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Title: Coping with the social challenges and emotional distress associated with hearing loss: A qualitative investigation using Leventhal's self-regulation theory

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ABSTRACT

Objective: To explore the lived experience of social challenges and emotional distress in relation to hearing loss and the coping mechanisms employed to manage them.

Design: Two focus groups and two one-on-one semi-structured interviews were conducted during February 2020. Transcripts were first inductively analysed to identify experiential categories of social and emotional difficulty, and then deductively analysed using Leventhal's self-regulation model to identify how individuals conceptualised these experiences and the coping mechanisms employed to manage them.

Study Sample: Adults with hearing loss and self-reported emotional distress due to their hearing loss (n=21) and their significant others (n=9).

Results: Participants described their social and emotional experiences of hearing loss in terms of negative consequences (social overwhelm, fatigue, loss, exclusion), identity impact (how they perceive themselves and are perceived by others), and emotional distress (frustration, grief, anxiety, loneliness, and burdensomeness). While many participants described a general lack of effective coping strategies, others described employing coping strategies including avoidance (helpful and unhelpful), controlling the listening environment, humour, acceptance, assertiveness, communication repair strategies, and accepting support from significant others.

Conclusion: Many participants described a lack of effective coping strategies and tended to rely on avoidance of social interaction, deepening their isolation and loneliness.

BACKGROUND

Hearing loss not only compromises a person's ability to hear, but also a person's ability to communicate, thus impacting on social participation, personal relationships and emotional wellbeing. Previous research has highlighted the bi-directional relationship between hearing loss and its emotional impacts (Helvik et al., 2008; Laird et al., 2020). Interviews with adults experiencing co-morbid hearing loss and psychological conditions described how the hearing loss exacerbated feelings of anxiety or depression through limitations on inclusion and interactions at social activities (Laird et al., 2020).These participants also described how the psychological distress negatively affected help-seeking for hearing loss, use of hearing devices, and outcomes of audiological rehabilitation. The impact of unmet emotional distress on the utilisation of hearing services have also been explored. One study suggests that use of strategies that interfere with or inhibit effective communication (such as social avoidance) are associated with an increased risk of hearing aid rejection (Helvik et al., 2008).

Previous research has documented the social consequences and emotional distress that accompanies hearing loss, and these include frustration, anxiety, social isolation and loneliness, among other manifestations of distress (Jayakody et al., 2018; Lawrence et al., 2020; Pronk, Deeg & Kramer, 2013; Vas, Akeroyd & Hall, 2017; Weinstein, Sirow & Moser, 2016). However, little is known regarding the coping strategies employed by people with hearing loss to move through these periods of distress. One way better to understand the experiential implications of living with hearing loss and its associated distress is to explore the patient's subjective experiences through qualitative research.

Recently, hearing research has turned to the discipline of health psychology to identify models that describe experiences and behaviours in relation to other chronic health conditions that may be successfully applied in the case of hearing conditions (Barker, Atkins & de Lusignan, 2016; Coulson et al., 2016; Heffernan et al., 2016; Laplante-Levesque, Hickson & Worrall, 2013; Manchaiah, 2012; Saunders et al., 2013). Heffernan et al. (2016) demonstrated the applicability of the self-regulation model (Leventhal et al. 2012; 2016) to describe the impacts of hearing loss in adults. The self-regulation model, or common-sense model of Leventhal, is a widely used theoretical framework describing beliefs about illness experience and self-management of a health condition. This model is particularly useful within the context of understanding chronic disease self-management (Clark, Gong & Kaciroti, 2001; Hagger et al., 2017). The self-regulation model proposes that people are active problem-solvers in managing their health; they self-monitor health-related experiences and symptoms and continuously (re)evaluate available alternatives for responding to perceived changes in health status (Hagger & Orbell, 2003). The model postulates that deviations from “normal health”, including progression of chronic health conditions, will prompt individuals to: (i) develop cognitive and emotional representations of their condition; (ii) select and implement coping strategies in an attempt to manage the new symptom; and (iii) ascertain the consequences of the coping strategies to inform whether they should be maintained or replaced (Figure 1). The model further provides a framework for understanding coping strategies employed by an individual.

Cognitive representations describe lay beliefs about the health condition, informed through personal experiences, pre-condition knowledge, and external inputs (such as those from medical interactions, significant others, and the media). Within the self-regulation model, cognitive representations of the health condition develop from five lenses: *identity* (severity of somatic sensations/symptoms and their possible meaning or label, and the ‘labels’ that coincide with having the condition); *cause* (factors that led to the development of the condition); *consequences* (functional, social, and financial); *time-line* (rate of illness onset, perception of illness duration and rates of decline), and; *control* (attempts with cures or lack thereof) (Leventhal et al., 2012). Emotional representations describe subjective reactions to the health condition, such as embarrassment, frustration or anxiety. Coping responses are actions taken to solve problems and/or to regulate emotions relating to the health condition. The five lenses of coping strategies include solution-focus, emotion venting, avoidance, seeking support, and cognitive reprisal. These coping responses may impact on the health condition and/or the experience of the health condition in a negative or positive way. For example, where hearing loss and distress may mean one individual avoids a large social gathering to preserve energy for a more intimate and important gathering, while another may begin to avoid all social experiences to reduce their feelings of embarrassment. If operating in an ideal, optimal, functional manner, individuals would then monitor and evaluate their coping strategies to determine their success; these experiences feed back into the cognitive and emotional representations of their condition. This cycle is depicted in Figure 1 (adapted from Hagger et al., 2017).

