Hearing Impairment and Identity

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Abstract: This study examines the identity of persons with hearing impairments. Participants were solicited from a support group for persons with hearing impairments. An interview methodology was used to qualitatively explore communication and identity. Analysis of data revealed: persons with hearing impairments often minimize hearing loss until adulthood, use various compensatory communication strategies, work hard at receiving and processing information, and are often misunderstood by educators. Implications for researchers, educators and persons with hidden/invisible disabilities are discussed.

Key Words: communication, disclosure, identity.

Background

The number of persons included in the minority group "persons with disabilities" has been growing yearly in the United States (Braithwaite, 1990). Since enactment of the Americans with Disabilities Act (ADA) in 1990, a conceptual change in the notion of disability has taken place. "Disabled" is no longer defined only as persons with publicly visible manifestations of physical difference (Merrigan, 2000). The predominant medical model of disability is yielding to a social/civil rights model of disability (Pfeiffer, 2001). Yet metaphors, terms and models of disability are still created by the dominant "able" society to understand and explain disability on its own terms (Corbett, 1996; Matthews & Harrington, 2000).

Recently communication scholars focusing on the notion of disability have stressed identity management, accommodation, and disclosure/privacy boundary management (Braithwaite, 1991; Merrigan, 2000). Interability communication has recently adopted cultural and co-cultural interpersonal theories to investigate issues of disability and communication. However, literature of medical practitioners and communication scholars has focused on readily identifiable physical disabilities and on issues of inclusion and acceptance of such persons in "normal" society. A dimension of disability not acknowledged until recently is the "hidden," or "invisible" disabilities. A common hidden/invisible disability is hearing impairment. In the case of hearing impairment there is no universally accepted standard definition of this widespread disability.

Research Questions

A person with a disability is aware of its stigmatizing effect from an early age. Often the individual attempts to render it unnoticeable to others in interpersonal communication contexts. At some point the disability may become more noticeable to others, and/or cause more significant difficulties for the communicator with the disability. This study seeks to understand and articulate the identity and communication strategies of persons with hearing impairments:

RQ 1: What was the nature of the identity of persons with hearing impairments when the disability was "hidden"?

RQ 2: How has the identity of the person with hearing impairments changed in the process of acknowledging it to other communicants?

RQ 3: How has involvement with other persons with hearing impairments in a support group affected identity communication?

Method

Participants were solicited from a support group for persons with hearing impairments in the San Francisco Bay Area. Members of this group range in age from 21 to 72, evenly male/female. Their hearing loss may be congenital or adventitious, mild to severe. Six persons volunteered to be part of two focus groups lasting one to two hours. Their occupations are retired educator, psychologist, rehabilitation counselor, interior designer, attorney, and scientist. Four use hearing aids, three have cochlear implants. All refer to themselves as "hard of hearing" or "hearing impaired." The interviewer opened the discussion by relating his experience as a person with a hearing impairment, inviting others to share their experiences. A microphone was passed to whomever gestured a desire to speak. In a group of persons with hearing impairments, many rely on lip reading (speech reading) and prefer to concentrate on one person at a time. Free-flowing turn-taking ensured that all participants had maximum potential for hearing, being heard, and sharing experiences. An interview methodology was used in this study to qualitatively explore communication of identity by hearing impaired persons. Tape recordings of the focus group discussions were analyzed and categorized according to the research questions. Significant comments that elicited affirmative responses from other focus group members were selected to include in the Findings. An interpretive framework guided analysis to identify reoccurring response patterns and themes.

Findings

Living with Hearing Impairment

Often the participant's mild to moderate hearing loss was first noticed during elementary school screening tests. Taking cues from others during such tests to pretend that hearing was normal, and bluffing at other times, was common. Those diagnosed were referred to specialists, but professional help could be a hindrance or misguidance. Audiologists recommended no hearing aid, powerful aids that worsened hearing, or didn't notice long term progressive loss. Physicians, audiologists, and specialists often had separate practices and didn't communicate. Poor treatment seemed to contribute to avoiding acknowledgment and significance of the hearing impairment.

