this instrument is difficult to assess on the basis of these data.

Table 11.6. Average group scores for stages of precontemplation, contemplation, and action, and overall pattern for RTCQ-H.

Group	Precontemplation (P)	Contemplation (C)	Action (A)	P C A
Experienced	4.25	2.29	2.14	- + +
No to rehabilitation	3.08	2.46	2.50	- + +
Yes to rehabilitation	4.25	1.79	2.02	- + +
Drop-out	4.13	2.63	1.88	- + +

Questionnaire Summary

The questionnaires used in the current study provide varying levels of information about the individuals and the groups. The COSI provides details of the participants' most difficult situations, and it was used to gather data on how they re-evaluated these situations after having participated in the rehabilitation program. The CPHI provided information on the communication performance, environment, strategies, personal adjustment, and importance of communication for the participants; this questionnaire did

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[53] Questions were answered on a Likert scale from 1 to 5, with 1 corresponding to strongly agree and 5 corresponding to strongly disagree. Numbers in the table represent average scores. The last column of the table shows whether the group's average score showed a greater support for a particular stage (+) than not (-).

[54] The appropriate non-parametric test, the Kruskal-Wallis H-test, was used to determine that the null hypothesis could not be rejected.

appear to distinguish between the 'No to rehabilitation' group and the remaining groups on several of the scales; however, these differences were not significant. The RTCQ-H did not distinguish between groups or provide novel information about the individuals in this study.

While some degree of information was gleaned from the questionnaires, these results provided little insight into the reasons these participants chose to participate in the group hearing rehabilitation program or did not choose to participate. I believe it is the qualitative data obtained throughout this study that provided the rich insights into this process.

Triangulation

Triangulation involved comparing data sources and identifying the similarities or differences in the findings. In this study, the variety of data sources provided both converging and complementary findings to strengthen the conclusions drawn in the research. Comments made in the interview sessions, comments written in the journal entries, and answers on the questionnaires supported the view that participants were largely consistent in their expressed beliefs and experiences.

An illustration of how data sources converged can be exemplified by Leslie's data. In the interview sessions, Leslie discussed a variety of difficulties experienced at work; she talked about her experience as a legal secretary and working in a noisy environment with time constraints and the serious consequences of misunderstanding at work. Leslie also listed work on the COSI questionnaire as a difficult environment in which she would like to cope better. Her CPHI score for importance on communicating at work was 4.67, indicating a high degree of importance. In her journal entries, Leslie wrote about her difficulty transcribing tapes and about her belief that she has to try harder to understand than the average secretary.

An example of the complementary nature of the data sources is illustrated by Michelle's data. In the interview sessions, Michelle discussed her acceptance of her hearing loss as one of the most valuable steps of coping with her hearing difficulties. In the second interview session, however, Michelle also discussed her concern that she might use her hearing loss as an excuse not to participate, and she raised the possibility that she might be hiding behind her loss. In her journal entries, Michelle wrote "I must be careful not to hide behind my hearing loss and not use it for an excuse for not taking

part in social activities". Her CPHI score for 'acceptance of loss' in the category 'personal adjustment' was 5.0, indicating a high degree of acceptance, and her withdrawal score was 2.86, indicating need for attention or intervention.

A final example of how triangulation strengthened the conclusions drawn in the research can be demonstrated through a comparison of different sources of data for Linda. Linda's interview session identified a high level of difficulty in communicating in noise, inability to communicate in social environments, and the pain related to her inability to participate socially with friends. Linda's journal entries indicate the same difficulties and frustrations:

> "Spent the afternoon with a friend while she worked on my computer. It wasn't constant talking for the first couple of hours, as she was busy typing away. Then a couple other friends joined us and we went for a walk and a bite to eat. So, I was with people for 7 hours in total. By about hour 5, my ears/head were starting to hurt. By hour 6, I couldn't bear the sound of voices. Every word made my ears throb."

Linda's CPHI scores indicate a definite need for intervention; Linda scored 1.0 for social communication performance, indicating a great need for intervention, and she scored 5.0 for problem awareness. Linda's response to the COSI also indicated the desire for better social communication; her list included social setting, restaurant, and one-to-one conversations as communication situations she would like to improve.

Summary

This chapter contrasted the groups from the current study, presented questionnaire findings, and discussed the complementary nature of the various sources of data. While the questionnaire data supported the interview data, the detail and richness of the information from the interviews was more informative for the purpose of this study. The questionnaires provided varying degrees of information. The COSI provided details of difficult listening situations as identified by the participants, both pre- and post-program. While the CPHI appeared to distinguish the 'No to Rehabilitation' group from the remaining groups on certain categories, the RTCQ-H was not able to differentiate between the groups. The following chapter discusses the theoretical framework, themes, and core category of the study.

Chapter 12: Theoretical Development

Overview

The purpose of this chapter is to integrate the findings of the current study and ultimately explain the core category of *ecological balance*. This integration will begin by revisiting the theoretical framework for the current study and describing the relationship between the five categories of *understanding hearing loss*, *personal experience with hearing loss*, *interaction between person with hearing loss and society*, *taking action*, and *reflections on rehabilitative experience*. The three themes of *identity*, *challenge*, and *adjustment* that weave throughout the data and relate to the categories will also be described. These descriptions and explanations will culminate in the explanation of the core category of ecological balance. All examples will be grounded in the participants' experiences with excerpts from the interviews.

Connections Between Categories in the Theoretical Framework

Two significant relationships exist among the five categories identified in the theoretical framework. First, the categories of *understanding*, *personal experience*, and *interaction between person and society* are related to one another. This interaction provides a more comprehensive understanding of the implications of hearing loss for the individual. The combination represents both intrinsic and extrinsic factors, moving from a focus on body to person to society, to explain the experience of living with a hearing loss (Figure 12.1).

Figure 12.1. Relationship between categories of understanding hearing loss, personal experience with hearing loss, and interaction between the person with hearing loss and society.
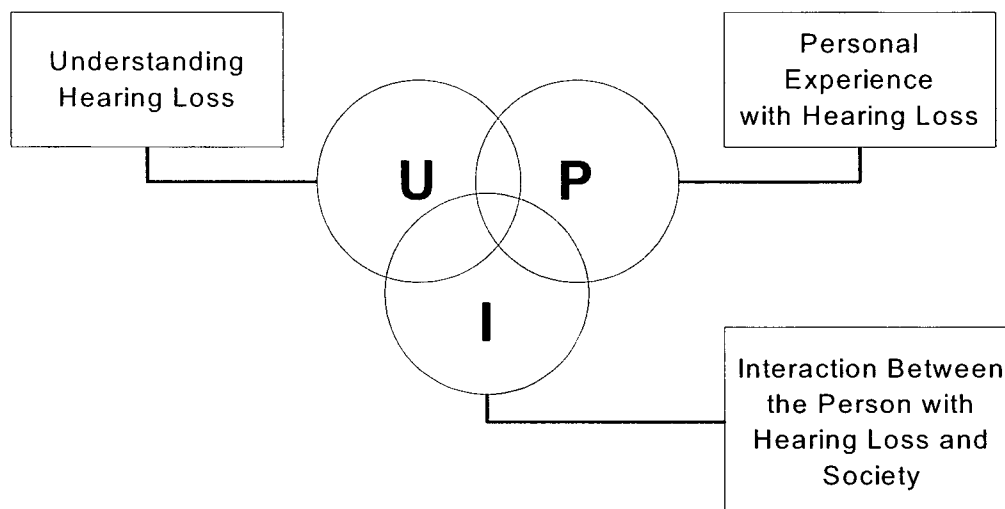
Second, the categories of *reflections on rehabilitative experience* and *taking action* are also related; rehabilitation experience is included within taking action, as it is one way to manage difficulties resulting from hearing loss. Participation in a group hearing rehabilitation program was defined as an advanced form of action-taking, while conversational strategies, communication strategies, and use of technological devices were also included in the category of action-taking (Figure 12.2).

Figure 12.2. Relationship between categories of 'rehabilitation experience' and 'taking action'.

Themes

Three inter-related themes[55], *identity*, *challenge*, and *adjustment*, emerge from the theoretical framework, and help to explain why some individuals with hearing loss seek advanced help in the form of group hearing rehabilitation programs, while others do not (Figure 12.3). The thematic connections within the categories are provided below with examples from the interview data.

Figure 12.3. Connection between categories and themes.
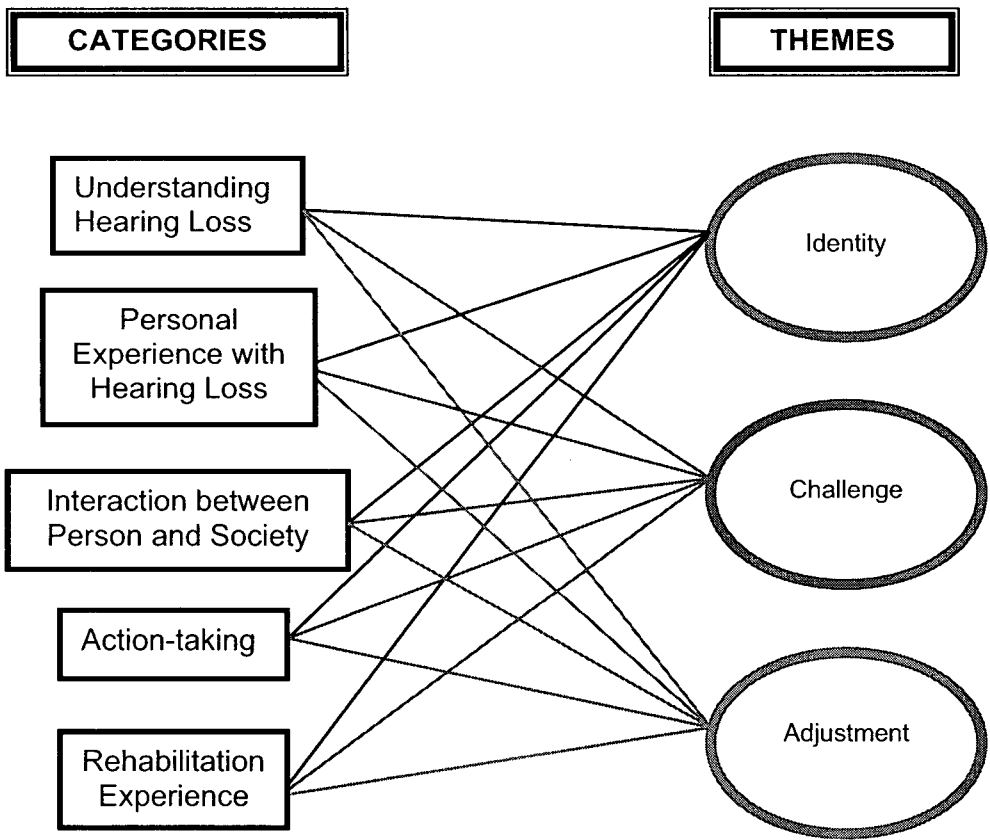
Identity

The theme of *identity* refers to the notion of defining and accepting a connection with a particular entity or self-definition. It encompasses belonging, accepting, and feeling

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[55] Themes are recurrent ideas that appear in slightly different forms throughout all parts of the framework.

part of a group. For the participants, the concept of identity involved defining the expectation of what is 'normal' at a particular point in time and in a particular situation. The participants' identities often aligned with a variety of people, groups, and experiences, as described below. The concept of identify also changed as individuals re-defined their abilities or discovered similarities to different individuals and groups. This theme appeared throughout the categories of the theoretical framework.

<u>Understanding Hearing Loss</u>

Participants discussed identity through the notion of what they considered to be normal, as they attempted to understand their hearing loss. At times the participants identified with people with normal hearing, while at other times their identity was aligned with those who had hearing loss. Derek was better able to accept his hearing loss than he had been when it was first diagnosed and believed his hearing difficulties to be a result of aging: "When you're 45 you think somehow you're going to beat this. But when you're 65, you know that most things come on cue". Wearing hearing aids was a new experience for Grace, and she was trying to fit her experiences of amplification into her new self image: "I pick up on things like florescent lights, which I think normal people do, don't they?". Hanna created her identity by contrasting her hearing loss with an even less desirable problem: "It's just a hard thing to get along with although I guess if it's just that you can't hear, it's not as bad as if you can't see". Claire struggled with her identity and she wanted to "find out more about the culture of hard-of-hearing people, not hearing people, and to try to understand that world better. It's a whole culture". Leslie identified with her father, who also had hearing loss, and she developed a better understanding of her family history of hearing loss:

> **Leslie:** And I don't -- I realize this too when I went back into the pool, I was at a place where the girls always go down a certain time for a break. And they said well come with us so I went down to the little in-house restaurant, a cafeteria type thing, in our firm and I remember sitting there and it's very noisy. I mean that's very typical, don't do well in really loud noisy environments. I avoid them at all costs
> **LDE:** Mhmm
> **Leslie:** And I remember sitting there and thinking I don't know what's going on. Laugh. And my dad -- I can always tell my dad was in a situation where he didn't know what was going on
> **LDE:** Mhmm
> **Leslie:** Because he'd smile a certain smile
> **LDE:** Yeah

Leslie: And he would nod. And he wouldn't know what was going on. And I do that too but I didn't realize that that necessarily had to do exactly with his hearing loss. I just thought it was something that he did as him, as a person.