The self-regulation model has been used to demonstrate how the presence of positive cognitive representations and solution-focussed coping strategies can predict positive health outcomes (Hagger et al., 2017). The self-regulation model is thus a well-suited framework for exploring the self-management of chronic hearing loss. Research shows that successful self-management of chronic hearing loss can be predicted by greater perceived difficulties with hearing and communication in everyday life, positive attitudes to hearing aids, and greater perceived self-efficacy for hearing aid use (Hickson et al., 2014). Furthermore, within the self-regulation model, distress-related emotional representations negatively impact illness-related and functional outcomes because people in high distress are less likely to employ coping strategies to manage symptoms or treatment regimens (Hagger et al., 2017). This process may explain why some adults with hearing loss appear to cope better with the social and emotional consequences of hearing loss than others.

Qualitative research on patients' experience of hearing loss have previously focused on how patients understand and engage with the diagnosis of hearing loss and audiological treatment (Heffernan et al., 2016; Grenness et al., 2014; Laplante-Lévesque et al., 2012; Linssen et al., 2013; Southall, Gagné & Jennings, 2010). Heffernan et al., (2016) described the experience of hearing loss using interviews with adults with hearing loss and hearing-healthcare professionals. They reported that the experience of hearing loss was described as having primarily negative connotations and consequences. Participants described tactics for coping with hearing loss to include both engaged coping (e.g. hearing aids, communication tactics) and disengaged coping (e.g. withdrawal from situations, withdrawal within situations). In this way, participants primarily described successful coping tactics in relation to hearing loss management and disengaged coping tactics as behaviours associated with the psychosocial impacts of the hearing loss. Shining the spotlight on this subset of adults with hearing loss can help us better understand their unique social and emotional challenges, how they cope with these and hence how we might be able to better support this group in the audiological clinical setting. Accordingly, this study sought to explore how adults with self-reported social challenges and emotional distress on account of their hearing loss, and their significant others, conceptualise their experiences and coping mechanisms for managing the social and emotional impact of hearing loss. Examining how people frame the nature of their secondary social challenges and emotional distress on account of the hearing loss, as well as the successful and unsuccessful social and emotional coping strategies they employ, may help inform appropriate care approaches to assist with reducing the disease burden of hearing loss.

METHOD

A pragmatic paradigm shaped the qualitative research presented in this report. Scholars have recently drawn on the epistemology of pragmatism proposing its value in the creation of knowledge for social sciences (Kaushik & Walsh, 2019; Creswell & Plano Clark, 2011; Feilzer 2010). Pragmatism is a deconstructive paradigm that “sidesteps the contentious issues of truth and reality” (Feilzer 2010, p. 8) and proposes that there are multiple realities that are open to empirical inquiry (Creswell & Plano Clark, 2011). Pragmatism focuses on 'what works' as the truth for answering the research questions under investigation (Tashakkori & Teddlie 2009) and orients itself toward solving practical problems in the ‘real world’ (Creswell & Plano Clark, 2011). The lived experience of coping with the social challenges and emotional distress of hearing loss are diverse and are described by individuals within multiple layers of objective truth and relative truth within multiple realities (Vas et al., 2017). Our research question sought to understand the coping strategies employed by individuals living with the social challenges and emotional distress of hearing loss, and to ascertain whether these strategies are helpful or unhelpful towards coping for the individual employing them. A pragmatism lens was chosen to frame this research as it has the potential to engage and empower marginalized communities, raising awareness of their experiences (Kaushik & Walsh, 2019). Pragmatism also allows for flexibility in data analysis and encourages the analysis of interview data quantitatively as well as qualitatively (Feilzer, 2010), as is often used when applying the self-regulation model to understanding coping strategies for chronic illness (Hagger et al., 2017).

In-depth semi-structured interviews and focus groups with adults were used to explore the coping strategies employed by adults with hearing loss, and their significant others, as they relate to social challenges and emotional distress on account of hearing loss. We used a mixed-methods approach, using both qualitative and quantitative analysis of the transcripts, framed by the self-regulation model as it is an established framework that describes beliefs and behaviours relating to the self-management of a health condition, such as hearing loss

(Heffernan et al., 2016). The self-regulation model has been previously used to better understand the lived experience of hearing loss (Heffernan et al, 2016). Although interview prompts used by Heffernan et al (2016) were broad, including questions such as “Can you describe the main ‘symptoms’ of your hearing loss?” and “Can you tell me about the things you do to cope with your hearing loss?” participants appeared to naturally focus their responses on the psychosocial impacts of hearing loss. To further extend our knowledge of how people cope with these psychosocial impacts of hearing loss, this study applies the self-regulation model to understanding self-management of specifically the social challenges and emotional distress associated with hearing loss.

Participants

Previous research reporting on the psychosocial impacts of hearing loss have explored this phenomenon through interviews with adults who had recently obtained hearing aids (Wänström et al., 2014), combining the experiences of adults with hearing loss and health professionals (Heffernan et al. 2016), and through the shared experiences of adults with severe hearing loss and their significant others (Hallam et al. 2008). In this study we recruited adults with hearing loss who self-reported firsthand experience with social challenges and/or emotional distress relating to their hearing loss in order to gain a deeper understanding of the experiences, thoughts, feelings and behaviours of these individuals. We also recruited the significant others of these individuals as both the role of significant others in supporting adults with hearing loss as well as the psychosocial impact of the hearing loss on the significant other is well documented (Scarinci et al., 2008; Vas et al, 2017).

