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An identification of the Social and Emotional Needs of People Living with Post-Lingual Hearing Loss

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Cover Page Footnote

Declaration of Interests: The authors have previously been, or are currently, employed at the Queensland Health Metro South Mental Health and Addiction Services, Statewide Deafness and Mental Health Service which provides consultation services, resources and workshops to the community and professionals. The Princess Alexandra Hospital Private Practice Trust Fund provided funding for real time captioning services for the project. Acknowledgements We would like to acknowledge and thank the various individuals and organizations that were involved in and contributed to the development of this project. Thank you to the participants who were involved in the project and for sharing your experiences with us. Thanks to the Princess Alexandra Hospital Private Practice Trust Fund for funding the Real Time Captioning and to Peter and Jill Lindley who assisted in organizing focus groups.

INTRODUCTION

An Access Economics Report (2006) found that one in six Australians experience a loss of hearing. Hearing loss is associated with challenges in achieving effective communication between two or more people. Although hearing aids and the cochlear implants can address some of the communication challenges for some, as evidenced in the 2015 American Airlines captioning Twitter campaign, the ways in which society and infrastructure operate can exclude and stigmatise people living with hearing loss (Media Access Australia, 2015). Subsequently, Deaf and hard of hearing Australians' ability to participate socially and economically (e.g., employment) is limited, affecting their social and emotional well-being (Hogan et al., 2001; Hogan et al., 2013; Noble, 2009). Ineffective communication in social interactions has been found to be associated with feeling isolated, restricted and demeaned (Gopinath et al., 2012; Strawbridge et al., 2000) impacting a persons' mental health and wellbeing (e.g., Briffa, 2001; Gopinath et al., 2012; Tambs, 2004). The social and emotional impact of hearing loss is further compounded by professionals and services lacking the necessary awareness, skills, knowledge and training in how to provide accessible and effective services for people living with hearing loss (e.g., Denman, 2006-2007; Iezzoni et al., 2004).

The provision of federally funded diagnosis and hearing technology programs in Australia (Department of Health, 2013; Better Start, n.d.) can misrepresent the needs of people living with hearing loss in that their needs extend beyond diagnosis, intervention and assistive hearing technology. There continues to be a demand for research into the social and emotional experiences of people living with hearing loss in order to identify gaps and inform best practice in the provision of support and mental health services to this population. The purpose of this study was to determine the unmet social and emotional needs identified by people living with hearing loss and elicit recommendations. People who were born with

severe to profound hearing loss and raised orally, as well as those who lost their hearing either suddenly or gradually after speech acquisition (postlingually) were the focus of this study.

METHOD

Participants

Following ethical clearance from the Queensland Health Metro South Health Service District Ethics Committee, participants were recruited through hearing loss and cochlear implant peer support groups in South East Queensland and by advertising in newsletters for hearing loss advocacy organisations. Pragmatic and financial factors informed the decision to organize the focus groups in areas geographically close to Brisbane. Forty-one participants volunteered to participate in the study, 36 of which participated in one of three focus groups. Two participants in the groups were spouses or partners without hearing loss, and the quantitative data were not collected from these two. Three people responded via a face-to-face interview and two responded via email. All responses were included in the analysis.

Ranging in age from 46 to 100, the average age of the participants was 70.9 years. The age at which the participants lost their hearing ranged from birth to 65 years, the average age being 29 years old; 16 participants reported having lost their hearing before the age of 25 years. There was considerable diversity in the etiology of the participants' hearing loss, including trauma, childhood illness, age-related and disorder of the ear. Each participant was asked to score their 'general sense of well-being' from 0 to 10, with 10 being the best a person could feel. The average score was 7.6.

Process

Data collection was coordinated by the first author, a qualified mental health nurse. Captioning services were employed where required. The participants were given the option of participating in one of three focus groups, being interviewed, or completing a

questionnaire via email. The second author co-facilitated the first focus group; real-time captioning was used for each focus group.