Personal Experience of Hearing Loss

Participants discussed the concept of identity through their personal experiences of hearing loss. Colleen admitted, "I choose to just act like someone who can hear", while Claire began to accept her hearing loss as part of who she was: "Now I look at it and say, no this is something that is part of you and this is the way you are and this is how you perceive the world". Ellen's sense of identity as a person who is hard-of-hearing was not negative, as she had experienced no stigma related to hearing loss, and she believed that "a lot of people have it and it could be worse". Janet admitted, "there's a lot of us who are getting harder of hearing in our age group and we understand one another". However, not all personal experiences supported a positive sense of identity as a person with a hearing loss. Some experiences created an imbalance or need to readjust the notion of identity. Leslie described her confusion regarding what was normal about her difficulties at work with transcriptions:

Leslie: ...but that's something that I have to really really hard time with and when I get something like that, I don't always know if it's acceptable or okay to say 'I don't understand'. 'I can't figure out what he's saying'. Because of course usually these things happen with extreme time constraints and you've got all that other pressure...And so I sort of sit there depending on where I am and I have to make these decisions. Am I hearing what's happening? Or am I only thinking I'm hearing what's happening? Now is this what I'm hearing, is it just hard for me or would it be hard for somebody who could hear normally? Is this something that's a really specialized? Something that a person coming in with a fair bit of experience in this area would necessarily know about? Or is this something that I should be catching on to? And I'll go through all of these little things in my head and I'll try to decide, what should I do? And I have a really hard time because usually there's not somebody to talk to.
LDE: Right
Leslie: Say I can't do this and then there's also that...So there'll be all these questions going through my head and I'll get confused. I mean even more so confused and I'll feel really bad about myself and about my performance and about how things are going and about how I'll never be able to do this.

Interaction Between Person with Hearing Loss and Society

Participants described their sense of identity resulting from interactions with others. These interactions could support an existing sense of identity, or they could create

dissonance with that identity. Matt described that his identity was shaped through participation in both groups for people with normal hearing and those who are hard-of-hearing.

> "I mean there's a lot of different aspects of a personality but it's like anybody, you want to spend time with people who want to spend time with you. That's one of the greatest things about the support group here is that we all share a disability and so we all have a solid footing and so we're all very, very tolerant of one another and that's the first time for me that that's happened, Yeah, so I spend more time with them. Or I spend some time with them but I don't like I said I don't give up on, I haven't given up on the hearing world. I mean they're the majority, they're the people that you have to work with."

Ian reported that he struggled to maintain a positive identity through difficult situations:

> "I was involved in the strata council at one time a few years ago and found that we would have our meetings in one of the apartments. People would speak in their normal voices. I would not be able to understand what they were saying. I would suddenly think of a brilliant idea and suggest it and find that's what they been talking about the last 10 minutes. So I'm quite ineffective in meetings so I've avoided that type of situation."

Claire admitted when faced with difficulties communicating that "I feel quite different sometimes", and Leslie described her identity conflicts before her hearing loss was diagnosed:

> **Leslie:** I was taking some linguistics classes once. A long time ago, another lifetime ago and before I knew. And I took everything I could and I got to the point where I couldn't do anymore unless I took a phonetics class. And I was always pretty good at school. I wasn't spectacular but I was always very strong and I could hold my own...I was good. At one time. And I got to this phonetic class and I didn't like the prof very much. I found him very unapproachable...But then stuff was happening and I couldn't hear it. But I didn't realize I couldn't hear it. I just couldn't understand why I wasn't getting it. I wasn't getting it
> **LDE:** Right
> **Leslie:** What they were talking about because there wasn't a difference. What are they talking about? There's no difference.
> **LDE:** Right
> **Leslie:** So I ended up dropping it. And that was another clue and I just thought well it's obviously not my thing...and I think that I've done that more than maybe more often than not I've run up against something that has been directly related to my hearing but not realizing it, not making that connection and having hit a wall, have decided, okay fine I don't want it anyway. And doing something completely different and not looking harder

or looking in another direction, or another way or a more creative way to work through it.

Taking Action

Participants' identities were either supported or tested as they took action to deal with hearing difficulties. For example, Roger reported that hearing aid use was becoming more acceptable and easier to identify with:

> "...And I see people with hearing aids all the time walking around or at the church and stuff like that and I think they just sort of accept it as normal. That's what you do, I mean if someone has a problem with walking, you use a cane...but you can't see hearing loss except for the hearing aids. And that's a very important thing that I had to learn. I'm not saying look at me, I'm hard-of-hearing but as I said to you before, the main purpose of wearing these is bilateral hearing and hearing things that my wife says. To hear them properly, as properly as you can. And that's the main reason for it."

Grace was learning to identify with her new ITE hearing aids:

> "And again it's not that I'm trying to hide them, it's just...they look okay to me and I'm the one who has to -- that's my comfort level... how I perceive or how I feel about them is what's going to affect me the most versus what other people are going to think. So whatever I'm comfortable with is fine."

While many of the participants re-evaluated their identity in a positive fashion when they connected with others with hearing loss, Linda resisted identifying with other individuals who are hard-of-hearing. After her first CHHA experience, she wrote in her journal "I found myself looking around the room and thinking, I don't belong here".

Reflections on the Rehabilitative Experience

Participants often reported a strengthening of their identity or the development of a new identity through their hearing rehabilitation experiences. Linda believed it was "really important to be connected with other people who do understand" the implications of hearing loss, Claire wanted to meet "people who are like me", and Leslie wanted "a connection to other people that work with a hearing loss on a daily basis". Ian reported, "in a group like that where everybody's hard-of-hearing, you're more comfortable than in a group of normal people". Robert described the positive group identity obtained through participation in rehabilitation programs and support groups:

> **Robert:** I think the sooner you come to classes, support groups, whatever, the better you feel about yourself, you start to understand that

there's literally hundreds of thousands of us. I'm not the only one. And the more of us that attend these different groups, classes, hard-of-hearing, the more things get done for us. We have more clout. Like we're getting close caption TV a lot more than we used to.

LDE: Mhmm

Robert: The airlines have to accommodate us and different things like that which, before they never did.

LDE: Right

Robert: So, by coming to these things, you're not only helping yourself, you're helping a lot of other people. And unless we band together and organize, these things never get done. You know, 10 percent- well who cares. But there's more and more of us. And people with good educations that know how do these things. Laugh. The rest of us just support them. Laugh. But that's, but again, everybody with a hearing loss, no matter how small, I think should attend. It can only benefit them. And they help us.

Colleen struggled to maintain an identity that was acceptable to her. Colleen reported benefiting from a hearing rehabilitation program "because you do feel alone. It did help to know that I wasn't the only one who was experiencing the same type of behavior from others". However, she also admitted she would not seek out her hard-of-hearing classmates on a social level because, "they were just too darn hard to talk to!".

Challenge

The theme of challenge refers to the challenges or difficulties experienced by the participants. The challenges described by the participants were multi-faceted and occurred throughout each of the categories of the framework. The challenges represented a variety of characteristics; some challenges were permanent, others had been experienced in the past. Some were personal, while others were social and environmental. The variations on the theme of challenge are presented below.

Understanding Hearing Loss

Participants reported challenges in their efforts to understand their own hearing loss and in their efforts to explain their difficulties to others. Colleen waited seven years for a definitive diagnosis of Ménière's disease, and Leslie struggled to find a health care professional who would understand her hearing difficulties:

"...when I went to the doctor, he didn't believe me first of all, that I had a hearing loss. And then sent me to a specialist that told me I didn't need a hearing aid and that maybe if my hearing got worse, I might and then when I went and I asked him and he said oh, there's nothing. So I was

asking the wrong questions or I was going about everything in the wrong
way and then I would get frustrated -- all these blocks"

Kelly described the challenges associated with separating her confusion between the sound of her tinnitus and the sounds of her fire alarm. Leslie talked about her difficulty explaining her hearing loss to others, and Roger believed that "the general public has a very limited view or understanding of hearing loss...this is a hearing world".

Personal Experience of Hearing Loss

Participants discussed challenges regarding their personal experiences of hearing loss, which included self-perceptions, disclosure, emotional reactions, personal concerns and specific problems that affected ability to hear and understand. Claire discussed how a personal challenge for her in seeking help was that she was in denial: "I was stuck for a while and I guess you need to be stuck sometimes"; she also believed that "you won't look for help if you don't feel you deserve any help". Acceptance was a challenge for Colleen, who admitted, "I can say I'm hard-of-hearing. I know it on an intellectual level but on an emotional level, I have not accepted it". Participants discussed challenges regarding not disclosing their hearing loss to others, and they discussed the challenges they faced in understanding and appreciating humor. Leslie and Robert discussed the downward spiral of negative emotions they could experience when they were having difficulty communicating. Finally, participants also discussed the difficulties relating to the environment, the speaker, and the message, such as loud background noise, visual obstacles, dim lighting, accents, fast speech, people turning away while speaking, or answering machine messages, and 'specials' in restaurants.

Interaction Between Person with Hearing Loss and Society

Participants experienced challenges in their interactions with others as a result of their hearing loss; these challenges occurred in personal relationships, at work or school, and created lifestyle changes and social concerns. Leslie described her difficulty in creating and maintaining social relationships at work- a result of difficulties understanding break-time conversations. Linda recognized her two-hour tolerance limit for time spent in public as a challenge. Ellen discussed her inability to hear in groups and the difficulties she experienced at luncheons and meetings. Gina admitted that her hearing loss "impacts on every aspect of my life: social, recreational, employment,

education. It affects my family life". Robert expressed his challenge to communicate through an analogy:

> "I sometimes tell people it's like being in a phone booth with glass walls all
> around. And I said you had a family reunion but you are in this glass
> booth, and you can see everybody and you can see their mouth going but
> you have no idea what they're saying. So, without communications you're
> alone, even in a crowd."

Roger believed that challenges also came from others:

> "It's a hard-nosed world out there and people – some people are not that
> sympathetic to people with any kind of handicap".

Colleen believed her biggest difficulty at work was that "because of my hearing loss, they chose to make me a scapegoat". Tony reported that many people did not understand the benefit he gained from speechreading, and he described the stigma he experienced at work:

> "People think I'm not the same as hearing world people- something like
> that. For example, people at my work think that I can't go on cash, not
> ever hear, they didn't give me a chance at all. But I just learn really fast
> and they realize oh- Tony can hear! He can do anything. So I mean they
> won't give me a chance."

Taking Action

Participants identified challenges with taking action towards solving hearing difficulties. Matt described "the difficulty of it is that there's not one solution for all people". Even once participants obtained hearing aids, most had negative comments about their aids, including cost, frustration with feedback, maintenance, and interference from florescent lights. Other challenges were identified; participants reported that requests for repetitions were not always appropriate, and CHHA meetings often had a crisis-oriented focus or catered to either the senior population or parents of children who were hard-of-hearing. Colleen also described a situation where one of her college professors would not wear an FM transmitter in the classroom. Derek expressed his disappointment with one of his strategies:

> "But usually at parties, especially if people drink, the noise level goes up
> so that yeah I think I do have a real problem because I try to control the
> conversation so at a table of six, I pick the one I can talk to, and have a
> one-on-one conversation and exclude the other four, which is often not fair
> but it's the only way I get something out of the evening. If I participate in a
> six-way conversation and it isn't controlled, like background music and you

know they insist on having the hi-fi going then I can only talk to my neighbor. And I guess most of the time, if you're determined, you can control that but ideally, it is not ideal because the interaction is between six people and not between two people and there are two conversations going on, sometimes three conversations going on one table, which is sad but I guess part of the price I have to pay for my hearing loss."

Reflections on the Rehabilitative Experience

Participants also identified challenges in their hearing rehabilitation experiences. For example, Claire recognized that, "sometimes you get things offered to you but you're not ready and so they just go over your head". Leslie recognized that maybe people struggle to accept the need for hearing rehabilitation and do not appreciate the possible benefit that could be gained from the experience:

> **Leslie:** I thought well maybe, maybe it doesn't apply to me because I just sort of found out. I started telling myself all the ways that it wasn't going to fit for me because I'm just so exclusive. Laugh. You know, a special case. But I thought wow! At the same time I thought wow, there's -- maybe the universe is working here and maybe there's something more for -- maybe there's something more than --. When I first found out, I was very excited about this place and then you go through peaks and valleys. I get very excited and I think the whole world is going to open up and then I take a step and it's not so much as I thought. Damn it. Okay. Do some more looking and I find something and spike again and oh, yes! Solve all the problems. No it's not. And then I got onto this little spike again and thought oh yes! This is going to do it. And then I heard rehab. Rehab? Oh! Laugh Hmm
> **LDE:** What does rehab mean to you?
> **Leslie:** What does rehab mean to me? I guess it means that I was -- at one time I was a certain way and now I'm not that way and I just need to get back to that way that I was. I guess that's what it sort of means to me
> **LDE:** Mhmm. So is rehab a good thing or bad thing?
> **Leslie:** Well, I don't know how I was, so I don't know how to get back to how I was. But I don't know if that ever applied to me.