Potential participants were recruited through a chain of hearing clinics in Perth, Western Australia. All clients on the clinic database who were aged 18 years or older, who opted to be contacted for research purposes, and who had attended the clinic in the past three years (when the recruitment for research option was changed from an opt out to an opt in process) were identified as potential participants. A random sample of 200 participants were selected using a random number generator in Microsoft Excel. No inclusion or exclusion criteria were placed on demographic factors, hearing sensitivity, or use of hearing amplification devices to ensure that the participants included a diverse sample of individuals. The invitation to participate specified recruitment of individuals with hearing loss and current or previous social challenges and/or emotional distress relating to their hearing loss. In the email, participants were told *"We are looking to hear from people who have ever felt one or more of the below: left out of the conversation, embarrassed after mishearing part of the conversation, nervous about attending a social event, anxious talking with people, lonely, down, or blue because of their hearing loss."* However, no formal assessment of distress was performed as we sought to include individuals who self-perceived firsthand experience with social and emotional difficulties on account of the hearing loss.

Participating adults with hearing loss (n=21) ranged in age from 60 to 88 years (M 73; SD 8); there were 13 females and 8 males. Years of hearing loss duration ranged from one to 64 years (M 16.9; SD 15.5). Two participants wore bimodal cochlear implants, 17 wore hearing aids and the remaining two were unaided. Participating significant others (n=9) consisted of seven partners, one friend and one daughter, who ranged in age from 19 to 80 years (M 67;

SD 66), of whom eight were female and one was male. Two significant others self-reported having hearing loss (two years and ten years duration, both unaided), and the others self-reported no hearing loss.

Procedure

Ethical approval for this study was granted by the Human Research Ethics Office of The University of Western Australia. All participants provided informed written consent.

Potential participants were offered two different time options for group participation, or the opportunity to attend a private one-on-one session, if preferred. Sessions were held in February 2020, with 11 participants attending the first focus group, 17 attending the second focus group and two participants attending private one-on-one interview sessions as they self-reported extreme difficulty hearing in group situations. Each participant attended one session only, with the group sessions lasting for 1.5 hours and the one-on-one sessions taking one hour each. The sessions were held in a quiet boardroom at the Ear Science Institute Australia, Subiaco WA. Participants sat in a circle on chairs facing inwards with both session moderators sitting within the circle. A hand-held Sony ICD-PX470 recorder was placed on a low table in the centre of the circle to record the conversation allowing for transcription and analysis of the dialogue.

The sessions started with the session moderator first setting the ground rules: (1) one speaker at a time, (2) clear voice so that the voice recorder can pick it up, (3) all views are welcome and valid, (4) make this a supportive environment and respect each other’s views, (5) speak freely as this is an anonymous conversation – what is said in the room stays in the room. Participants were given the opportunity to ask any questions before the session started. Following this, the lead session moderator (RJB) asked the participants a series of semi-structured questions inviting them to share their personal experiences relating to social challenges and emotional distress relating to their (or their significant other's) hearing loss. The experiences of social and emotional difficulties explored within the data collection sessions were derived from the existing literature (Heffernan et al. 2016; Wänström et al., 2014; Hallam et al. 2008), with care taken to ensure that the words and phrases used in the data collection sessions mirrored those used by adults with hearing loss in previous qualitative studies. Participants were prompted to describe (1) their experience, (ii) what thoughts were in their mind at that time, (iii) how it felt, (iv) how they managed the situation, and (v) whether they had ever sought to change how they manage the situation when it occurred (Appendix 1). During the sessions, questions were delivered in a neutral tone and participants were further prompted to elaborate on their responses and encouraged to build on each other's' responses. All members of the group were given equal opportunities to provide input. While some participants were more vocal than others, none seemed to dominate the conversation. All participants contributed to the discussion, and contrasting opinions were expressed. All procedures were the same for the focus groups and the interviews.

The act of engaging in research may actually affect the phenomenon being studied. To address these potential biases, qualitative researchers use 'reflexivity", the explicit examination and acknowledgement of the researchers' own views, biases and assumptions. The research process, integrity, trustworthiness, and accountability was protected throughout this project through three intentional acts. First, the research team was selected to intentionally include individuals with prior knowledge relating to audiology research (RJB & RHE) and also those with no prior knowledge of audiology research (MO & LS) to counterbalance potential biases arising from prior knowledge in the research design, execution and reporting. Second, the session was conducted by a clinical audiologist (RJB) and a clinical psychology student. The role of the audiologist was to lead the data collection sessions, use her clinical experience to ensure that the sessions were run in a way that met the hearing needs of participants, and use her familiarity with the discourse relating to the social and emotional impacts of hearing loss to help the participants open up and tell their stories. The role of the clinical psychology student was to use her prior knowledge and experience of psychological distress to ask additional questions, to probe deeper into the thoughts, feelings and behaviours raised by participants during the session. Third, data analysis was conducted by two authors with different prior knowledge of the subject area and dataset. RJB is a clinical and research audiologist and was present at all of the data collection sessions, thus enabling her view the data with an audiological lens and also to reflect on the feeling in the room at the time of recording. MO had no prior knowledge of the psychosocial impacts of hearing loss, but as a psychologist, brought significant prior knowledge of psychological processes and coping strategies for social and emotional difficulties in a general sense. Having the two researchers work together during data analysis assisted to reduce biases as they were able to discuss and interpret the data from different standpoints.