In some cases, familial pressure demanded denial of an impairment. The lack of parental acknowledgment and support for the hearing impaired child encouraged ignoring the condition. For some parents imperfection was unacceptable, or the unfamiliarity of a disability rendered them helpless. It was easier to cope by ignoring or denying an unnoticeable disability. Other parents took the role of advocates, demanding that their impaired children be "mainstreamed." These parents advocated inclusion, hard work, and "overcoming" disadvantages. Participants reported that teachers rarely acknowledged their hearing impairment. Often it was ignored. Some

related difficult experiences in early grades, feeling that teachers singled them out, ostracizing them unfairly. More often these hearing impaired students had to compensate in different ways: choosing optimal seating places, requesting notes, reading carefully, and becoming serious, attentive students. When they reached university studies, they had a repertoire of coping skills for varying situations and were able to function in educational settings without referring to their disability.

Three participants resumed studies after age thirty, receiving doctorates and professional licensing. Each reported that they advocated for themselves more than before, requesting accommodations in the form of note takers and assistive devices, and disclosing their hearing impairment to others, especially professors. They felt that they did well, despite hearing obstacles, since they worked extra hard and actively advocated for themselves. While some in the academic community were sympathetic and helpful, others shunned them or regarded the disability as insignificant. Teaching proved harder for hearing impaired participants. Paying close attention to students (in order to hear) lead them to be perceived as serious yet caring teachers. However, it proved stressful and exhausting to perform in front of an audience. As hearing deteriorated, some felt they could not control their classes, and the feeling of "missing something" in class became stronger.

Denial and Acknowledgment of Hearing Impairment

Often, traumatic childhood experiences associated with the first diagnosis and testing encouraged the participants to choose to "pass" as a person with normal hearing. They feared being found out, felt like outsiders, and experienced misunderstandings. When confronted, persons with hearing impairments chose to avoid people who might guess about a hearing "problem." Participants recognized that their personality and social image was affected by their hearing impairment. They might be perceived as quiet, thoughtful, insightful or working hard on a task. Unsure of what they heard, misinterpreting, or missing some things, they constantly needed to make decisions about whether to ignore it or ask again and somehow "spoil the moment."

There was incentive, and encouragement by others to compensate, hide, and ignore the disability. Participants developed communication strategies and coping skills at an early age. Speech therapy corrected pronunciation and speech reading provided communication cues. Personality quirks coupled with "bluffing" enabled some to get by in difficult communication situations. Initially labeled "different" because of out of the classroom speech therapy and speech reading training, they were eventually able to hide their hearing loss when aided by communication strategies or hidden hearing aids. They might have few difficulties in school, but never be sure what they missed. Unintended misunderstandings resulted in being regarded as inattentive, arrogant or stupid. "Passing" as normal was stressful, as one participant put it, "... It was hiding, hiding, hiding."

When the person with a hearing impairment disclosed, it introduced the possibility of others identifying the person as the disability. Disclosing alleviated difficulties in noisy situations and work performance. It also improved perception and potential miscommunication, but, on the other hand, had the effect of labeling the person as the "hard of hearing person who does a great job." Disclosure of ones hearing impairment entailed risks. People attempted to be empathetic, but often misunderstanding and resentment were the result. Disclosing one's hearing loss did not make as much a difference as controlling a communication situation.

Sudden worsening of hearing necessitated a change in communication strategies. Having a new cochlear implant or hearing aid and adjusting to it lead to disclosing to coworkers and friends about dealing with worsened hearing. Yet at times these people said "you seem to be normal now," thinking the affected is "cured." In fact, participants said that hearing impairment was a communication disability that was highly situational, subtle in manifestations, involving a high degree of communication uncertainty. No formula fit all persons in every situation every time. Ever changing players and contexts in communication situations often caused these participants with hearing impairments to be stressed and exhausted.