Michelle reported that a challenge of rehabilitation was over-coming what she considered typical difficulties and attitudes about being a senior:

> **Michelle:** sometimes we older people -- oh that's not fair -- we're slower about – well we get kind of set in our ways and this is the way it is, I'll just put up with it
> **LDE:** Mhmm
> **Michelle:** Mmm, I think most of the things that I do now at my age -- I don't go out looking for new things say, I do them because somebody recommends them or
> **LDE:** Mhmm

> **Michelle:** One thing that I notice too is that everything makes a difference as to how my energy level is at that time.

Roger recognized that many individuals with hearing loss, as well as hearing professionals, focused on technological solutions for hearing loss, and he discussed that "the next step is how do we work this person through a life system and that's I think where the big challenge is".

Adjustment

The theme of adjustment captures the notion of, and desire for, change. Participants in this study referred to their efforts and desires to make adjustments on a variety of levels and throughout the five categories, as presented below.

Understanding Hearing Loss

Participants reported a desire to document changes in their hearing abilities and a desire to improve the way they explained their loss to others. Kelly discussed how, if a change was discovered in her degree of hearing loss, she would also adjust her help-seeking; Kelly believed:

> "my hearing has deteriorated somewhat. In fact, I've been thinking about coming in and getting it checked again and maybe either get an adjustment in the hearing aid I have or maybe I think there are always new things coming out".

Participants who did not have a definite cause for their loss continued to search for answers; for example, when Linda's MRI showed no signs of an acoustic neuroma, she made an appointment with a neurologist. Leslie explained the benefits of the improvement she had made in explaining her loss to others:

> **Leslie:** And I'm much -- I feel much more comfortable explaining to people. I feel like I kind of know a little bit more -- like I don't feel so victimized I guess maybe is the word
> **LDE:** Right
> **Leslie:** If somebody asks me about it, I can sort of explain what I hear a little more which I think really benefits them in the long -- well in the whole I think it sort of helps our relationship as they're aware a little more aware of why I do what I do if it seems a little odd.
> **LDE:** Right. So give me an example of what you would have said before?
> **Leslie:** I probably wouldn't have said anything…I'd avoid them
> **LDE:** And what do you say now? Like if someone does this {covered mouth with hand} at work and is talking really fast

Leslie: Oh if they did that I would say 'I need to see your mouth when you're talking to me'.
LDE: And before you would not have
Leslie: I wouldn't have.
LDE: That's a big change.
Leslie: I would have smiled and nodded.

Personal Experience with Hearing Loss

Adjustments were reported by the participants as a result of their personal experiences of hearing loss. Michelle reported that after her rehabilitation experience, she felt differently about asserting herself; she felt more positive about her abilities and was less apologetic about her difficulties understanding in groups. Leslie described personal adjustments that helped her to feel better about herself and her abilities:

> **Leslie:** ...I'm thinking of more salvaging factors rather than just giving up and saying fine, I'll just suffer through this. Laugh. And I'm prone to do that...Yeah, I feel more empowered and better and I think it's because there's more -- like I have a reason now
> **LDE:** What's your reason?
> **Leslie:** I know more now. That's my reason. Before I would think there's just me – I mean I would know that it wasn't just me but I would be thinking about trying to process all the stuff coming in and not being able to be objective about it...I feel more accepted now, more normal, a part of the human population!

Participants reported a greater awareness of the factors that affected their abilities to hear and speechread; for instance, Derek had changed his behaviors when he attended meetings:

> "...to make sure that I get the seat that I need. I sit next to the most important person and furthest away from the one I think doesn't contribute much to the conversation..."

Interaction Between Person with Hearing Loss and Society

Participants made adjustments or changes in response to their interactions with others. Claire reported that she had become more aware of her difficulty in restaurant environments and had made a decision that "if it gets noisy, I leave within an hour". When she's in a crowd of people, Ellen decided, "I just don't try to hear cause I know I can't", and Gina decided she would no longer attend movies in theatres in an attempt to cope better with the frustrating experience of not understanding the film. Colleen admitted that she made changes to accommodate others, as well as herself, so that

others are not uncomfortable with her loss and her subsequent difficulties communicating. Matt reported a change in his approach toward communicating with others:

> "The other thing is once you've got the technology, is immerse yourself as much as you can handle -- I would really recommend something like Toastmaster's where you're forced to listen. You've got to develop those communication skills because without them you're dead in the water. So if you blow out and everybody has good laugh, then laugh along with them, it's not the end of the world. You know you'll get a lot more respect for trying than you ever will just hiding away and then, you know feel good about yourself. I don't know how you do that some days, but if you can do all that -- then you're going to have a good life. You'll have a life. Laugh."

Taking Action

The participants discussed steps they took to seek help for their hearing losses, before (or instead of) their participation in a hearing rehabilitation program. Ellen (in the 'No to rehabilitation' group) acknowledged that, "because I lost the hearing in this ear, I knew I had to have a hearing aid". Leslie decided to wear her hearing aid during her dancing classes and demonstrations, which were environments where she had never worn her hearing aid previously. Hanna discussed her satisfaction with her hearing aids. Kelly reported that she got a special phone "so that I could put the volume up and change the tone a little bit", and Cathy used an infrared ALD in order to understand better at the theatre. Robert reported that his wife also helped him cope better in difficult situations:

> "So I say to my wife, if they're directing their conversation to me, you let me know what they're talking about, so I can respond to them. Otherwise, I won't know what they're talking about. Now, if she does that, then it's not too bad."

Reflections on the Rehabilitative Experience

Individuals in this study reported adjustments made as a result of their participation in hearing rehabilitation programs. Robert believed that without this participation, he would be a different person:

> "But I think if I hadn't gone to a meeting, I would be a very disliked person. Like I would be pulled back into a shell and just strike out at people. If I get angry, I am good at that. I think I would've retreated in to a shell and just said let the world go by."

Colleen reported that she became more assertive through her participation in the hearing rehabilitation program "because I had been backing off and not realizing that I was backing off as much as I was". Claire admitted that the rehabilitation program encouraged her to incorporate all possible methods of support that were available to her in an effort to improve how she managed her hearing loss, instead of resisting them; she was going to use an FM system and had attempted to lighten her approach to hearing loss with humor. She believed all the strategies she learned helped her to hear better because, "I just relaxed and didn't have this anxiety and when you relax, you hear better.". Linda acknowledged her efforts in speechreading:

> "Because when I'm having problem hearing I remind myself that I have to really focus on speechreading and it does make a big difference...what I didn't realize is that just by concentrating on it, just how much more I could hear."

Core Category

The core category identified through this study was *ecological balance*. Ecological balance refers to the efforts made by the participants to maintain a balanced state between identity, challenge, and adjustment. Balance is achieved by accepting a particular self-identity, identifying challenges, and making necessary adjustments to address those difficulties; this enables satisfaction with identity, abilities, and performance in personal environments. Figure 12.4 depicts the concept of ecological balance as it pertains to advanced help-seeking for hearing loss; the figure demonstrates the connection between the categories and themes within the concept of ecological balance. This sense of equilibrium can be disturbed in several ways. A person who is not satisfied with his or her self-defined identity experiences an imbalance in the system. This could prevent a person from addressing challenges and possible solutions. Equilibrium could also be disturbed by the introduction of a new challenge. To re-establish the equilibrium, individuals must re-define their identity to incorporate acceptance of the unaddressed challenge, or make an adjustment to counter-act the challenge. Once this is accomplished, identity is re-defined, and the balance is re-established. Finally, the balance can be disturbed if adjustments or solutions are not identified or cannot be implemented.

Figure 12.4. Model integrating categories, themes, and core category.
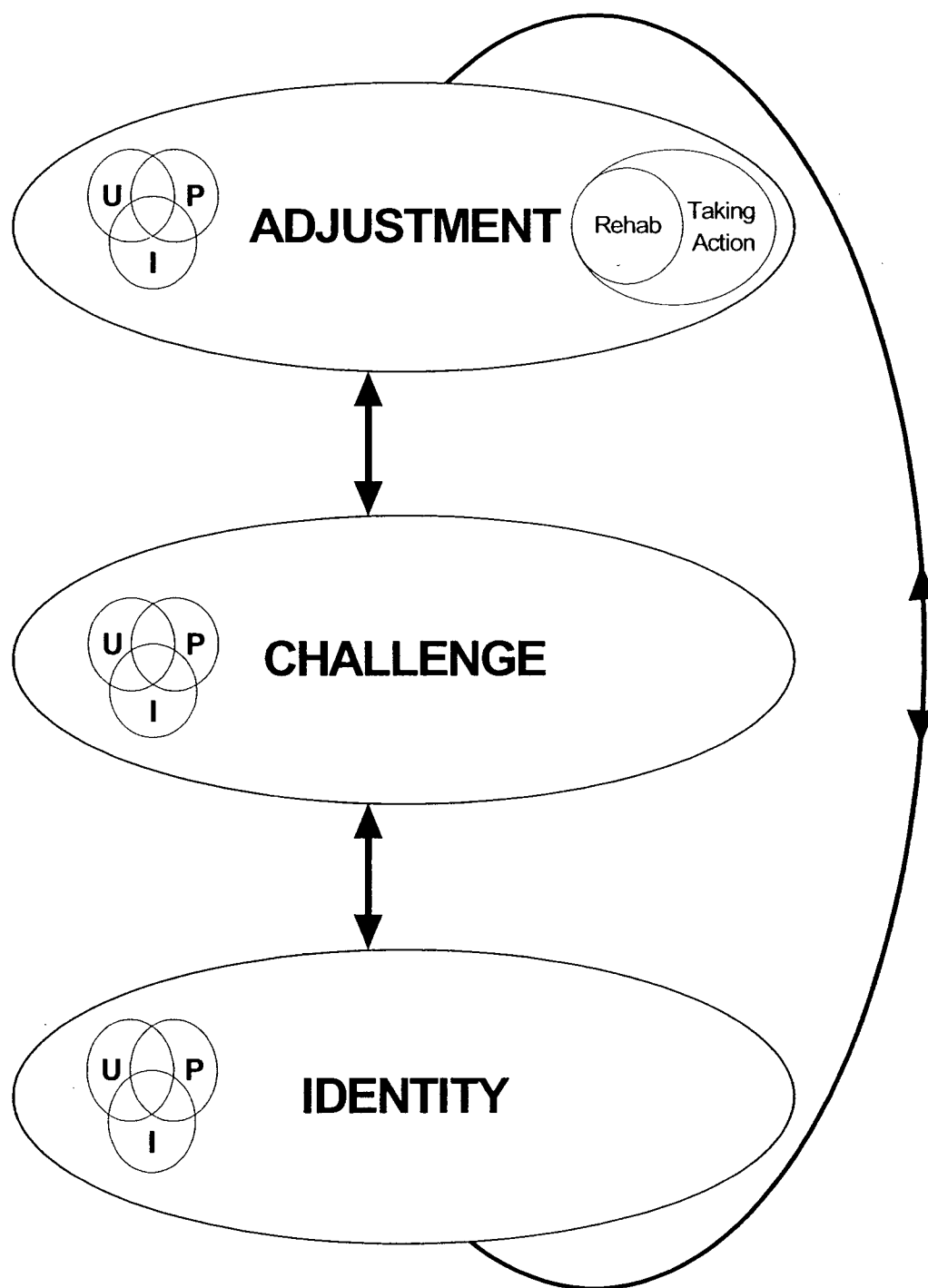
Individuals in this study presented different thresholds of tolerance for challenges. Some individuals could accept a great deal of imbalance before being compelled to make an adjustment. Others had very low tolerance and needed help sooner to cope with difficulties; balance within the model was more susceptible to challenges. Several of the older individuals discussed the difference between retired life and the difficulties associated with employment; they admitted they faced fewer challenges. They also admitted that their identities, as persons with hearing loss, were more acceptable because many members of their peer cohort were also hard-of-hearing. In contrast, many of the younger participants struggled to a greater extent, and sooner, to incorporate their hearing loss into their identity. They also described a frequent inability to control their work environment, which introduced significant challenges into their lives. These employment challenges were often the catalyst for help-seeking; difficulties in the work environment disturbed the ecological balance and propelled the individuals to find adjustments that could help them to cope with the challenges or re-define their expectations. Colleen described this process:

> **LDE:** What did you consider in your decision to participate in that class? Was it a hard or easy decision for you to make?
> **Colleen:** Well, the alternative was worse. It wasn't that hard a decision. It's part of my searching for better strategies.
> **LDE:** Mhmm
> **Colleen:** I was having problems at work. I was being slapped down and saying 'I didn't say that, you didn't hear, I said this' and I know darn well otherwise. But my hearing loss was being used against me
> **LDE:** Mhmm
> **Colleen:** so I needed more strategies. I needed to find other ways of dealing with people who were choosing to make me the bad guy.

Leslie also discussed that challenges at work encouraged advanced help-seeking:

> **Leslie:** When I was getting ready to leave my permanent desk {within the law firm} I was very desperate. And I went to the CHHA website and I hooked up with two of the e-mail groups, Internet groups
> **LDE:** Mhmm
> **Leslie:** and through them I found Ear Wear but then as a link off of the CHHA site, I found the Western Institute and then when I came here the first time I saw the Vancouver branch and so I've been to that once
> **LDE:** okay
> **Leslie:** and they are fabulous.