Data analysis

Data were analysed using a combined inductive and deductive thematic analysis (Diesing, 1971), to investigate the presence of belief patterns, and identify coping strategies in line with the self-regulatory model (Leventhal et al., 2012). Thematic analysis was conducted in line with Braun and Clarke (2006) by two members of the research team (RJB & MO). As previously mentioned, these research members were selected for their respective differing qualifications (RJB is a clinical audiologist and MO is a psychologist; both are research trained in qualitative and quantitative methodology). First, they familiarised themselves with the data through repeated rereading of the transcribed data set. One researcher (RJB) then split the transcript into sections (meaning units) representing individual participants' stories; crosschecked by a second researcher (MO). Second, the two researchers (RJB & MO) independently identified relevant meaning units and manually coded them for relevance to expression of distress associated with hearing loss, using an inductive approach to identify experiential categories of distress (such as withdrawal, loneliness, anxiety). These datasets were combined with any discrepancies resolved through discussion. The number of times that participants raised a particular aspect of distress were counted by summing the number of meaning units within each of these 'distress' categories. Third, thematic 'nodes' were set up to correspond with each of five lenses of Cognitive Representations and the Emotional Representation of the condition (consequences, identity, cause, time-line, control and emotional representation) and also the five lenses of coping strategies (solution-focussed, emotion venting, avoidance, seeking support, and cognitive reprisal), as per the Self-regulation theory. Meaning units were deductively coded across the 'nodes' as perceived appropriate by one researcher (RJB). The content of each 'node' was cross-checked to ensure that the data accurately corresponded to the respective category (MO). The number of times that participants raised a particular cognitive/emotional representation or coping strategy were counted by summing the number of meaning units within each of these ‘nodes’. Finally, all members of the research team discussed the data together to derive the main themes within the nodes.

Of note, the framework was used to interpret the data, not design the questions. This was done purposely so as to elicit the participants’ perceptions of their condition not pre-empt their structure. As such, not all representations within the framework were spoken to, *e.g.,* timeline, below. Typically participant stories were multi-faceted, fitting across multiple codes.

RESULTS

The results reported here present the participants’ described experiences living with and coping with social challenges and emotional distress on account of hearing loss. These results are presented in order of the three phases of the self-regulation model (Figure 1): (i) Cognitive and emotional representations of the condition; (ii) Coping strategies employed in an attempt to manage symptoms; and (iii) Consequences of the coping strategy.

(i) Cognitive and emotional representations of the condition

Participants described emotional distress on account of their hearing loss across 22 categories. The most common experiences were Social overwhelm (described by participants n=38 times), Frustration (n=34), Fatigue (n=21), Loss (n=19), Exclusion (n=17), Conflict with significant others (n=15), and Sadness & disappointment (n=14). Participants most often described these experiences of distress through cognitive representations of *consequences* (n=163), and *emotional representations* (n=82), with limited discussion relating to cognitive representations of *identity* (n=26)*, cause* (n=7)*, time-line* (n=0)*,* or *control* (n=9) (Table 1).

Cognitive representation – Cause

The *cause* lens encapsulates individualistic ideas about the perceived cause of the condition (in this case, distress relating to the hearing loss), which may not be medically accurate. These representations will be based on information gathered from personal experience as well as the opinions of others, health professionals, and media sources.

Participants described the experience of emotional distress to be mainly caused by both the hearing loss and others' lack of understanding and compassion. For example:

> *"And I do get a bit of that, that people, they give up or they think you're stupid, that you haven't got a brain. And actually, I do have a brain. So that's the side that's frustrating, but I don't know how one can educate the masses to understand that we're human."*
>
> *"I was going to say that it's the invisible impairment. If you were sitting there in a wheelchair, you would get so much more attention, sympathy, understanding, but because it's invisible, nothing. And I think also the portrayal from the media too in this respect seems to compound that."*

Cognitive representation – Identity

The identity lens considers the severity of somatic sensations/symptoms and their possible meaning or label, and the ‘labels’ that coincide with having the condition a shift in how they are perceived by others. It describes the transitions of becoming a person *with* the condition.

Participants described how the hearing loss distress impacted on their sense of self, and also on how others perceived them. For example:

> *“So, I came in here and got hearing aids, but I fought it like crazy because I thought, I’m going to be so old, I feel old, I’m going to look old, just that whole thing and I had my hair really long covering it. And now I’m getting it shorter and shorter so I know I’m getting more accepting.”*

> *“And we were intubating a patient in an emergency situation. That’s basically putting a tube down the throat to make them breathe. Part of the procedure is that, after the tube goes down, you listen to the chest to see that there’s equal air entry. And the nurse on the other side said to me, [Name], listen to the air entry. And I said, no, you can do it. And she got quite offensive. And I had to say to her, I’ll have to have my hearing aids out if I have to do the procedure. Because normally when I’m in that situation, I would take my hearing aids out for the procedure. It’s a bit like taking your teeth out and putting them on the table. That’s what it’s like. And all this nurse could say to me in this situation was ‘I thought you were just dumb’.”*

Cognitive representation – Consequences

The consequences lens describes ones individual beliefs about the consequences of the condition and how this may impact on them physically, socially and emotionally.

The most commonly described cognitive representations were Social overwhelm (described by participants in 38 instances), followed by Fatigue (n=20), and Loss (n=18).