Confidentiality and process of consent were discussed at the beginning of the focus groups. Submitting a completed questionnaire via email was considered consent. A one-item measure of well-being was included to evaluate the participant's risk of suicide or depression prior to responding to the questions. A list of questions was used to guide the focus group discussions, and the same questions were included in the survey and interviews. These questions focused on significant issues, and the impact of hearing loss at various stages of life (e.g., with parents and siblings, education, workplace, social relationships, mental health, mental health system and other). They were also asked, "What helped?", and if nothing helped, "What would have helped?" Saturation was reached after the third focus group, with no new information arising. The first author provided debriefing at the end of the focus groups and interviews. The participants had positive responses to the initial findings as provided in presentations at various locations to interested parties.

Analysis

An inductive and semantic approach to thematic analysis, established by Braun and Clarke (2006), was used to analyze the focus group transcripts, along with the interview and survey responses. We did not start with pre-determined concepts; rather, they were identified within the data. Following the process as outlined by Isaacs (2014), separately, both the first and third author read through the data and developed descriptive codes from the transcripts, adding and refining codes with each reading. After discussing the descriptive codes and agreeing on discrepancies, the third author entered the descriptive codes and corresponding data into a matrix in Microsoft Word to develop a coding framework. The third author read through the framework, interpreting instances of talk. In this process, the third author identified an overarching theme, *adjusting to impaired communication*, and three sub-themes,

discussed below. To establish rigor, the first and third author discussed the identified themes, and there was no disagreement. Relevant excerpts highlighting the different themes were chosen by the third author. Ellipses denote text removed from participant comments, for the purpose of conciseness, and square brackets indicate text added for clarification.

The rigor of this analysis is further reinforced through the first and third author's experience and qualifications. The first author is a hearing mental health nurse and paraprofessional Australian Sign language/English interpreter with considerable experience in deafness and mental health. She is acutely aware of many of the issues commonly experienced by people living with hearing loss or deafness, and was able to build rapport with the participants. The third author is also hearing, and has Australian Sign Language skills and several years of research experience in the area of deafness and hearing loss.

RESULTS

Through exploring the participants' discussion of the significant issues they experienced, an over-arching theme was identified and labelled as *adjusting to impaired communication*. Adjusting to impaired communication refers to the ways in which hearing people, hearing institutions, and the participants adjusted to impaired communication, and how the adjustments informed (e.g., created, or met) the participants' social and emotional needs. Within this theme, three sub-themes were identified and we labelled *responses of hearing people, hearing institutions, and strategies to manage impaired communication*.

Adjusting to Impaired Communication

Hearing loss results in the need for people to adjust the way they communicate. The individual themselves, and the hearing people with whom they interact, can develop (mal)adaptive strategies in efforts to habituate to communication needs. In this over-arching theme, the ways in which the participants have adjusted to living with hearing loss and

impaired communication, and focusing on their relationships and careers (other domains were discussed), are discussed.

Several participants recounted how their efforts to adjust to their own or their partner's hearing loss had altered relationship dynamics. One woman described how taking on the role of communicating on behalf of her husband resulted in anger and frustration.

One of the issues that [husband] and I had in the past was over the telephone when I had to be his go-between. One of the best things that happened to us was getting a TTY... just with that piece of equipment made a big difference to the way we could function. I didn't have to take responsibility and he didn't get angry because I said the wrong thing.

In their effort to adjust to the husband's hearing loss, this participant and her husband each took on roles in their relationship that they otherwise might not have. The participant inferred that taking on these roles had created unnecessary emotional pain and placed additional strain on their relationship, which was alleviated through technology providing greater access to telecommunication. Some participants also described how their social activities and relationships were affected by impaired communication. Another woman recalled how she and her friends were unable to successfully adjust to hearing loss and the altered communication needs, negatively impacting her social lifestyle.

I find that I've lost practically all my friends ... I also had to give up on my choir, which I absolutely adored. Also the friendships, the social things we did at the weekends, "Oh, [name] we're going to see this movie. You've got to come and we'll probably have coffee at such and such." I have missed all that. There is just an emptiness there and although I try to make new friends, it is very hard when I have to be in a certain situation, preferably outside in a coffee shop or such, and to make this

— to build up a relationship. So to me, I've just found the aloneness and being apart from life when I'm a fairly sociable person has been very big.