Work environments were not the only obstacle to satisfaction and ecological balance; acknowledging the negative social consequences of hearing loss also compelled individuals to make adjustments:

> **Grace:** They have a big impact just in the degree to which you can develop friendships or relationships with people or feel close
> **LDE:** Mhmm
> **Grace:** Because if you miss out- people often speak softer when they're speaking more intimately or more from the heart
> **LDE:** Mhmm, mhmm
> **Grace:** And if you miss out on something like that -- you miss -- and I've noticed that you know when it happens and it's really really sad that I've missed on an opportunity to be close with somebody because I didn't hear something that was said. Which really I can't ask them to repeat or if I do, it takes away from the moment entirely
> **LDE:** Mhmm
> **Grace:** So that's the kind of thing that I was noticing that really pushed me to do something about it

Participants also described situations in which ecological balance was maintained, and there was no need for adjustment through help-seeking behaviors:

> **LDE:** Do you have any future goals that a class- a future class might meet?
> **Cathy:** Pause. Well, I guess it depends how my hearing goes. If I get – if my hearing goes further down, I might need to join a class to learn a bit more about lipreading and that kind of thing
> **LDE:** Mhmm
> **Cathy:** But at this point, I'm managing just fine so I don't know
> **LDE:** Right. So you think it's a matter of not functioning as well as you want to? So if you found you were not functioning well, you would look for other means?
> **Cathy:** I would seek help.
> **LDE:** But when you're coping, you don't see the benefit really, because you're doing just fine?
> **Cathy:** Yeah, yeah

Finally, participants were also able to acknowledge the difficulty of making an adjustment when faced with challenges:

> **LDE:** Do you think there's anyone who is not ready to take a course like that?
> **Roger:** If they're not, if they haven't come to grips with the fact that they need it. Or they don't have -- it's always much better if they have a friend or wife who can be a support to go. It's a difficult step for a lot of people to take, I think.
> **LDE:** How do you think they come to grips that they need it? How would that happen?

Roger: I think it can happen in two ways: first of all, they've been involved with the Western Institute and they probably have hearing aids and they realize that now they're hearing things that they haven't heard before. They understand that it's not a miracle instrument, it's something that can really help. I think that having come to grips with that is the fact that they have to realize that, you know, it's not a personal thing, it's also a social thing. Hearing is personal to a point but it's social to a big point cause hearing is social.

LDE: Mhmm

Roger: And if they want to become involved, more involved, more relaxed socially, this is the thing to do cause you also have other people who have the same problem as you and it's good for them to see that they are all, like a lot of people have different ways of dealing with this problem, they have different degrees of hearing loss and this is a good place to be to understand that.

LDE: Mhmm

Roger: And it's not threatening thing. It's very, very easy to do. And you learn something about how to better function, function better in this whole aspect of wearing a hearing aid and learning what you haven't been doing right, you know, in the past.

The core category of ecological balance incorporates the categories of the theoretical framework and the thematic concepts that were observed throughout the qualitative data. By examining the challenges faced by the participants, as well as their tolerance for challenge, the category of ecological balance can help us understand the reason why some individuals seek advanced help for hearing loss in the form of group hearing rehabilitation programs, while others do not. Help-seeking for rehabilitation programs might be prevented if ecological balance is not disturbed. However, it might also be prevented through difficulties or resistance in identifying or accepting the issues that might occur at any level of the model: identity, challenge, or adjustment. Alternatively, help-seeking for rehabilitation programs might be promoted by acknowledgement of imbalance-laden difficulty from any level of the model. A hearing rehabilitation program could address each of these types of difficulties, and this awareness should exist on the part of the individual with hearing loss and the hearing health care professional.

Summary

This chapter described the thematic development and core category of the present study. Examples were presented from the interview sessions to support the themes of identity, challenge, and adjustment, and the core category of ecological balance was presented. The following chapter will discuss the implications of these findings.

Chapter 13: Discussion

Major Contributions

The purpose of this study was to try to understand the factors that prevent or promote adults with hearing loss from seeking advanced help through group hearing rehabilitation programs. The findings from this research provide a substantive theory of help-seeking, which involves the themes of identity, challenge, and adjustment. A model of ecological balance was developed. Although this ecological balance model is grounded in the information obtained from a group of adults who were hard-of-hearing, and describes advanced help-seeking for hearing loss, this idea of ecological balance has implications that extend beyond this population and health issue. The premise of ecological balance, as described by this model, appears applicable not only to adults with hearing loss, but it also has possible applications for health psychology in general.

The model demonstrates the process of help-seeking, for those individuals with hearing loss who are coping well with the difficulties related to their hearing loss, and who *flow* through the model. The model also provides an understanding of the issues facing those individuals who are experiencing difficulties in coping with their hearing loss and seeking appropriate help; the model provides a conceptualization of where the breakdown in help-seeking behavior might exist. Finally, this model relates to existing theories of identity, coping, adjustment, and help-seeking. The theoretical and practical implications of the model of ecological balance are discussed below. Implications of the findings are presented later in the chapter, as are the strengths and limitations of the research project.

Significance

The findings of this study have practical significance for audiology practice, contribute to audiological knowledge, and have theoretical significance related to help-seeking for hearing loss specifically, and health psychology, in general.

Practical Significance

The implications for audiologic practice come from both the general and the specific discoveries reported in this dissertation. The experiences and perceptions discussed throughout the results chapters are presented in the words of the participants. It is my

hope that these insights will help audiologists (and others) to better understand the consequences of hearing loss, as experienced in everyday lives. A greater understanding of these consequences could influence the depth of knowledge, degree and type of support, and the empathetic nature of approaches to working with those who are hard-of-hearing; service provided to this population should, therefore, be empathetically improved.

More specifically, the model of ecological balance can help audiologists understand the issues relevant to their clients and related to advanced help-seeking for hearing loss through rehabilitative programs. It is not simply enough to identify an individual as a help-seeker or not; it is important to acknowledge the process of help-seeking and the variety of obstacles to help-seeking. It is important for audiologists to acknowledge clients' perceptions of identity, challenge, and adjustment as they relate to the model. If a problem exists, and a client is experiencing difficulty, is this difficulty the result of how a client feels about himself, the problems he is facing, or what he can do about these problems? It is the *client's* perception of these components that will affect the decision to seek help. Understanding this distinction and the componential aspect of decision-making, on the part of the hearing healthcare professional, might result in the recommendation or adoption of a more specific, and more relevant, course of action. When *flow* is achieved and individuals perceive themselves to be coping well in their environment, the three components of the model can be thought of as balanced; the loop is intact, and there are no perceived problems or imbalances for the client.

Obstacles to help-seeking might exist in each of the three components. Figures 13.1 to 13.3 provide three distinct representations of possible obstacles in this model; the obstacle is represented through enlargement or expansion of that particular theme. Figure 13.1 represents a problem with identity. Perhaps the individual is experiencing a personal struggle related to acceptance of the hearing loss or is feeling isolated due to the lack of understanding by friends, relatives, and co-workers. It is necessary to acknowledge those issues, identify the challenges to solving the problem, and make the necessary step in order to adjust.

Figure 13.1. Model of ecological balance: focus on identity.
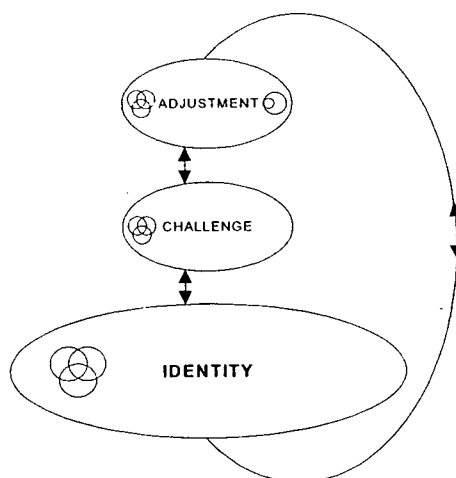
For some individuals, the significant obstacle to help-seeking might be best represented through the theme of challenge, as shown in Figure 13.2. For example, an individual might have difficulty understanding during a meeting at work, might experience problems with family members when the television is too loud or might misunderstand dinnertime conversation. In these situations, the individuals might need help in clarifying the problem and then problem-solving possible and feasible solutions. Identification of the problem, and the discovery and implementation of solutions would establish, or re-establish, progression through the model.

Figure 13.2. Model of ecological balance: focus on challenge
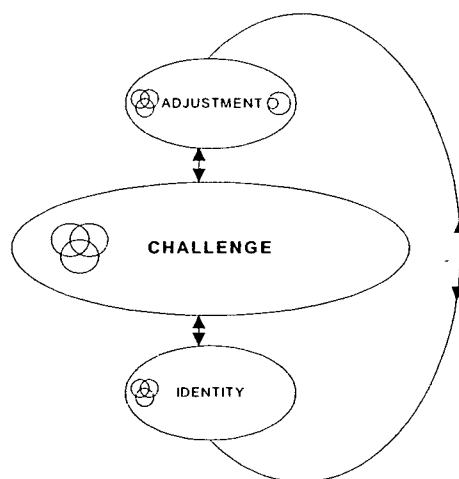
Figure 13.3 represents a situation where a person has identified relevant challenges but is unsure of how to proceed in making the appropriate adjustment to reconcile the problem. Problem solving and identifying an appropriate solution should reinstate progression through the ecological model of help-seeking. Re-evaluation of the challenge might also be beneficial in such a situation.

Figure 13.3. Model of ecological balance: focus on adjustment
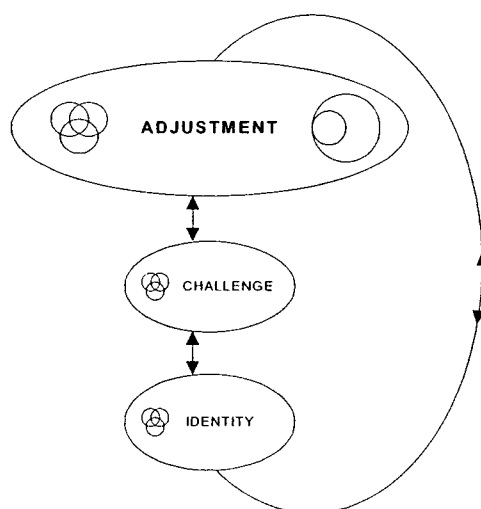
The presence of the loop in the model represents a cyclical, or iterative, process. Progression through identity, challenge, and adjustment does not indicate a completion

or 'graduation' from the help-seeking process. The findings of this study indicate an ongoing process, and it is important for both the professional and the client to recognize this process. Perceptions of the need for help constantly change as environment and personal factors change. Feelings of identity, abilities, and personal acceptance are constantly evolving. Challenges are a part of life, as the world and our 'ecology' are never static. Adjustments come in many forms, and they also experience evolution. This cycle of help-seeking can occur many times and for many different reasons.

As discussed above, the flow through the model proceeds from identity to challenge to adjustment. Flow through the model is however represented by a bi-directional line because other paths are possible. For example, if 'challenge' is the key component for an individual at a particular time, but she is not ready to address the adjustment possibilities, movement could proceed and return to the identity component. This effectively demonstrates a reverse flow through the model.

The rate of flow through this help-seeking process is idiosyncratic. Participants in this study demonstrated that tolerance for questionable identity issues and challenges depended on the individual; some individuals tolerated uncertainty and difficult situations without much disruption. Other participants, however, could experience significant problems with similar or comparable experiences. Some of the mediating factors seemed to be age, social, and work environments. For example, some of the older participants who were retired and had more control over their environments had a greater level of tolerance; others who were still in the workforce felt a more urgent need to address problems. However, it is difficult to provide a list of issues that would indicate the need to attend a group hearing rehabilitation program. Clientele who might benefit from the rehabilitation experience could be overlooked. Importantly, assumptions should not be made as to whether individuals should or would participate in these programs. The comments from the participants in this study demonstrated that individuals may chose to partake in a program for a variety of reasons and may choose to participate without indicating a recognizable interest or desire to participate. Clients should be given the choice of whether they want to attend.

Prior to this study, I believed if I spent an hour talking with someone about the effects of his or her hearing loss on daily life experiences, I could confidently predict whether he or she would choose to participate in a group hearing rehabilitation program. However, I discovered this decision could neither be accurately predicted based on what the

participants had told me throughout their interview session, nor from their opinions of rehabilitation opportunities. For example, Michelle believed that such classes were designed for everyone but her, and she believed she already knew what she needed to know about hearing loss. Nevertheless, she agreed to participate in the classes and reported great benefit from her participation.

Contribution to Audiological Knowledge

The present dissertation makes a contribution to audiological knowledge. These results supplement the research on aural rehabilitation and help-seeking.

Aural Rehabilitation

While the focus of this study was on the decision to participate in a group hearing rehabilitation program, the results also capture the experience of nine individuals who participated in a program as part of the research study. The positive change experienced and reported by many of the participants supports, and is supported by, the work of Israelite and Jennings (1995) and Backenroth and Ahlner (2000). The participants in the current study, through their own voices as participants in qualitative research, described their decisions, reflections, and obstacles related to their participation in a hearing rehabilitation program. These experiences were fundamental in the development of the model of ecological balance. The utility of the model redefines and enhances approaches to audiological rehabilitation, as described in the previous section. The details presented throughout Chapters 6 through 10 provided a wealth of information relating to rehabilitation sessions and programs.