Social overwhelm included descriptions of feeling as though things were too much to handle, there was no power to change the circumstance, and passive disengagement. For example:

> *"Those social events are just too much for me now, I can't handle the stress of the people and the noise. No, it's too much."*
>
> *"I find that I don't initiate conversations with people, if people speak to me, I respond. That's it."*
>
> *"The word I was going to use in response to your question, certainly in my case, the word is withdrawal. You withdraw back in yourself more and you don't realise you're doing it, but you are in effect hiding from the problem because you can't accommodate it, you can't handle it, you can't change it and you just let it happen. Like a tide coming in it's going to happen, so just sit back and do nothing."*
>
> *"They will often say, oh he's zoning out toward the end of a night."*

Fatigue was described to include listening fatigue but also fatigue in relation to having to be responsible for organising events and controlling situations to ensure equitable circumstances for access to the conversation.

> *"On the subject of not going to social events, I think one of the reasons why I don't go because it's just so exhausting trying to hear. You have a lot of noise, you try to focus on a conversation, and it's just exhausting, and it's easier just not to go or just to sit, because it's too tiring, and I think a lot of people in this room would have that same issue. "*
>
> *"It's exhausting having to always think ahead and plan and check if it's going to be too loud or if it's the right restaurant or where to sit."*

Loss described the cognitive realisation that they were missing out on parts of the conversation, on experiences, on connections, and missing out on life.

> *"Birdsong, I will miss. My wife will say, can you hear those birds? No, I can't. But I can hear normal voice range, but there are certain pitches that I miss out on. And particularly birdsong, I'd love to hear the birds, but I don't always hear them. And also maybe things like, not that we hear crickets that often, but all those little things that are normal everyday life, you only seem to get a certain range of frequencies that you really tune in on."*
>
> *"I used to go to Yoga and I loved it, but there might be 40 people in the room and the teacher's down the other end and you're lying down and you can't hear anything. So, I've stopped going and that's one thing I really miss because you have to keep one eye open to see what everybody else is doing."*
>
> *"My family usually crack up laughing and I know that I've missed the joke, and it was funny to start with. I used to think it was funny, and then it ceased to be funny because I was going to all the family things but didn't know what was going on. So I got my hearing aid so it's slightly better, but I still miss a lot what's going on. Apart*

> *from anything else, young people talk so quickly now, and they look at you as if you're a bit whacko, you're getting on a bit."*

Exclusion described the experience of being excluded from events and conversations.

> *"It's got so bad I don't even get invited anymore"*
>
> *"Yes. I don't get included. Nine years ago, my son got married and I went to Melbourne for the wedding, and the night before the wedding, I was told I wasn't going to be speaking."*
>
> *"But recently, we went to a vet, and they're not cheap, vets, and we have two cats. And I said to the vet, as I always do, I smiled, I look them bang in the eye and then go, 'I don't hear as well as you do', so that's a clue, but the vet then talked to my daughter. You cease to exist. I'm the one who's paying the bill. But still, you cease to exist."*

Cognitive representation – Time-line

The time-line lens considers the predictive belief about how long the condition might last. None of the participants described their distress in relation to time, or beliefs about the duration of the emotional distress they were experiencing.

Cognitive representation – Control

Curability/controllability: the beliefs about whether the condition can be cured or kept under control and the degree to which the individual plays a part in achieving this.

Some participants described beliefs relating to the extent to which emotional distress associated with hearing loss can be controlled, treated, or cured.

> *"I don't want to talk to my psychologist. Instead I'd rather a buddy system, or I'd rather a local support group, or I'd rather talk to other people with hearing loss and mental health concerns so that we can get through it together."*

Emotional Representations

Emotional representations describe subjective reactions to the health condition, such as embarrassment, frustration, or anxiety. The most commonly described emotional representations related to frustration (n=30), grief (n=11), anxiety (n=9), loneliness (n=9), and burdensomeness (n=9).

Frustration was also described by participants as grumpy, annoyance, or irritability. Participants described feeling frustrated with themselves and others.

> *"[I] get really annoyed and I get home and I think, I got really grumpy there and I started getting grumpy with somebody and I think and I shouldn't have because it's not their fault. It's just me; I just think I can't keep up this intense concentration for that length of time all the time, I'm getting old."*

Grief was described as a response to missing out on things and a shift in identity (*e.g.,* loss of aspects of self).

> *"I think it's a form of grief, because suddenly you're not quite all there when you've lost your hearing. Up until then you're reasonably okay, but then suddenly you're*

> *losing bits of your body almost and it's almost a grief for what you're losing. You get over that initial shock I think that your body's not quite right, you're getting old for some and some they're not getting old, some get it when they're younger. Yes, I think it's a form of you're losing a bit of yourself."*

Anxiety was described to arise due to stress over communication challenges caused by the hearing loss.

> *"And I think the reason that happens is because you're going into a crowd of people that you mostly know as family and you're going to have to deal with all these multiple conversations. And being a lot of family events, there's often conflict, and I don't know, but I've sometimes said something in the middle of a family argument and got blown out of the water because I haven't heard properly. And because they don't have a hearing loss, they tend to not understand it and they tend to think the behaviour's deliberate when it's not, and I think that's what causes me stress. So often, I won't go to family things if I know certain people are going to be there because it's not worth the strain of trying to make certain I don't say the wrong thing, and I just think that's part and parcel of the condition basically. That's how you deal with it."*
>
> *"Yes, I think I go into a certain stress level, which is become anxious in certain situations because I don't know what that situation's going to be before I get there. So, a lot of the time I know and I'm prepared for it, but if I'm not prepared and I don't know what I'm going into I get very stressed, yes."*

Loneliness described the emotional consequence of not being able to socially and emotionally connect with loved ones.