Describing herself as a “fairly sociable person,” changes in her communication needs have had a negative impact on her social lifestyle, likely having affected her sense of belonging and mental well-being (Meyer & Kashubeck-West, 2011). However, this participant indicated that her communication needs, and ability to build a social network, could be facilitated through selecting the venue or environment.

A strategy several participants commented they used was selecting the environment when making career decisions. Some participants selected employment based on the work environment, with one participant describing a preference to work for small businesses in positions that offered independence. A few participants described how adjusting to their communication abilities had constrained the type of roles and tasks they performed in the workplace. One participant described how her hearing loss affected her in the workplace.

... I had a higher level of anxiety than other people seem to in terms I felt I had to, especially at work, do better than everybody else because people know I've got a hearing problem and all that sort of thing. And I've felt I have had to show them I can actually do better.

She felt added pressure, and experienced high levels of anxiety, to outperform her hearing colleagues. Feeling that pressure to perform to higher standard likely compounded the stress she experienced communicating in the workplace, potentially affecting her mental and physical health in the long term. Several described heightened experiences of long-term stress:

I find the hearing loss very stressful to the point where when other things crop up in life to try and cope with other stresses and you find it extremely difficult when you tend to give up or give in because you've already got a day-to-day 24/7 stress.

Participants also described how ordinarily (without having impaired communication) they would have been able to cope and that living with hearing loss had constrained their ability, through expending their emotional and psychological resources, to cope with additional stresses. The participant's tendency to give up or give in suggests that there is a perceived lack of appropriate professional or community support and resources available to strengthen their ability to adjust to the stresses of everyday life, life events and living with a hearing loss.

This perception is reinforced through another participant's experience: "When I got diagnosed as needing hearing aids, there was nothing. They just gave them to me and sent me off crying." This participant demonstrated that receiving a diagnosis of hearing loss could be a traumatic process for the individual and that the health professional's response to her changing medical and communication needs was an important element of her experience. Her experience also highlights an opportunity for the health system to better meet the social and emotional needs of people being diagnosed and then living with the hearing loss by providing psychological resources and social support. Based on numerous participants' comments, the family and work environment could be further improved through the provision of the same resources and support for hearing family and colleagues.

The experience of living with hearing loss requires the individual, and the people they interact with, to adjust their relationships and careers to incorporate their altered communication needs. The participants described the ways in which this process of adjustment affected their social and emotional well-being, and the lack of professional and community support they perceived as available. The process of adjusting to living with hearing loss and subsequent communication needs is shaped by the ways in which hearing people and institutions in the community adjust to the communication needs of people living with hearing loss, and in turn, the strategies people living with hearing loss employ to

facilitate their adjustment. The various responses of hearing people and institutions and the strategies employed by the participants are labelled here as subthemes of *adjusting to impaired communication*.

Responses of Hearing People

This sub-theme includes the various ways the participants reported hearing people had responded to their hearing loss and communication needs. The participants described the responses by hearing family members, educators, peers, colleagues, members of the community and professionals as largely negative.

Participants who had experienced hearing loss since childhood recounted how their parents and siblings responded to their impaired communication needs. Several described how they perceived their parents as “at a loss” for how to adjust to their hearing loss and communication needs. One participant recalled how her mother refused to acknowledge their hearing loss:

My mother denied that there was anything wrong and so all the family had to conform with her very strong wishes from birth ... and it took me quite a while to adjust to that and get used to it and I got my first hearing aid when I was in my 40s.

Despite the family not recognizing the participant’s communication needs, the participant described her family’s denial as positive in some aspects in that she “hit the world without thinking there was a problem... I just proceeded.” Contrastingly, a few participants recalled how their family was supportive and attributed their success to their families’ support; one said, “I don’t think they [siblings] treated me much differently as they would to any other sister...my parents were supportive.”

The participants recalled the responses of educators and hearing peers during formal education as significant experiences. They described educators as mostly unresponsive to their communication needs. However, teachers who did adapt their teaching methods were

recalled as particularly important to the participants' process of adjusting to their hearing loss. Several participants recalled how they were bullied at school as a result of their hearing loss. One recollected the insults saying, "They called me deaf idiot, deaf Dumbo. You can't hear anything, you stupid deaf idiot." Another participant's experience at school emphasized the importance of how teachers and peers responded to people living with hearing loss.