Help-seeking

The literature available for help-seeking for hearing loss is somewhat meager. However, this trend is changing, as evidenced in the work of Mahoney, Swan and Gatehouse (Mahoney et al., 1996; Swan & Gatehouse, 1990), and most recently, Carson (2000). The present study adds to this literature by providing a greater understanding of the process of help-seeking by adults with hearing loss through group hearing rehabilitation programs. The present study was specific in its focus on a group hearing rehabilitation program, but the model appears to provide a process of help-seeking that could be generalized to a broad spectrum of help-seeking, including initial consultation for diagnoses and amplification. This research provides a significant

addition to the current literature through the description of the process of help-seeking as involving the concepts of identity, challenge, and adjustment. While the thematic components of the model of ecological balance are not novel, the integration, explanation, and grounding in the data make this model innovative.

Theoretical Implications

While concepts contained within this model of ecological balance have been explored through existing theoretical models, I do believe that this model represents the process of advanced help-seeking for hearing loss, and help-seeking in general, in a novel way. The current model demonstrates the importance of identity, challenge, and adjustment in the process of help-seeking; these concepts have not been highlighted in previous models. The model of ecological balance is a meta-model. Existing theoretical models that were presented in Chapter 2, as possibly being relevant to the current research project, can be seen as overlapping and strengthening various concepts in the current model. Figure 13.4 provides an overview of this interaction.

Figure 13.4. Interaction between the model of ecological balance and existing theoretical models and frameworks
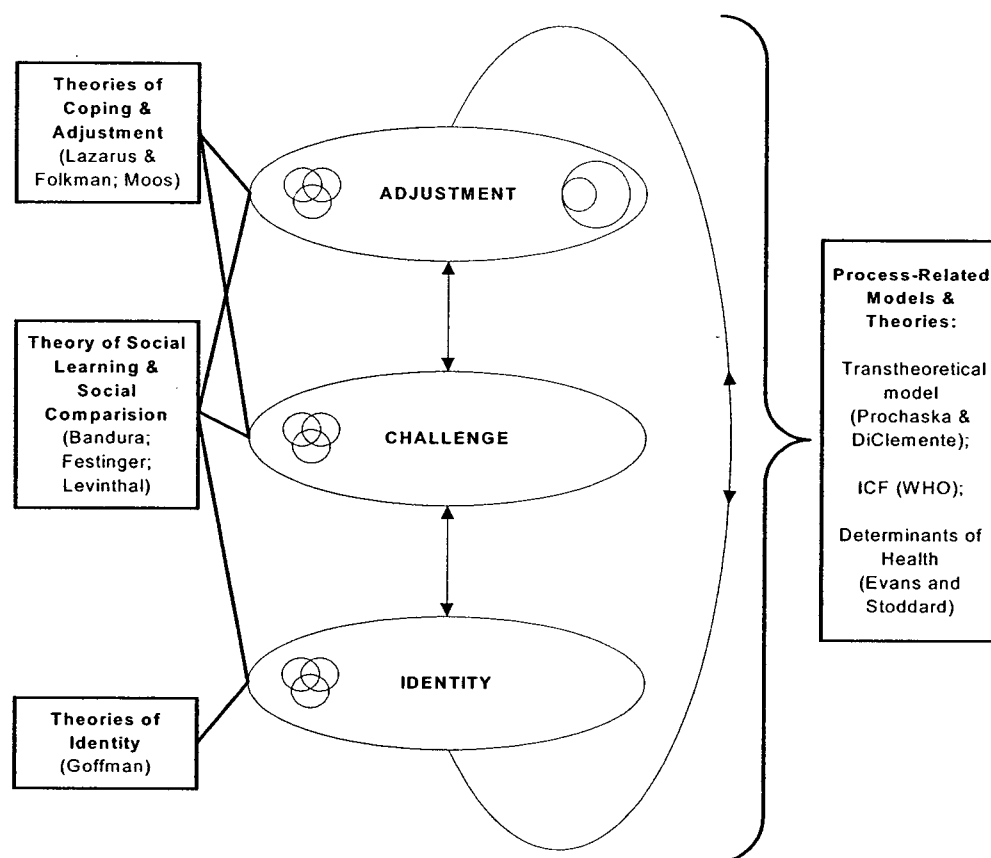
Ecological balance, the core category of the current study and the concept of the model, has enhanced my belief in the importance of the environment, as relevant to the experiences and perceptions of an individual. The development of the idea of environmental influence enhanced and supported the view of the consequences of a health condition by the World Health Organization through the development of the ICF (WHO, 2001) and Evans and Stoddard, through the model for the determinants of health (1990). The ICF (2001), the transtheoretical model (Prochaska & DiClemente, 1986), and the determinants of health (Evans & Stoddard, 1990) can be described as process-related theories and models. The model of ecological balance depicts a process of help-seeking and has a temporal dimensionality not addressed by the existing models. The current study also supports the ecological approach to audiology, as described for example by Noble and Borg (Borg, 1998; Noble, 1983; Noble & Hetú, 1994). When the model of ecological balance developed from this research is

compared with the ecological perspective put forth by Borg (1998), the new model from this study appears to provide a framework which is easily transposed onto a variety of experiences described by individuals with hearing loss. It provides a sense of movement, or process, through an experience. The model presented from this study, while appearing more simplistic, captures the help-seeking process.

Theories of identity, such as Goffman's (1963), are certainly relevant to the current findings, because identity is a major component of the model of ecological balance. Participants in the study spoke of the stigma related to hearing loss, and they discussed their frustration with these attitudes, and the effect of these attitudes on their own behaviors and the behaviors of others. Existing theories of identity provide insight into the depth of the issues relevant to identity and the acceptance, denial, or struggle with hearing loss, or any health condition, and subsequent help-seeking behavior.

The theory of social comparison (Festinger, 1954; Leventhal et al., 1997) appears relevant to, and supportive of, the ecological model. Superficially, the social comparison theory acknowledges the impact of other people and the environment, a definite tenet of the current study. The comparison theory was also relevant, through the words of the participants, to identity issues, challenge determination, and adjustment options. Participants reportedly compared their abilities and impairments with other individuals, whether friends or classmates in the rehabilitation program. Challenges discussed and experienced by others mediated the seriousness of the participants' challenges. Finally, adjustment options or solutions were also borrowed from others. In some circumstances, social comparisons also served to re-evaluate a previously bothersome problem; certain issues seemed to become less important when compared to the experiences of others.

Theories of coping and adjustment (Lazarus, 1976; Lazarus & Folkman, 1984; Moos, 1986) relate to the help-seeking process. In order to seek help, or to address a problem, individuals must assess the situation and determine a course of action. A progressive flow through the ecological model would seem to indicate a problem-focused, or appraisal-focused style of coping. A more stagnant or restrictive style of coping might be indicative of an emotion-focused style of coping. Additional investigation into the relevance of these, and other, existing theories should continue in order to take advantage of knowledge that already exists and to strengthen the model proposed here.

The model of ecological balance can also be compared to existing models of audiological rehabilitation and help-seeking for hearing loss. A seminal model of aural rehabilitation, proposed by Goldstein and Stephens (1981), categorized candidature for rehabilitation into four attitude types. The first attitude type was strongly positive towards hearing aids and audiological care. The second attitude type was essentially a positive attitude towards aural rehabilitation, but with some complications. The third attitude type was fundamentally negative, although a small amount of cooperative intent was present. The fourth attitude type rejected hearing aids and the entire rehabilitation process. According to this model, people of type four are not considered candidates for aural rehabilitation because they are not yet ready for these services. Furthermore, the authors seemed to suggest that promotion of help-seeking behavior is out of the scope of aural rehabilitationists because those type four individuals are not encouraged to participate in rehabilitation. Additionally, this model (Goldstein & Stephens, 1981) does not appear to suggest exactly how this categorization into attitude groups should be carried out. The new model of ecological balance, however, demonstrates that the goal of rehabilitation process is not to remedy *the* problem experienced by a client, but to understand the relationship between the individual, the challenges faced by the individual, and the help-seeking process. The current model differs as well from the historical model, as it emphasized the perceptions of the client as key. The findings from the current study also stress the importance of presenting all available options to the client, without making assumptions of the need or desire for services.

Schow's model of audiologic rehabilitation (2002) was discussed in Chapter 2 and depicted in Figure 2.1. This model consists of two components that describe assessment and management of hearing loss. While this model provides a comprehensive view of the components of rehabilitation, it does not describe the help-seeking behaviors, beliefs, or needs of the individuals with hearing loss who are consumers of these rehabilitative services. The new model of ecological balance provides insight to, and understanding of, the factors that bring an individual to seek and partake in these rehabilitative measures.

Carson's study of help-seeking for hearing loss provided a theoretical framework of *the spiral of decision-making in self-assessing hearing* (2000). Carson describes the significant factors in self-assessing as *contrasting/comparing, cost/benefit analysis*, and *control;* these factors help explain how personal experiences influence the process of

help-seeking for initial consultations within the audiological system. While agreeing with and complementing Carson's findings, the model of ecological balance provides a more global picture of the help-seeking process. The model of ecological balance describes help-seeking as an iterative process throughout the hearing loss experience. It also appears beneficial in describing various forms of help-seeking behavior.

Reflections on the Current Study

The present research study successfully developed a substantive theory that is grounded in the data. The research proposal for this study arose from a professional interest in audiological rehabilitation, a specific clinical-practice interest in group hearing rehabilitation programs, and the observation that this service was underutilized. The ultimate proposal evolved from a series of ideas related to rehabilitation before the final method was determined. Data collection occurred over eight months and data analysis, as determined by grounded theory, began once data collection was initiated and continued until this dissertation was written. The presentation of findings in this document provides the understanding of the data at this point in time; however, this understanding continued to evolve during writing. The present section of the chapter examines the strengths and limitations of the study.

Strengths

This study possesses the hallmarks of good qualitative research, as discussed in Chapter 3. As the researcher, I deliberated on ethical considerations. Specifically, recruitment, informed consent, and confidentiality of participants were carefully managed, and these methodological considerations were described in Chapter 3. The imposition of dominant theories was minimized; a search for, and the comprehension of, relevant theoretical models occurred after the majority of the analysis had occurred and the model of ecological balance had been developed. In addition, 'off the record' comments of participants and my personal experiences were considered throughout the project and carefully handled as described in Chapter 3.

This research meets criteria for being valid. Specifically, researcher-participant relationships and researcher bias were considered. Researcher-participant relationships were acknowledged through memos and also through the interactions documented in the interview sessions and rehabilitative classes. Researcher bias was

also acknowledged and addressed through researcher memos, which documented thoughts, opinions, and judgments.

Auditability is the ability to identify and verify the processes and findings of a study. Auditability of this research is supported through triangulation and transparency of method. Triangulation of the research was presented in Chapter 11; the various sources of data utilized in this study converged to support the findings and increased the strength of the convictions proposed ultimately in the form of the model of ecological balance. Transparency of method has been provided; the methods presented in Chapter 3 detail every step of the data collection and analysis. The presentation of the findings in the results chapters is accompanied by many quotations, an indication of the grounding of the data and subsequent model.

I completed each step of the data analysis strategy, including interview sessions, transcription, coding, framework development, thematic development, and instruction of the rehabilitation program. This level of involvement provided consistency of method and also enabled me to understand the experiences of the participants on a more comprehensive level. While this degree of control over analysis might be considered detrimental due to the possibility of bias, both the coding and framework development were checked and agreed upon by members of the supervisory committee throughout the process.

The primary research question was: *What are the factors that promote and prevent individuals with hearing loss from seeking advanced rehabilitation in the form of group hearing rehabilitation?* Through the process of answering this question, additional research questions emerged. These supplementary questions, which became categories of the framework, were: How do individuals who are hard-of-hearing understand their hearing loss? What is the personal experience of living with hearing loss? What are the social implications of living with hearing loss? What can individuals do to cope with hearing loss? What are the implications of participating in a hearing rehabilitation program? These questions provided rich details that helped to answer the primary research question and culminated in the model of ecological balance. Like the primary question, the supplementary questions were all well-suited to the use of a grounded theory approach because they concern processes and experiences.

Another strength of the current study involves the videotaping of the interview sessions. Videotapes were useful as a backup to the audiotaped interviews, but they

also provided information that supplemented the audio signal. In cases where the audiotaped conversation was unintelligible, the visual speech cues from the videos often provided information necessary for accurate transcription. In two interview sessions, there was a technical problem with the tape recording assembly which did not function properly, so that the videotapes provided the sole recording of the sessions; these interviews might have been lost otherwise. Although non-verbal cues were not analyzed in the current study, these cues may provide an interesting addition to future analytical examination of the data.

Saturation is an important hallmark of qualitative method. I believe saturation was reached through the participation of 20 individuals. Seven participants provided a comprehensive view from the perspective of experienced consumers of hearing rehabilitation programs. The remaining 13 participants also provided a 'saturated' perspective concerning the factors that prevent and promote advanced help-seeking for hearing loss, whether they declined, accepted, or dropped out of the offered rehabilitation program. Indeed, overall there were far more similarities than differences between participants in the four groups, as discussed in Chapter 11. Saturation was also reached for each participant, in that the time I spent with the participants enabled me ample opportunity to discuss relevant issues. Additional participants certainly would have provided additional examples from their own personal experiences; however, I do not believe that the participation of additional individuals would have influenced the categories, themes, or core category that emerged from this study.