> *"But I found the staff room was worse. You'd be at tables just like this, going along, and you could have a conversation with a person on your good ear or maybe straining to hear across the table, but you'd miss out on a lot of conversations. And you'd feel very isolated"*
>
> *"Just on the loneliness side of it that you alluded to earlier, it is a big issue for people with hearing loss mainly because it doesn't happen overnight. It happens gradually. Things strip away. You don't go to that restaurant for tea, you don't go to a movie. And I don't really cope with that very well at all because I used to do all those things and I don't anymore."*

Burdensomeness was described by participants as an overwhelming sense that they were putting unnecessary negative pressure on their loved ones because of their hearing loss.

> *"That's when I realised I had better do something and I thought that was a nuisance, but then if I have to ask them so many times a day, please say that again, will you say that again, what did you say. I think that was frustrating for them and it hasn't got to the stage where they were complaining, but I imagine that it would be frustrating."*
>
> *"They were getting embarrassed and I was saying, your answer's probably right, but I just can't hear you so can you say it louder and they'd get softer because they get embarrassed when you draw attention to them."*

(ii) Coping strategies employed in an attempt to manage symptoms

Participants described the various coping strategies they, and their loved ones, employ in an attempt to manage the emotional distress experienced on account of the hearing loss. Coping strategies employed mainly related to Avoidance (n=136), followed by Solution-focussed (n=48), Support seeking (n=12), and Cognitive reprisal (n=3). Use of Emotion venting was not described by participants as a coping strategy, albeit that attendance at these focus groups are a form of emotion venting.

Coping Strategies – Avoidance

Participants described helpful avoidance strategies (such as selectively choosing to remove one's self from a difficult situation), and also unhelpful avoidance (such as in giving up on things and avoiding them due to the emotional difficulty of the environment).

Helpful avoidance, briefly removing oneself from stressful situations or emotions so as to regain energy, was generally driven by cognitive decision-making***.***

> *"If the grandchildren are a bit overwhelming I'll just choose to either just sit back and relax and watch, or go outside for a while and it feels very pleasant because I'm having a rest. It's like running up hill and then I've decided to stop at the side of the road and have a rest, it's really nice. And I then go back when I'm ready."*
>
> *"I find like I've gone out a couple of times with my husband and the kids to something and there's a lot of people there and having the cochlea and a lot of noise. If I turn it off or take it off I'm profoundly deaf on the left side so you can't hear anybody or anything, but you can't just block out certain things you get all the noise, everything that's going on. So, if they're on my bad side I just can't separate voices and I tend to*

> *just say, guys, I'm just going outside and I'll go find somewhere to sit in a coffee shop, and then meet up again afterwards."*
>
> *"I would like to say I have only had a mild problem, but I do notice that sometimes in a big gathering it gets very tiring and so you could call it withdrawing, but I will stop mingling with everyone and trying to keep up with everything. And I might take a coffee and go and sit outside for a while, but when I do that it doesn't feel bad for me because it's my choice and it's sometimes a relief."*

Unhelpful Avoidance, in this context, described the impulsive and/or fore thoughts relating to avoidance of social situations and/or interactions. The avoidance was most often in response to embarrassment, ridicule, or fatigue.

> *"So I don't tend to go to things where there's going to be a lot of people because I embarrass myself or I don't hear the joke or I say something completely inappropriate because I've misheard."*
>
> *"But I've been invited to a Christmas party in the early stages, I said to my husband, we're going out so they think we've got something else on because if they know we're at home they'll think we're being antisocial. Well, I was antisocial because it was just more embarrassment I think that you have to keep saying, excuse me, I'm sorry I didn't hear what you said or I'm sorry, what was your number I'll tell you later."*

Coping Strategies – Solution-focussed

Controlling the listening environment was described within the context of improving ones hearing capabilities so as to reduce the unwanted emotional distress that occurs when not hearing well. However, controlling the listening environment comes at a cost, as some described the fatigue associated with always having to plan ahead and others described the push-back received from communication partners when trying to control the listening environment.

> *"I love going out for dinner where there's max four people at a table, any more than that and you think you can wipe half the conversation off because you can't hear them."*
>
> *"As a driver, I always prefer to be in the driving seat because if I'm in the passenger seat, I can't hear what the driver is saying to me, so I try to drive as much as I can."*
>
> *"It's exhausting being the one that has to always try and control or manipulate the situation"*

Humour, making light of themselves or the situation, was used to disarm or cope with emotionally volatile situations.

> *"I totally misinterpret the origin of the sound. Its good fun, you've got to maintain your sense of humour, if you don't do that then you've got a real problem."*

Coping Strategies – Seeking support

Assertiveness was a common theme, with participants describing being assertive in social situations. For example, asking for repeats, letting it be known that they had a hearing loss and needed extra support, or calling out bad behaviour from communication partners (such as ridicule or exclusion) in an attempt to prevent possible emotional distress.

> *"And we shouldn't be leaving ourselves out, we should be saying, look, include us and the only way you can include us is by recognising what we need."*
>
> *"There's a lot that depends on your personality. Because I would just say to people I'm sorry, I'm deaf. I still miss out on a lot, but I enjoy watching and being there and seeing what's happening even if I sometimes don't know and everybody laughs and I don't. But I don't find it a stress to me because it's my problem, I'm deaf and if I miss out I've missed out. But I'm quite happy to say, look, I'm sorry, I'm deaf and I'd rather sit outside the background noise is just too much. So, I don't find it stressful."*

Use of communication repair strategies, such as asking for others to repeat themselves or slow down their speech, was described as an important skill for maintaining inclusion.