Identifying with Other Persons with Hearing Impairments

Participants expressed a range of tolerance for different labels of hearing impairment. Some preferred hearing impaired, others prefer hard of hearing, but not deaf. Labels and misconceptions were "... someone else's problem...(but) deaf is a final condition...you spend a lifetime trying to avoid that with hearing aids, with the cochlear implant you have beaten deaf." Participants desired to be recognized for who they are, people who wish to be a part of the hearing world but cannot do so completely. For some, balancing labels was difficult: "...I prefer hard of hearing. 'Disability' doesn't tell anyone what a person's needs are...people with hearing loss as being unique...for us at the heart of it is loneliness, isolation, depression or anger...over lack of communication," said one participant.

Persons with mild to moderate hearing impairments were often taught to compensate. They did not consider themselves "hard of hearing," and would not seek out those with similar conditions. Often participants felt isolated most of their lives, believing that no one else shared their experience: "... I didn't know anyone deaf or hard of hearing ...I wanted to disassociate myself from anyone having a hearing loss." Attempts to connect with other persons with hearing impairments were not always successful. Being involved with a support group for the hearing impaired offered a way to break out of the isolation and created a context of community. Said one member, "I'm no longer the lone ranger, no longer black in the middle of all white. I no longer stand out. I hear people talking about experiences that I've had, and I meet really nice people that I would have liked to meet anyway; and I have support."

Sometimes the personality difficulties a person with a hearing impairment experienced were not considered related to the disability. Because of lifelong "passing" and coping strategies, depression, anger, grieving and interpersonal communication difficulties were not connected to hearing impairment until the person became involved in a support group. The support group enabled some to affirm their multidimensional identity by meeting together to recognize one facet: hearing impairment identity. Making this connection created community for these people. "Feeling relaxed, these are people who understand...they know exactly who you are....we have this huge commonality... its community - our identity is different."

While there is similarity within the whole category of persons with hearing impairments, there is room for appreciating difference. For example, "One thing [that] comes out in the group is that people have different levels of functionality...[there] can be big differences even with the same experiences...social, family, work situations...loss manifests itself differently with others ...in a group we talk about it." The sharing of experiences carried effects beyond the group, to disclosure and self confidence in social situations. Outside the group, people felt they could move beyond the question of disclosing or not, to specific needs and finding ways of meeting them.

Conclusion

Hearing impairment is a disability that can be invisible or hidden. Persons with hidden or invisible disabilities are acutely aware of the social stigma of their disability. Not disclosing entails misunderstandings, isolation, and mental and physical stress. Communication difficulties may be situational, contextual or personal. This may foster a perception by hearing others of normal one moment and deficient another, as if by whim. Participants in this study desired inclusion in society, and have compensated in a variety of ways in order to be included. All participants experienced a liberation of identity by discovering and becoming involved in a support group for persons with hearing impairments. The shift in identity and forming of a community enabled participants to experience personal and social growth.

This study, while rich in depth, was limited in scope due to the small, specific sample. Participants were well educated, articulate professionals representing a narrow generational part of the population. Although some inferences to other hidden/invisible disability groups may be made, this study only begins to examine the identity and communication issues of persons with hearing impairments. A larger study with a broader representative sampling of persons with hearing impairments should be a conducted. Although a survey instrument was used in this study, the small number of respondents provided little conclusive data for triangulation. Future research should qualitatively explore the dimensions of living with hidden/invisible disabilities from the perspective of persons with other hidden disabilities. Deep insight into their unique perspectives can be gained by bringing participants together in a focus group interview approach. Hidden/invisible disabilities have a subtle yet profound effect in an educational setting on the person, the educator and fellow students. With the expanding population of older persons living longer, there is a need to understand issues of those with hearing impairments. By understanding their perspectives, educators and helping professionals will be better equipped in imparting knowledge and treatments that are respectful and well received.

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