Limitations

In addition to the strengths, there were also limitations of the research project. The qualitative method utilized throughout this project was time consuming. Complete transcriptions of the interview sessions were arduous; however, the time spent transcribing the interviews provided a level of intimacy with the data that would not have been achieved had someone else transcribed them.

A second limitation of this research project was the shortsightedness of my instructions regarding the journal. The participants were asked to write in a hardcopy journal that was provided to them at the time of their initial interviews. At the end of the study, two of the participants reported that they had not written in the book but believed they would have written through emails and made notes on the computer. Because this

variation of journal keeping was not explicitly encouraged, they neglected to write about any daily experiences with hearing loss. Two other participants did keep notes in a computer document and forwarded them to me at the conclusion of their participation in the rehabilitation program.

A third limitation of this study concerns the questionnaire data. While the data from the CPHI and the COSI did not contribute significantly to the model of ecological balance, they did contribute as a source of information used in triangulation. The plan for the study proposed that the RTCQ-H might distinguish between those who wanted to participate in a hearing rehabilitation program and those who did not. However, the questions were not specific enough to distinguish between the groups or to decide on the utility of this questionnaire as a means to distinguish between the participants and their *stage*.

I am confident that saturation was reached and that a sufficient number of participants was involved in the current study to provide an accurate understanding of the process of help-seeking for advanced hearing rehabilitation programs. However, there were certain limitations placed on the study by virtue of the hearing rehabilitation programs that should be acknowledged. Class size was restricted to between six and ten participants due to the nature of hearing loss and the difficulties of group participation. Because I was just as interested in discovering the factors that prevented participation as those that promoted it, I had hoped to encounter a number of individuals who chose *not* to participate in the program, before I encountered enough people to fill the class. I interviewed four individuals who did not want to participate before I completed interviews with nine individuals to provide a sufficient class size. Another view of factors that prevented participation also came from those participants who did participate in the class; these individuals spoke of the reasons they had not participated in the past.

This study depended on the voluntary nature of the participants. As is the case with any study that requires voluntary participation, it is important to recognize that each of these participants was self-selected. Such self-selection was the basis of another concern I had before the study began: Would I obtain the participation of individuals who already knew they did not want to take part in the rehabilitation program? I did interview two such individuals who agreed to the initial interview knowing they would not participate in the group program. The remaining two participants who decided not to

participate in the rehabilitation program did not make this decision until the time of the initial interview.

Directions for Future Research

The model of ecological balance was developed through the participation of 20 individuals with hearing loss, and it provides an understanding of the help-seeking process of these adults. This research study and the findings presented in this dissertation provide evidence for the utility of qualitative methodology in audiological research and in health psychology research in general. Qualitative inquiry into audiological issues should be encouraged. While this model appears to be applicable to other individuals with hearing loss, as well as other health conditions, further research would confirm the applicability of this model. Although it was not a focus of the current project, the information gained through this study qualitatively demonstrates the perceived benefit of a hearing rehabilitation program for adults with hearing loss; this benefit should be further documented and promoted. Appropriate evaluation procedures should be promoted. Finally, audiology practice would benefit from a greater understanding of the model presented here and a clinical tool based on the model; this would help audiologists to assess clients with regard to the need and potential benefit of audiologic rehabilitation. A tool to promote understanding of the perceptions of the client might be beneficial. The ability to identify the obstacle in help-seeking experienced by clients and the ability to direct clinical skills toward the reduction or elimination of that obstacle would certainly increase the benefit obtained through audiologic consultation. This optimized service should result in a more comfortable and satisfactory communication experience.

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Appendix A: WIDHH Information

Western Institute for the Deaf and Hard of Hearing
Mission Statement

The Western Institute for the Deaf and Hard of Hearing exists to address the needs of deaf, deafened, and hard of hearing individuals by providing products, services and programs that work towards ensuring accessibility to their environment which is equal to that of hearing public.

Departments

Audiology
- Hearing tests
- Hearing aid evaluations
- Supervised hearing aid trials
- Individual counseling
- Community education

Employment Services
- Job search assistance
- Resumes and covering letters
- Interview skill development
- Worksite assessment and adjustment
- Follow up and support

Counseling Services
- Vocational Rehabilitation Services
  - Career counseling
  - Vocational assessment
  - Job shadowing, work experience
- Psychological and psychiatric assessment
- Personal counseling
- Life skills
- Education and Outreach

Communication Aids
- TTYs
- Visual alert systems for the telephone, doorbell, intercom, baby cry, smoke detector, and alarm clock
- Assistive Listening Devices (ALDs) including systems for the television, telephone and one-to-one communication devices
- Closed captioners
- Individual demonstrations
- Community education and displays
- Wide area installations
- Service department

Interpreting Services
- Medical interpreting
  - General appointments
  - 24-hour emergency service
- Legal interpreting
- Mental health interpreting
- Vocational support interpreting
- Practicum placement
- Public education

Appendix C: WIDHH Executive Director Letter of Support

Name
Address

HELP-SEEKING FOR ADVANCED HEARING REHABILITATION:
THOSE WHO DO AND THOSE WHO DON'T

Dear

Would you like to help with a research project concerning hearing loss?

Lisa Dillon Edgett, an audiologist and doctoral student from the University of British Columbia, is doing a research project here at the Western Institute for the Deaf and Hard of Hearing. She wants to know why some people choose to participate in courses that teach people how to manage their hearing losses, while others do not.

According to our records, you have participated in a hearing rehabilitation course in the past. Lisa would like to talk to you about your experiences in that class and about the effects that hearing loss has on your daily life. If you choose to participate, you will be asked to complete a questionnaire, attend one interview session and make journal entries over the course of four weeks on how hearing loss affects daily experiences.

We support this project and would like to encourage you to participate. We believe that the findings of this study could help us understand why a small number of people enroll in available programs. This is also an opportunity to help others understand what it is like to live with a hearing loss.

If you are interested in participating or would like more information on this study, please complete the form on the following page.

Sincerely,

Marilyn Dahl, OBC, Ph.D.
Executive Director
Western Institute for the Deaf and Hard of Hearing

Appendix D: Interview Schedule

	Introductory interview	Second interview	Final interview
Robert	May 17, 2001	-----	-----
Roger	May 24, 2001	-----	-----
Ian	May 25, 2001	-----	-----
Janet	May 25, 2001	-----	-----
Matt	May 25, 2001	-----	-----
Colleen	May 29, 2001	-----	-----
Kelly	June 6, 2001	-----	-----
Hanna	October 2, 2001	-----	-----
Grace	October 5, 2001	-----	-----
Judy	October 9, 2001	-----	-----
Ellen	October 12, 2001	-----	-----
Claire	August 23, 2001	November 26, 2001	January 12, 2002
Michelle	September 28, 2001	November 26, 2001	January 21, 2002
Derek	September 28, 2001	N/A[1]	January 12, 2002
Tony	October 5, 2001	N/A[2]	January 21, 2002
Hillary	October 5, 2001	December 4, 2001	January 17, 2002
Leslie	October 12, 2001	December 1, 2001	January 12, 2002
Linda	October 10, 2001	N/A[3]	January 15, 2002
Cathy	October 4, 2001	N/A[4]	December 6, 2001
Gina	October 17, 2001	N/A[5]	January 12, 2002

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[1] Not available due to travel out of the country.
[2] Not available due to busy schedule.
[3] Not available due to illness and busy schedule. Completed questions via email.
[4] Not applicable since no longer attending classes.
[5] Not applicable since no longer attending classes.

Appendix E: The Rehabilitation Program

Topics discussed during the hearing rehabilitation program included:

- How the ear works
- Understanding the audiogram and audiogram of familiar sounds
- Speechreading exercises and homophonous sounds
- Relaxation exercises
- Factors affecting ability to hear and speechread:
    - Environment
    - Speaker
    - Listener
    - Message
- Assertive behavior
- Strategies for specific environments: e.g., restaurants, telephone
- Hearing aids and assistive listening devices
- Gestures and facial expressions
- Stress management
- Hearing loss and its effect on relationships
- Hearing loss and the workplace
- Tinnitus
- Canadian Hard of Hearing Association (CHHA)
- Humor as a strategy to cope with hearing loss
- Pacific Assistance Dogs Society (PADS)
- Cochlear implants

Appendix F: Core Questions

Interview Protocols

<u>General Interview</u>
All participants: first session

Tell me about your hearing loss.
▪ How long have you known about it?
▪ How long did you suspect that you had a problem before you saw someone about it?
▪ What made you decide to see someone?
▪ What did you do about your hearing loss before you went to get your hearing tested?
On a day to day basis, when are you aware of your hearing loss?
▪ Has this changed since you first discovered your hearing loss?
▪ Tell me about significant life decisions you made where hearing loss was a factor.
▪ Examples of difficult listening situations...What did you do? How did you feel?
Has your hearing loss changed your lifestyle?
▪ If you changed, why did you start doing that?
▪ Are these one-time changes or permanent changes?
▪ Do you think you've changed the way you talk to other people?
▪ Have you changed the people you spend time with?
▪ Have you changed the things you like to do?
Are there negative attitudes attached to hearing loss?
▪ How have you been treated as a person who is hard of hearing?
▪ What do you think the general public knows about hearing loss?
▪ What do they need to learn?
▪ How do you feel about telling others you have a hearing loss?
Is there anyone who should do more about making it easier to listen?
▪ What could you do?
▪ What do you think other people can do?
▪ How could they do it?
▪ What would get them to do it?
What efforts have you made to reduce your hearing difficulties?
▪ Do you wear a hearing aid? Since when? Does it make a difference?
▪ Have you used any assistive listening devices?
▪ TV amplifier/Phone/FM system/Alerting devices
▪ When do you like to use them?
▪ When do you not like to use them?
▪ Have you heard of CHHA (Canadian Hard of Hearing Association)? Have you attended a CHHA meeting?
▪ Do you know other people who are hard of hearing?
▪ Are you aware of anything else you could do?
▪ Of all the things you've done to deal with your hearing loss, what had the most value?

Appendix G: Experienced Interview Questions

<u>Past Rehab Program Interview</u>
Participants with prior rehab experience: first session

General interview question protocol plus...

Tell me about the rehabilitative class that you participated in.

- Specific program description:
  - When was it?
  - Who taught you?
  - Number of people in the class, number of classes, hours per session
  - What did you learn?
  - Did you think it was a good way to learn?
  - Did you like the way the class was run? (breaks, overheads, types of exercises...)
  - Would you change the class in any way if you went to another one?
- Program evaluation:
  - Did you use what you learned in everyday situations?
    - Is there anything in particular that you use more often?
  - Would you want to participate in other classes?
    - Would they be different in any way?
    - What would you want to learn in additional classes? Why?
  - What are your criteria for a successful class?
  - What did you think you would gain from the class?
  - How do you feel about the other members of the class?
    - Did you compare your loss with theirs?
    - Did your comparison change over the course of the classes?
  - Over the whole class, what experiences stand out to you?
    - What was your most important experience in the class?

What did you consider in your decision to participate?

- Who encouraged you to participate? How did they encourage you?
- Who discouraged you from participating? How did they discourage you?
- What made it hard or easy to decide?
- Was there a time when you thought you were not ready to participate?
- If so, what happened to change your mind?
- Do you know anyone else who's taken a class?
- Do you see yourself being a class instructor?
- How did you find out about it?
- If you had never gone to that class, where do you think you'd be today?

Have you taken classes for any other health condition?

- If you took one, how did you feel about it?
- Can you think of any other class that might similar to a hearing rehab class?
- Do you encourage friends/family members to participate in classes that may help them?

What would you say to someone who is thinking about classes but is having trouble deciding?

- Who do you think would get something out of participating in this?
- What do you think may be preventing them from participating?
- What would you say to encourage them to participate?
- Who do you think would not be ready to participate?
- What advice would you give to others who are just learning of a hearing loss?

Appendix H: Preliminary Questions

<u>Preliminary Interview</u>
Participants with no prior rehab experience: first session

General interview question protocol plus...

Have you thought about participating in a rehabilitation class?
- Do you know of any rehabilitation classes?
- What do you imagine a rehabilitation class to be?
- What would your dream course about hearing loss be like?

Would you be interested in enrolling in a class here at WIDHH?
- If yes, what do you expect to gain from such a class?
  - ⇨ If no, continue with 'rehabilitation rejection interview' questions

Appendix I: Rehabilitation Rejection Questions

<u>Rehabilitation Rejection Interview</u>
Participants, with no prior rehab experience, who do not want to enroll in rehab
program: first session

General interview question protocol plus...

Preliminary interview protocol plus...

How strongly do you feel about not participating?
- Would anything change your mind?

Can you explain why you do not want to participate in a rehab class?
- Is the content a concern?
- Are practical arrangements a concern?
- Other concerns?
- Do you feel that these classes would not offer you things that you need or want?
- What do you want?

Do you think you might want to enroll in the future?
- If yes, what do you expect to change between now and then?
- If no, can you imagine a situation that would compel you to enroll in the classes?

Do you think that you would get support from family and friends to enroll?
- What do you think they would say about such a course?

Do you have preferences for other ways to meet you needs?
- Do you feel you don't have any needs?