> *"And so I'll ask the person next to me what's to happen about such and such."*
>
> *"The number of times I've had a phone call and I say can you please slow down because I simply cannot understand a single word you are saying."*

Accepting support from significant others plays an important role in providing understanding and support.

> *"I have got five grandchildren and they don't treat me any different to anyone else. When I went down to Grandparent's Day at the school, I could've cried. My grandson took my hand and took me in and said, this is my grandmother. She can't hear very well so you'll all have you speak loud."*

> *"We've got friends who understand, and I actually get sat in the best seat in the restaurant."*

Support groups were raised as a means of seeking social support, with acknowledgement that support groups should draw together people with similar experiences.

> *"I'm in a lot of Facebook support groups, single-sided deafness groups, it's a worldwide thing."*
>
> *"So if you are using groups of deaf people they need to be people of a similar age, similar IQs. A bit of similar sociology."*

Coping Strategies – Emotion venting

Emotion venting is used to express intense emotions, often in an exaggerated way, and most often with a significant other. Participants did not describe use of emotion venting as a coping strategy, but rather a few participants appeared to emotionally vent when retelling their story during data collection.

> "*And they slow down properly for three words, speed up and then back again and I asked three times and then in the end I said it's no use speaking to you, either you put your supervisor on or I'll ring back and get somebody else."*

As emotion venting was not directly described but indirectly perceived in the mannerisms of some participants, we did not rate this as a coping strategy in this analysis.

Coping Strategies – Cognitive reappraisal

Cognitive reappraisal was used in an attempt to reinterpret a difficult and disturbing situation in such a way that it is understood differently and the emotional impact is lessened. Cognitive reprisal strategies mainly focussed on accepting that leaving is not suitable and change is not possible, and instead non-judgementally allowing the situation to be.

> *"I don't find it exhausting or challenging. I accept it as part of my lot in life or whatever you want to call it. To me, sitting complaining about it doesn't help the problem, so this is where you've ended up, get on with life, be happy. So that's how I feel about it."*
>
> *"For me, I find I don't get stressed because I've come to the level where this is me now, after years of thinking my hearing's going to come back and I've just got to make the best of what I've been dealt with."*

Lack of effective coping strategies

Few participants described the use of solution-focussed coping strategies to overcome hearing loss distress. The most commonly employed coping strategy used by participants was that of avoidance, which was generally deemed not to be effective in overcoming the distress, but rather tended to amplify the underlying distress. This amplification may be due to avoidance maintaining any maladaptive cognitive representations particularly regarding consequences, as avoidance prevents the opportunity to disprove anticipated negative consequences or learn how to cope with and overcome any true negative consequences. This in turn deepens both emotional distress and social isolation.

Furthermore, many participants described not having coping strategies to address the distress in particular situations. The distressing experiences with low counts of coping strategies employed included Frustration, Exclusion, Conflict with significant others, Sadness & disappointment, and Embarrassment (Table 1).

Participants specifically described wanting strategies to help them cope with missing out on being able to participate in social interactions, highlighting the role of the audiologists in facilitating development of these skills, and expressing disappointment that these services are not currently provided within current hearing healthcare services.

> *"And that's where, I don't know if audiologists can help us with that, but somewhere along the line coping with such a demand on trying to understand people, trying to cope better would be very helpful to people, as individuals that is."*

(iii) Consequences of coping strategies

Although some participants described how their coping strategies assisted them to manage individual situations (such as the successful implementation of communication repair and using helpful-avoidance strategies), others described the negative consequences of their coping strategies. Importantly, these stories describe how not the hearing loss, but the emotional distress experienced on account of the hearing loss had negative consequences for the individual.

Avoidance strategies can negatively impact employment and/or enjoyment in the workplace.

> *"I'd like to share my experience, more professionally. I actually gave up work because of it. Retired. I couldn't hear, going to meetings, didn't have hearing aids sorted out. It was so unprofessional to go to a meeting, a board meeting, and not be able to hear what was going on, so for my self-esteem, it was a huge blow and the decision was made, through ear problems, to give up work and retire."*
>
> *"I was straining to hear all the time, so by the end of the day, it was very tiring. And for that reason, I resigned from teaching."*

Avoidance strategies can negatively affect how individuals self-manage their underlying medical condition.

> *"I was coming down here to see you. I lost my cochlea implant a couple of weeks ago. And then I thought I should go and see [the receptionist] and tell her that we've received a reply from the insurance company, and also this one's got a weak magnet in it and it keeps falling off. I should see her about getting a stronger magnet. But I thought to walk down there and then have to talk to her, or somebody else. It's just I'd rather not do it. I'd rather cope with the wrong magnet and we'll send her an email, and try to sort it out that way."*

In some cases the emotional distress spurred solution-focussed behaviours relating to hearing loss management.

> *"I was a teacher, I've given up teaching because it was just too hard, but that's what spurred me on to finding out what was wrong with my hearing because I can't hear*

> *the kids in the class and I keep having to ask them to tell me three times. And then they get frustrated and actually they get softer, the more often they have to say it they get more embarrassed."*

DISCUSSION

The purpose of this study was to explore the lived experience of social challenges and emotional distress in relation to hearing loss, and to describe the coping mechanisms employed by adults with acquired hearing loss and their significant others. Participants described their experiences primarily through cognitive representations of consequences (fatigue, exclusion, loss, conflict with significant others, and stigmatisation) and emotional representations (frustration, sadness, disappointment, anxiety, grief, burdensomeness, embarrassment and loneliness). Coping strategies included avoidance (helpful and unhelpful), controlling the listening environment, humour, acceptance, assertiveness, use of communication repair strategies, and accepting support from significant others. Participants specifically described a lack of coping strategies to manage their hearing loss distress, with some participants expressing disappointment that these services are not currently provided within current audiological practice. These findings suggest that hearing healthcare services could be improved through inclusion of support services helping adults with hearing loss to better understand and manage their emotional distress relating to the hearing loss.