Despite the caring of my family, they didn't really understand the implications of post-lingual hearing loss, nor did the teachers or the children I associated with. So I was in a position where I was very isolated, and even at that very early age, it was very traumatic for me.

Antia et al. (2011) suggested that experiences during formal education also hold broader implications for the individual, particularly in relation to language development, relationship skills, and employment prospects, which in turn inform social and emotional well-being. We suggest that this impact is likely further compounded for people living with hearing loss due to the lack of professional support available with expertise in or lived experience of hearing loss (e.g., Munro et al., 2008).

Participants also recalled lack of awareness and understanding of hearing loss as a common experience in the workplace. In some cases, the participants withdrew from actively participating in their workplace; one said, "I withdrew. I felt going to meetings I was wasting my time, so I would use my time usually writing up files or something like that, but withdrawal I felt was the only option open to me." Social isolation, as a result of withdrawing from professional and social contexts, has broader implications for social and emotional well-being (See Thoits, 2011, for discussion). Furthermore, withdrawing may result in diminished opportunities to attend social functions and connect with superiors who may facilitate opportunities for career advancement (Backenroth, 1995; Harris & Bamford, 2001).

Education for hearing colleagues and communication support within the workplace would

facilitate equal opportunity for social inclusion and career advancement for people with hearing loss.

It was evident in the participants' responses that the ways in which hearing people adjusted to communicating with the participants had shaped their social and emotional well-being. The participants recalled experiences of how their family, educators, peers and colleagues were (un)able to adjust the way they communicated and how this affected their well-being. These experiences are further contextualized by the institutions people operate within, and the norms and policies of these institutions that inform how people can participate and what is socially acceptable behavior.

Hearing Institutions

The sub-theme of hearing institutions comprises of the various ways institutions within society, such as universities, schools, workplaces, and the broader community, have accommodated the communication needs of people living with hearing loss. It should be noted that there have been considerable improvements to the practices and policies of many of those institutions. However, the consequences of these lived experiences remain poignant for these participants, illustrative of the long-term implications of policies and practices for the social and emotional well-being of people living with hearing loss.

In the context of education, several participants commented on the lack of support made available to them and the challenges they faced accessing course content, particularly in the tertiary education system. One shared:

By Grade 9, when the impact of my hearing loss was fully realized and I needed a hearing aid to cope, the impact was severe. There were no support services of any kind in my school ... It was socially isolating to say the least. ... I did well enough at school to just scrape into [university] [degree] in [year]. There was no support there either for deaf students ... I was the only student there with a hearing aid. ... I was

offered a [name] scholarship and attempted an honours year in [year]. I never completed it after falling apart mentally, panic anxiety disorder, depression. ... I went to work [for a government department] and stayed there for my entire working life. Went back to [university] in [year] and acquired a graduate diploma in [degree]. While I received no direct support because of my deafness, the education process there at that time was much more deafness-friendly with published lecture notes being available.

The participant's experiences highlighted how the education system was not set up, nor did it function, to meet the needs of people living with a hearing loss (Hyde et al., 2009). Several participants described how they adapted their learning practices, where possible, to function within mainstream schools. Participants who had returned to university, either as students or as lecturers, commented that improvements in the resources available such as electronic lecture notes to university students had particular benefit to people with hearing loss. The participants' experiences demonstrate the importance of educational institutions adapting their practices and resources to the needs of students living with hearing loss.

Extending on their education experiences, many participants experienced a similar lack of support and access in their workplaces. Several participants recalled how their workplace or employer was not willing to adapt their work environment (e.g., technology, room set up) or practices (e.g., technology, note taking, training) to incorporate their communication needs. One said:

An occupational work therapist came to my workplace and assessed what my needs were and then as a result of that the government paid fully for that occupational therapist and the Job Access equipment ... I found that my own organization to be the least receptive to the technology.