Appendix J: Mid-rehabilitation Questions

<u>Mid-rehab interview</u>
Rehab class participants: third/fourth session

Revisit general interview question protocol plus...

Is this class what you thought it would be?

- How is it different from what you thought it would be?

Would you like to continue with the remaining weeks of classes?

- If yes, what would you like to accomplish in the next four weeks of classes?
- If no, revisit 'rehab rejection' interview protocol

Appendix K: Post Rehabilitation Questions

<u>Post-rehab interview</u>
Rehab class participants

Revisit general interview question protocol plus...

Were you satisfied with the program?

- Is this program what you thought it would be?
- Overall, how would you rate this program, on a scale from 1 to 10?
- What parts were most helpful?
- What parts were least helpful?
- Were you satisfied with the length of the classes and program? (# hours, days, weeks)
- Over the course of the program, did your feelings about the classes change?

Have you used the things you learned in this class?

- Have you used/do you intend to use strategies and knowledge that you gained in this class in the situations you encounter as a result of your hearing loss? Please explain.
- What was the most important thing you learned in this class?
- What would you like to change about this class?
- What was your most important experience in this class?
- Over the whole class, what experiences stand out to you?
- Who contributed the most to those experiences?

What are your future goals?

- Did the class meet your objectives?
- Do you now have new objectives and new goals?
- Could your new objectives be met with a new course?

Did it make a difference that you were a research participant?

- Did the journal entries, weekly reports or questionnaire affect your level of satisfaction with the program?

Appendix L: Program Evaluation Form

Hearing Rehab at WIDHH
Fall/Winter 2001

Instructor: Lisa Dillon Edgett, M.Sc., Audiologist

A Final Course Evaluation:

Overall, how would you rate this <u>course</u>:

Excellent				**Poor**
1	**2**	**3**	**4**	**5**

Overall, how would you rate this <u>instructor</u>:

Excellent				**Poor**
1	**2**	**3**	**4**	**5**

What were the topics you found most helpful?
1.

2.

3.

What were the topics you found least helpful?
1.

2.

3.

What are some topics you wish had been covered in this class?

Were you satisfied with the depth at which the topics were covered? Please explain.

Appendix L: Continued

Were you happy with the length of the class?
- two hours per week:
- one class per week:
- 10 weeks total:

Were you happy with the day and location of the class?
- Saturday mornings

- WIDHH Brodie Hall

What would you like to change about this class?

What is the most important thing you learned in this class? Why is it important?

Was this class what you expected? Please explain.

Have you used/do you intend to use strategies and knowledge that you gained in this class in the situations you encounter as a result of your hearing loss? Please explain.

Please tell us anything else you would like to share about this class.

Appendix M: Instructions for Journal Writing

Instructions for Journal Writing

I am giving you a blank book for you to write about your daily experiences with hearing. I am also interested to learn about how these experiences have been or could be influenced by knowledge and strategies learned in hearing rehabilitation. Do you think about your decision to participate or not participate in hearing rehab when you encounter certain situations?

Some people keep a journal or diary all the time; others have never kept a journal. The following comments should help you with this part of the study.

⌘ Try to write every day starting today for **four weeks**. Ten minutes a day is all that is asked of you. Please feel free to write more than ten minutes if you are inspired to do so.

⌘ You may find it helpful to get in the habit of writing at the same time each day, such as bedtime or just after breakfast.

⌘ Don't worry about the form your writing takes- grammar and spelling are not important here. The **content** is the most important aspect of this journal. Please write what you feel and don't worry about how it looks.

⌘ If you need another notebook, please contact me and I will send one to you immediately:
- 899-XXXX (phone)
- 899-XXXX (fax)
- lisa@edgett.bc.ca

⌘ You are asked to write about your daily experiences with hearing. Your experiences may be positive, negative, or neutral. Please date each journal entry. Examples of things to focus on are:
- An activity you were involved in and how it may have been affected by your hearing;
- Your mood or emotions and whether you think your hearing may have played a factor in how you felt;
- An interaction with a friend, family member or stranger and how hearing played a role;
- Your reflections on how you reacted to any listening difficulties, the possibility of improving communication problems, and how this improvement is likely to occur.

⌘ When you have completed this task, please place the journal book in the addressed, stamped envelope provided.

Thank you for taking the time to complete this task.

Appendix N: Readiness to Change Questionnaire- Hearing

Readiness to Change Questionnaire- Hearing

Please indicate whether you: strongly agree, agree, are unsure, disagree or strongly disagree with the following statements:

		Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
1.	I don't think I miss much as a result of my hearing loss	❏	❏	❏	❏	❏
2.	I am trying to do something about my hearing difficulties	❏	❏	❏	❏	❏
3.	I believe I am having more trouble communicating than I used to	❏	❏	❏	❏	❏
4.	Sometimes I think I should do more to reduce my hearing problems	❏	❏	❏	❏	❏
5.	It's a waste of time thinking about my hearing problems	❏	❏	❏	❏	❏
6.	I have just recently done something to reduce my hearing problems	❏	❏	❏	❏	❏
7.	Anyone can talk about wanting to do something about their hearing problems, but I am actually doing something about it	❏	❏	❏	❏	❏
8.	I am at the stage where I think I should think about doing something to help my hearing problems.	❏	❏	❏	❏	❏
9.	My hearing loss is a problem sometimes	❏	❏	❏	❏	❏
10.	There is no need for me to think about enrolling in hearing rehab classes	❏	❏	❏	❏	❏
11.	I am actually doing something to help my hearing loss now	❏	❏	❏	❏	❏
12.	Enrolling in hearing rehab classes would be pointless for me.	❏	❏	❏	❏	❏

Appendix Q: Theoretical Framework

First Category

Category	Property	Dimensions	Dimensions
Understanding hearing loss	Hearing loss history	Time with hearing loss	
		Degree of hearing loss	
		First signs	
		Cause	
		Tinnitus/vertigo	
		Improvement in hearing	
		Childhood experiences	
		Testing	
		Prognosis	
	Family history of hearing loss		
	Comparisons with hearing loss	Hearing loss to hearing loss	
	Comparisons with hearing loss and other disabilities	Vision	
		Mobility	
	Comparisons of concepts and experiences	Ages	
		Attitudes	
		Communication	
		Experiences	
	Comparisons involving hearing aids		
	Explaining to others	Explaining hearing loss	
		Explaining hearing aids	
	Awareness of others' hearing losses		
	Technology: general	Psychological	
		Problems	

Appendix Q: Continued

Second Category

Category	Property	Dimensions	Dimensions
Personal experience with hearing loss	Self-perceptions	Acceptance	
		Denial	
		Assertiveness	
		Awareness of own hearing loss	
		Lifestyle	
		Abilities	
		General positive	
		General negative	
	Disclosure	Purpose	
		Method	
		Process	
		Reasons for not disclosing	
		Of hearing aid	
	Emotional reactions	Hearing loss	
		Communication difficulties	
		Possible solutions: positive	
		Possible solutions: negative	
	Effect on communication	Desire to communicate	
		Inability to communicate	
	Underlying personal concerns	Voice	
		Safety	
		Humor	
		Social	
		Work	
	Identification of specific problems from personal experience	Environment: noise	
		Environment: other	
		Speaker	
		Listener	
		Message	

Appendix Q: Continued

Third Category

Category	Property	Dimensions	Dimensions
Interaction between person with hearing loss and society	Effect of hearing loss on personal relationships	Wife	Positive
			Negative
		Husband	Positive
			Negative
		Family and friends	Positive
			Negative
		Exceptions	Positive
			Negative
	Influence of hearing loss on lifestyle	Change of activity	People
			Events
		No change of activity	People
			Events
		Removal from situation	
	Relationships with professionals	Doctor	
		ENT	
		Audiologist	
	Social concerns	Work issues	
		Socialization issues	
		Advocacy issues	
		Funding issues	
		Service issues	
		Age-related issues	
		Understanding hearing loss	
	Misunderstandings by others	Regarding not hearing	
		Regarding technology	
	Stereotypes	Towards hearing loss	
		Towards hearing aid	
		Towards person with hearing loss	
	Work and school environments	Work	Details
			Difficulties
		School	
		Volunteering	

Appendix Q: Continued

Fourth Category

Category	Property	Dimensions	Dimensions
Taking action	Technology: use and awareness	Hearing aids	History
			Positive comments
			Negative comments
			About two hearing aids
			Expectations
			Cost
			Amount of hearing aid use
		Infrared	
		FM	
			Conference microphone
		Loop system	
		Sound Wizard	
		Phone	
			VCO and MRC
		Closed captioning	
		Real-time captioning	
		Rear-window captioning	
		Computer/internet	
		Fax	
		Alerting	
		Cochlear implant	
		Other/general	
	Conversational strategies	Request for repetition	
		Identification of topic	
		Anticipating	
		Bluffing	
		Guessing	
		Repeat what was heard	
		Specific suggestions	
		Giving up	
	Strategies and support	Environment	
		Written material	
		Speechreading	
		Sign language	
		Vision	
		People	
		Dogs	
		Humor	
		CHHA	
		Earwear	

Appendix Q: Continued

Fifth Category

Category	Property	Dimensions	Dimensions
Reflections of rehabilitation experience	Rehabilitation experience	Expectations	
		Positive comments	
		Negative comments	
		Description	General
			Ear anatomy
			Audiogram & audiogram of familiar sounds
			Factors affecting abilities
			Hearing aids & assistive listening devices
			Pacific Assistance Dog Society
			Working with hearing loss
			Assertiveness
			Speechreading
			Relaxation exercises
		Comparisons	
	Observations	Of self	
		Of others	
	Participation in the hearing rehabilitation program	About own decision	
		To encourage others	
		What's next?	
	Positive change resulting from rehabilitation experience		
	Dropping out of the rehabilitation classes		
	Factors affecting participation of people with hearing loss	Preventing participation	
		Promoting participation	
	Study reflections	Journal	
		Positive effect	
		Negative effect	

Appendix R: Communication Profile for the Hearing Impaired Data

First Administration – Part 1

		Robert	Ian	Janet	Matt	Roger	Colleen	Kelly	Hanna	Judy	Ellen
Communication Performance	Social	1.5	1.2	3.2	3.8	2.5	2.8	2.8	1.5	3.3	2.4
	Work	2.2	2.0	3.3	3.8	3.0	3.2	2.8	1.8	3.4	2.5
	Home	1.5	2.3	3.3	3.8	3.0	4.0	3.2	2.2	3.3	3.7
	Average	2.2	2.3	4.0	4.2	3.3	4.1	3.5	2.2	3.5	3.3
	Adverse	1.0	1.3	2.4	3.3	2.3	2.4	2.3	1.4	3.1	2.7
	Problem Awareness	4.6	5.0	4.4	4.0	4.3	4.4	4.0	4.4	3.6	4.4
	Average	**2.2**	**2.3**	**3.4**	**3.8**	**3.1**	**3.5**	**3.1**	**2.2**	**3.4**	**3.2**
Communication Environment	Need for Communication	3.0	2.0	2.0	1.5	2.0	2.0	2.0	3.5	1.5	2.0
	Physical Characteristics	3.0	2.6	2.6	3.0	3.4	3.0	2.6	4.0	4.0	3.3
	Attitudes of Others	2.9	4.4	4.6	3.1	4.5	2.0	4.4	4.3	3.6	4.8
	Behaviours of Others	2.9	3.6	3.9	2.9	4.3	2.5	4.3	4.2	3.9	4.5
	Average	**3.0**	**3.2**	**3.3**	**2.6**	**3.6**	**2.4**	**3.3**	**4.0**	**3.3**	**3.7**
Communication Strategies	Maladaptive behaviours	2.7	2.8	1.3	1.9	1.7	2.0	1.3	1.6	1.6	1.4
	Verbal Strategies	4.3	3.4	3.3	3.8	3.3	3.4	3.3	2.5	3.0	2.1
	Nonverbal Strategies	4.9	4.8	4.5	4.8	4.8	4.8	3.8	3.0	3.9	3.3
	Average	**3.9**	**3.6**	**3.0**	**3.5**	**3.2**	**3.4**	**2.8**	**2.4**	**2.8**	**2.3**
Personal Adjustment	Self Acceptance	3.6	4.0	4.1	3.1	3.8	4.0	3.5	3.8	4.1	4.5
	Acceptance of Loss	4.2	4.1	4.8	4.2	3.9	4.2	4.0	4.4	4.6	4.6
	Anger	2.2	4.5	4.2	3.1	3.0	3.7	4.0	3.3	4.0	4.0
	Displacement of Responsibility	1.2	3.6	3.4	2.1	3.0	3.2	4.0	2.6	2.8	2.0
	Exaggeration of Responsibility	4.0	3.3	3.8	3.8	3.8	4.0	3.0	2.8	3.7	3.2
	Discouragement	2.3	4.3	4.0	2.1	2.8	3.7	3.2	3.3	4.7	4.2
	Stress	2.0	3.8	3.6	2.5	3.3	4.1	2.9	3.0	3.9	3.9
	Withdrawal	1.7	1.9	3.0	3.3	3.3	2.1	2.7	3.6	4.4	3.0
	Denial	3.8	2.9	3.0	3.9	3.4	3.4	3.3	3.5	3.4	2.7
	Average	**2.8**	**3.6**	**3.8**	**3.1**	**3.4**	**3.6**	**3.4**	**3.4**	**3.9**	**3.6**
Importance	Social	2.0	1.5	2.2	3.1	3.3	3.0	3.2	3.3	3.3	2.8
	Work	2.4	3.7	3.8	4.0	4.5	4.3	4.5	3.5	3.8	2.5
	Home	2.5	2.8	3.0	4.0	3.5	3.3	3.5	2.5	3.0	3.0
	Average	**2.3**	**2.7**	**3.0**	**3.7**	**3.8**	**3.6**	**3.7**	**3.1**	**3.4**	**2.8**