Believing oneself to be a productive member of society is an important element of an individual's social and emotional well-being (McKee-Ryan et al., 2005). Subsequently, a lack of accommodation in the workplace may lead people to feel devalued and influence their willingness to be a productive member of a working team (Grimby & Ringdahl, 2000; Punch, et al., 2007).

The social and emotional well-being of people living with hearing loss and deafness can be shaped through their experiences with hearing institutions. The participants frequently reported that educational institutions and workplaces did not sufficiently adapt to their communication needs. They also frequently described their experiences as “how it is” and “that’s life.” Due to their communication needs being unmet, many of the participants described the various strategies they employed to manage the situation and their needs.

Strategies to Manage Impaired Communication

Many of the participants described the strategies they employed, and continue to employ, to adapt to their own communication needs. They also described strategies that were, or should be, utilized by hearing people and institutes. In this sub-theme of strategies to manage impaired communication, the potential implications to social and emotional well-being that may result from the long-term use of these strategies are explored.

Technology (e.g., hearing aids, hearing loops, captioning, FM systems, visual and tactile alarm systems, and office equipment) was frequently identified by the participants as useful for staying connected with family and friends, and functioning in the workplace and in school. However, the participants also discussed the limitations, including group situations, noisy environments, unavailability, and equipment cost. Hearing aids were the most frequently discussed strategy. Although participants described hearing aids as useful for facilitating communication, they described how their access to communication was limited in some contexts:

I find the hearing aids are good if we're just talking one person at a time. But in our walking group we're sitting at a table about this size and there is chairs around here and chairs around there and there might be four or five conversations going and it's just bedlam to me.

In situations where there were multiple sources of information, such as group conversations, meeting rooms and concerts, the participants who made use of hearing aids described feeling stressed and overwhelmed, sometimes giving up participating due to exhaustion.

Other strategies included educating conversation partners on communication strategies, relying on hearing partners, dominating conversations, or faking comprehension. Educating conversation partners ensures that specific communication needs are met; however, the participants reported that this was exhausting and stressful and often they had to repeat the information multiple times to the same people. This strategy is also limited in that it requires educating each new person they meet. Several participants identified the importance of increasing general awareness and comprehension of hearing loss in terms how the (hearing) person needs to adapt communication. Participants with hearing partners recalled how their partners would often instinctively step in and fill them in on the discussion or answer for them and how this sometimes negatively affected their relationships. Some participants described how they talked over people in order to be able to know what was being discussed. Several participants commented that they resorted to appearing to follow the conversation by nodding and smiling, when in reality they had not understood much of what was being discussed. One participant explained:

I go out and if I go out to friends for dinner or afternoon tea or anything, half the time I don't understand what they say and I can hear the voices but I have just taught myself not to let it worry me. I am out with them, I am seeing them.

These strategies of managing impaired communication facilitate some access to communication. However, the use of these strategies may have unintended negative consequences; one participant said that sometimes “people think that you're standoffish, that you don't want to interact.” In this way, faking comprehension may affect the quality of their relationships and constrain their ability to contribute meaningfully to group conversation. One participant's perception illustrates the social and emotional consequences of hearing loss and maladaptive communication strategies: “I feel as I'm not worthwhile. There is really nothing to give or nothing to participate in. So why would people want to see me and be friends with me?”

Several participants developed resilience that had facilitated their ability to manage the limited success of alternative strategies, the perceived lack of resources available, and hearing people not adapting their communication behaviors. Participants described how they “simply had to cope” and “that's the way it was.” While the participants had found resilience a useful quality, as Young and her colleagues (2008) discussed, the social and structural barriers that contribute to the adversity the participants experienced remained unchallenged.

The most effective strategy the participants discussed was being able to meet people through peer support groups comprised of others also experiencing hearing loss. The effectiveness of this strategy was largely due to having shared experiences, reduced feelings of isolation, and not having to educate each other on hearing loss and communication. Several participants commented on the value of having a supportive family and how this contributed to their social and emotional wellbeing; one said he had “supportive parents – told me I could do anything I wanted.” The participants who experienced a loss of social

connections, isolation and high levels of stress, anxiety, and depression reported that distraction was a strategy they used to cope; engaging in activities such as gardening, cleaning, walking and reading books helped. In an educational and workplace context, the participants commented that captioning and having access to an agenda and written materials ahead of time facilitated their ability to participate.

The participants implemented a broad range of strategies in response to hearing people and institutions (failing to) adapting to their communication abilities. Although the participants found varying levels of success with their strategies, the strategies have predominantly required continual effort on behalf of the individual with hearing loss or significant people in their life (e.g., partners and children). As the participants noted, in society, there is minimal discussion of and education about the strategies the general community, hearing people, and hearing institutions can implement to better incorporate the needs of people living with hearing loss. Ideas proposed by the participants included public lectures and seminars about hearing loss, implementation of mandatory teaching of Auslan in schools, and greater visibility of hearing loss and associated issues in public media (e.g., television, magazines).

DISCUSSION

Through exploring the participants' experiences of living with hearing loss and the significant issues they negotiated, an overarching theme was identified and labelled *adapting to impaired communication*. Within this theme, three sub-themes were identified in which the social and emotional needs of people who are hard of hearing; responses of hearing people were recognized, along with hearing institutions and strategies to manage impaired communication. It was apparent, in the participants' responses, that despite their resilience, their social and emotional well-beings were negatively affected through (mal)adaptive responses to the communication needs that result from hearing loss.

The participants recalled how hearing people, including family, partners, educators and colleagues, and hearing institutions such as workplaces and universities, had a significant impact on their experiences of living with hearing loss. While positive responses facilitated well-being, maladaptive communication had a detrimental impact on the participants' social and emotional well-beings. The participants described the various strategies they implemented to manage the impaired communication they experienced. Based on their comments, it became apparent that living with a hearing loss and the resources needed to interact with hearing people in hearing institutions could subsequently constrain their ability to cope with everyday stressors and life events. The perceived lack of professional services and support further compounds the negative impact of hearing loss on an individual's well-being (Munro, et al., 2008).

The findings of this study demonstrated the unmet need, and importance, of providing services and support that extend beyond diagnosis, intervention and assistive hearing technology. The participant's experiences suggested that there is need to expand the mental health and well-being services to support the habilitation process of newly-diagnosed individuals, and to include professionals with expertise in, or lived experience, of hearing loss. The findings also suggested that hearing people's understanding of, and ability to adapt to, the communication needs of people with hearing loss contributed to the participants' well-being. Many of the strategies largely placed the responsibility of adapting to communication needs onto the person living with hearing loss, with limited reciprocation from hearing people and institutions. These findings provide empirical support for increasing awareness within the broader community of the communication needs and lived experiences of deafness and hearing loss and to increase communication education.

LIMITATIONS

The findings of this study are constrained by the diversity of the recruited sample. Due to funding and time restrictions, we were limited to organizing focus groups in our immediate area, and as such, our sample has limited geographic diversity. Within Australia, access to health services differs between rural, regional, and urban areas; people living in rural areas may have different experiences and additional social and emotional needs. However, improvements in service provision to meet the social and emotional needs of hard of hearing people in urban and regional areas can be expanded to serve the needs of rural areas. The findings of this analysis are further limited by a lack of consideration for the social and emotional needs of people who live with multiple sensory, cognitive or developmental disabilities (e.g., deaf-blind). Future research can build on the findings of this study by expanding recruitment strategies to incorporate organizations that service consumers living with multiple disabilities.

RECOMMENDATIONS

Based on the study findings, and the suggestions provided by the participants, three main recommendations were developed. The first is an increase in the media presence of people, and issues, related to the lived experience of hearing loss and sensory disabilities. Increasing the presence of hearing loss in the media provides a visual demonstration and model of the communication behaviors hearing people can adopt to improve their abilities to communicate with people who are hard of hearing.

The second recommendation focuses on improving the skills and knowledge among health professionals. While professional development courses on hearing loss are available, they are not considered a requirement. Standardizing the inclusion of hearing loss into all health professional training courses (at a tertiary education level) is recommended. Lastly, expanding the federally funded National Auslan Booking and Payment Service to include

funding for real time captioning services for private health appointments is the final recommendation.

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