Appendix R: Continued

First Administration – Part 2

		Claire	Michelle	Derek	Tony	Hillary	Leslie	Linda	Cathy	Gina
Communication Performance	Social	3.2	2.7	3.0	1.7	4.0	2.2	1.0	3.2	1.8
	Work	3.8	2.8	3.3	2.0	3.2	2.5	2.0	3.5	2.3
	Home	3.2	3.5	3.7	3.0	3.2	2.7	2.2	4.3	2.7
	Average	4.1	3.3	4.1	2.5	3.8	2.9	2.2	4.1	2.9
	Adverse	2.5	2.6	2.5	1.9	3.0	1.9	1.1	3.1	1.5
	Problem Awareness	4.3	4.5	4.9	4.0	4.3	4.5	5.0	4.0	4.9
	Average	**3.5**	**3.2**	**3.6**	**2.5**	**3.6**	**2.8**	**2.3**	**3.7**	**2.7**
Communication Environment	Need for Communication	1.0	1.5	2.0	3.0	2.0	1.0	1.0	1.5	1.0
	Physical Characteristics	1.8	2.2	2.8	3.6	3.2	1.4	2.0	2.2	3.0
	Attitudes of Others	2.6	4.0	4.8	3.4	4.1	1.5	4.4	4.3	3.5
	Behaviours of Others	3.7	3.4	4.5	3.0	4.1	1.5	3.3	3.7	4.1
	Average	**2.3**	**2.8**	**3.5**	**3.3**	**3.4**	**1.4**	**2.7**	**2.9**	**2.9**
Communication Strategies	Maladaptive behaviours	2.3	2.2	2.3	1.8	2.7	3.3	2.6	1.4	1.9
	Verbal Strategies	3.3	3.8	3.5	2.5	3.8	3.4	3.0	3.4	3.8
	Nonverbal Strategies	4.6	4.6	3.9	3.4	3.5	4.5	4.5	4.4	4.6
	Average	**3.4**	**3.5**	**3.2**	**2.5**	**3.3**	**3.7**	**3.4**	**3.1**	**3.4**
Personal Adjustment	Self Acceptance	2.5	4.4	2.3	3.6	3.3	1.1	2.0	3.0	3.6
	Acceptance of Loss	2.9	5.0	3.4	4.1	3.8	1.9	3.3	4.3	4.7
	Anger	3.7	4.5	2.8	3.8	2.7	2.3	2.3	3.2	3.2
	Displacement of Responsibility	3.0	2.4	3.6	2.0	2.6	2.0	3.2	2.6	2.4
	Exaggeration of Responsibility	3.0	3.7	3.5	3.8	3.0	2.0	2.2	2.0	3.5
	Discouragement	3.2	4.2	2.3	3.5	1.8	1.5	1.3	4.2	3.3
	Stress	1.8	4.1	2.1	3.8	2.3	1.3	1.5	2.4	2.4
	Withdrawal	2.4	2.9	1.7	3.3	2.1	1.1	1.1	3.9	2.3
	Denial	3.6	2.1	4.6	3.5	3.9	4.4	4.6	3.6	4.3
	Average	**2.9**	**3.7**	**2.9**	**3.5**	**2.8**	**2.0**	**2.4**	**3.2**	**3.3**
Importance	Social	3.7	3.3	2.6	2.8	2.8	3.2	4.3	2.3	3.2
	Work	4.2	3.2	4.2	4.2	4.2	4.7	4.5	4.0	5.0
	Home	3.5	3.2	3.0	2.8	2.8	2.8	3.3	3.2	3.7
	Average	**3.8**	**3.2**	**3.3**	**3.3**	**3.3**	**3.6**	**4.1**	**3.2**	**4.0**

Appendix R: Continued

Second Administration

		Claire	Michelle	Derek	Hillary	Leslie	Linda	Cathy	Gina
Communication Performance	Social	2.7	3.0	3.0	3.8	2.3	1.3	3.0	2.0
	Work	3.8	3.0	3.0	2.5	2.7	2.3	3.5	2.5
	Home	3.5	4.2	3.5	3.0	3.0	2.3	3.8	2.5
	Average	3.6	3.7	3.9	3.4	3.0	2.7	4.1	2.7
	Adverse	2.9	3.0	2.4	2.8	2.3	1.1	2.6	1.9
	Problem Awareness	4.5	4.0	4.5	4.1	4.3	5.0	4.3	4.4
	Average	**3.5**	**3.5**	**3.4**	**3.3**	**2.9**	**2.5**	**3.6**	**2.7**
Communication Environment	Need for Communication	1.0	1.0	2.5	5.0	1.0	1.0	1.0	1.0
	Physical Characteristics	2.6	3.2	3.0	2.6	1.8	1.8	2.0	3.0
	Attitudes of Others	4.1	4.3	4.4	4.0	2.7	4.3	3.6	4.0
	Behaviours of Others	3.4	4.0	4.3	3.7	2.5	3.3	3.2	4.3
	Average	**2.8**	**3.1**	**3.6**	**3.8**	**2.0**	**2.6**	**2.5**	**3.1**
Communication Strategies	Maladaptive behaviours	2.4	1.8	2.7	3.1	2.4	2.8	2.3	1.9
	Verbal Strategies	3.0	3.3	3.8	3.6	3.1	3.0	3.6	3.8
	Nonverbal Strategies	4.6	4.3	4.8	3.9	4.9	4.5	4.9	4.9
	Average	**3.4**	**3.1**	**3.7**	**3.5**	**3.5**	**3.4**	**3.6**	**3.5**
Personal Adjustment	Self Acceptance	2.9	4.6	2.9	2.6	3.0	2.3	3.0	3.3
	Acceptance of Loss	3.4	4.7	3.3	3.4	3.1	3.2	3.7	4.3
	Anger	3.5	4.3	2.7	2.3	3.3	2.3	3.3	3.2
	Displacement of Responsibility	2.2	3.0	1.6	1.8	2.4	2.8	3.2	2.4
	Exaggeration of Responsibility	3.7	3.5	3.3	2.5	3.3	3.0	1.7	3.3
	Discouragement	3.0	4.5	3.3	2.0	2.5	1.5	3.7	2.7
	Stress	2.3	3.9	2.4	2.1	1.9	1.8	2.8	2.3
	Withdrawal	2.4	3.1	2.3	2.0	2.3	1.3	3.7	2.1
	Denial	3.8	1.9	4.0	4.0	4.1	4.4	4.0	3.9
	Average	**3.0**	**3.7**	**2.9**	**2.5**	**2.9**	**2.5**	**3.2**	**3.1**
Importance	Social	2.6	3.0	2.6	3.0	2.5	3.7	2.0	3.0
	Work	4.3	3.0	4.2	4.3	4.8	4.0	4.0	4.0
	Home	3.0	3.7	3.3	2.8	4.2	3.7	3.2	2.4
	Average	**3.3**	**3.2**	**3.4**	**3.4**	**3.8**	**3.8**	**3.1**	**3.1**

Appendix R: Continued

Researcher Estimates

		Claire	Michelle	Derek	Tony	Hillary	Leslie	Linda	Cathy	Gina
Communication Performance	Social	2.7	3.2	2.7	2.7	2.5	3.0	2.3	3.7	3.0
	Work	3.0	3.7	3.0	2.8	2.8	3.2	2.7	3.8	3.5
	Home	3.0	3.5	3.3	2.5	2.7	3.2	2.5	3.7	3.2
	Average	3.3	3.8	3.3	3.1	3.0	3.4	3.1	4.1	3.7
	Adverse	2.4	3.0	2.6	2.1	2.3	2.8	1.8	3.3	2.6
	Problem Awareness	4.1	4.1	4.1	4.3	4.3	4.3	4.0	4.0	3.8
	Average	**3.1**	**3.5**	**3.2**	**2.9**	**2.9**	**3.3**	**2.7**	**3.8**	**3.3**
Communication Environment	Need for Communication	1.0	4.0	1.5	2.5	2.0	2.0	1.0	1.0	2.0
	Physical Characteristics	3.2	3.6	3.8	2.2	3.2	3.0	3.6	3.2	3.2
	Attitudes of Others	3.8	4.3	3.6	3.6	2.7	2.8	3.2	3.8	3.9
	Behaviours of Others	4.0	4.0	4.0	4.1	3.9	3.8	3.3	4.2	4.2
	Average	**3.0**	**4.0**	**3.2**	**3.1**	**3.0**	**2.9**	**2.8**	**3.1**	**3.3**
Communication Strategies	Maladaptive behaviours	2.0	1.9	2.6	1.9	2.3	2.7	2.7	1.7	1.8
	Verbal Strategies	3.4	3.5	2.5	3.4	2.9	2.1	3.0	3.3	3.5
	Nonverbal Strategies	4.4	3.5	3.3	3.6	3.5	3.5	3.9	3.8	4.8
	Average	**3.3**	**3.0**	**2.8**	**3.0**	**2.9**	**2.8**	**3.2**	**2.9**	**3.3**
Personal Adjustment	Self Acceptance	3.4	4.4	3.0	3.9	3.0	1.6	3.0	3.6	4.3
	Acceptance of Loss	4.3	4.6	3.4	4.2	2.9	2.6	3.0	3.8	4.6
	Anger	3.7	4.0	3.2	3.0	2.7	2.7	2.2	3.3	3.7
	Displacement of Responsibility	2.6	3.4	2.6	2.0	2.0	2.6	2.0	2.2	2.4
	Exaggeration of Responsibility	3.7	2.7	2.7	4.0	3.5	2.5	3.7	3.7	4.0
	Discouragement	3.3	3.8	3.3	3.3	3.0	2.0	1.8	3.8	3.8
	Stress	3.1	3.6	3.3	3.1	3.1	1.9	2.0	3.1	3.5
	Withdrawal	3.6	3.4	2.9	3.3	3.1	1.9	1.6	3.7	3.0
	Denial	3.3	3.0	3.5	3.8	3.9	4.0	3.6	3.4	3.1
	Average	**3.4**	**3.7**	**3.1**	**3.4**	**3.0**	**2.4**	**2.5**	**3.4**	**3.6**
Importance	Social	2.5	2.5	2.2	2.2	2.2	2.3	2.0	2.5	2.0
	Work	4.2	2.8	3.8	3.5	3.5	4.0	3.3	3.8	3.8
	Home	2.7	2.8	2.8	2.5	2.3	2.5	2.3	2.8	2.7
	Average	**3.1**	**2.7**	**2.9**	**2.7**	**2.7**	**2.9**	**2.6**	**3.1**	**2.8**

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Appendix S: Readiness to Change Questionnaire- Hearing Data

First Administration

	1	2	3	4	5	6	7	8	9	10	11	12
	P	A	C	C	P	A	A	C	C	P	A	P
Robert	5	1	2	5	5	1	1	1	1	4	1	4
Ian	5	2	2	3	4	4	2	3	1	4	2	4
Janet	4	2	2	3	5	4	2	3	2	4	2	4
Matt	2	1	4	2	5	2	2	2	1	4	4	5
Roger	4	1	2	4	5	1	1	2	2	4	2	4
Colleen	4	2	2	2	5	4	4	4	1	4	4	4
Kelly	4	2	2	2	5	2	2	2	2	4	2	4
Hanna	5	2	2	4	5	2	2	4	2	3	2	3
Judy	2	1	1	2	2	1	1		2	2	1	3
Ellen	3	4	2	2	3	4	5	3	2	3	5	3
Claire	4	1	1	1	5	1	1	5	1	5	1	5
Michelle	5	1	2	2	4	1.5	2	2	1	4	2	5
Derek	4	2	1	1	5	2	2	1	1	5	3	5
Tony	2	2	4	4	4	2	3	2	2	4	4	2
Hillary	5	3	2	2	1	3	3	2	1	4	2	5
Leslie	5	2	1	2	4	2	2	2	1	4	2	4
Linda	5	1	1	3	4	2	3	1	1	5	1	5
Cathy	4	2	2	3	4	2	2	2	2	4	2	4
Gina	5	1	4	4	4	2	2	3	1	4	2	4

Second Administration

	1	2	3	4	5	6	7	8	9	10	11	12
	P	A	C	C	P	A	A	C	C	P	A	P
Claire	5	1	1	3	5	1	5	2	1	5	1	5
Michelle	4	2	4	4	2	2	2	4	2	3	2	3
Derek	4	2	3	1	5	3	2	1	2	5	3	5
Hillary	4	2	3	2	4	2	3	2	1	0	3	5
Leslie	4	1	3	2	5	1	1	1	2	5	1	5
Linda	5	2	1	4	4	2	2	3	1	3	2	4
Cathy	2	2	4	4	4	2	2	2	2	4	2	4
Gina	5	2	3	4	4	2	2	4	2	4	1	4