Coping is an active, purposeful process that includes behavioural, emotional, and cognitive attempts to manage the demands imposed by a stressor. Coping strategies heavily influence how individuals experience both hearing loss and the subsequent social and emotional challenges relating to hearing loss. Coping strategies that appeared to provide positive outcomes included: helpful avoidance, controlling the listening environment, humour, acceptance of their condition, seeking and accepting support from significant others, assertiveness, use of communication repair strategies, and attending support groups. Previous studies have demonstrated the effectiveness of these coping strategies for improving communication (Hallam et al., 2008; Hickson, Worrall & Scarinci, 2007; Pang et al., 2019; Sparrow, Lind & van Steenbrugge, 2020), and thus it is not surprising that these same coping strategies, when employed, reduce the emotional distress experienced on account of the hearing loss. Humour has previously been described as an effective therapeutic tool supporting successful coping with hearing loss (Bally & Marcus Bernstein, 2019; Helvik et al., 2007). Others warn that while humour can be used as a coping strategy to ease discomfort with an unfavourable situation, it can also be used by adults with hearing loss to conceal their true emotional state from others (Hricová, 2018). Use of group support services are demonstrated to improve communication skills (Hickson et al., 2007; Kramer et al., 2005), environmental modification skills (such as identifying and reducing background noise), hearing device use (including when and where devices are used as well as the skills for cleaning and maintaining them) (Ferguson et al., 2015), and reduce the burden of hearing loss on the individual and their significant other (Getty & Hétu, 1991; Hickson, Worrall & Scarinci, 2007; Hickson et al., 2019; Preminger & Meeks, 2010; Preminger & Yoo, 2010). Adults with hearing loss have previously described the benefits of group support sessions to include: (i) Acquisition of practical and accessible information about hearing loss; (ii) Increased sense of social belonging leading to personal transformation; and (iii) A sense of accomplishment and purpose associated with helping others (described as “paying it forward” in the form of advocacy work to benefit people with hearing loss in their communities) (Southall et al., 2019). Importantly, research has shown that use of positive coping strategies (active coping strategies, such as problem-solving or positive thinking strategies) is associated with higher levels of quality of life in adults with age-related hearing loss, and their significant others (Lazzarotto et al., 2016). It is worth noting that these types of strategies were not well represented in this current sample of adults with hearing loss and self-reported distress in relation to hearing loss. It may be that experiencing distress makes utilising such strategies intuitively difficult to do, or the absence of these strategies as a natural way of coping leads to a distress response.

Examples of unhelpful avoidance strategies described within the current study focused on withdrawal from social activities, reduced interactions within social situations (such as responding when spoken to but not initiating conversation), and withdrawal within social situations (such as “tuning out”), echoing previous reports (Heffernan et al., 2016). Participants in the current study described their withdrawal to be driven by their own desire to avoid a situation (due to fatigue, embarrassment, and/or frustration), but also driven by the actions of others, such as exclusion (not being invited to events or not being included in conversations) or ridicule (being “teased” or reprimanded for mishearing or responding inappropriately). The detrimental consequences of these unhelpful avoidance strategies included negative impacts on maintaining employment and/or work performance and enjoyment. While previous research has suggested that reduced employment rates for adults with acquired hearing loss are likely due to reduced skill and ability to complete work-related tasks due to the hearing loss (Hogan et al., 2009; Jung & Bhattacharyya, 2012), participants in the current study emphasised how it was the emotional impacts of the hearing loss (the anxiety, loneliness, frustration, shame) that inevitably caused them to leave the workforce.

Participants described a lack of coping strategies to address their distress in particular situations, in particular relating to managing frustration, exclusion, conflict with significant others, sadness, disappointment, and embarrassment. Participants specifically described wanting strategies to help them cope with missing out on being able to participate in social interactions, even calling on audiologists to provide services that assist adults with hearing loss to develop helpful coping strategies to better manage the distress associated with the hearing loss. Psychology research demonstrates the benefits of cognitive behavioural therapy in addressing distress relating to similar conditions, social isolation and loneliness for example, in older adults (Hendriks et al., 2008). However, the application for addressing the emotional distress and social difficulties experienced on account of hearing loss is yet to be explored, but may provide a potential starting point when considering how to fulfil this identified consumer need.

Just as hearing loss can be socially and emotionally challenging for the person with hearing loss, it can equally trigger similar concerns for significant other(s) (Govender et al., 2014; Scarinci, Worrall, & Hickson, 2008). Although the Self-regulation model does not specifically explore the involvement of significant others, participants in the current study provided detailed descriptions of the pivotal role of significant others, both in contributing to their hearing loss distress, and providing support for coping with the distress. For example, participants described how significant others contributed to the representation of the condition through both positive (providing support, being understanding and accommodating) and negative interactions (through excluding or ridiculing the person with hearing loss). Furthermore, participants described the involvement of significant others in the execution of coping strategies, both successful coping strategies (supporting helpful avoidance strategies, such as moving to a quieter location to continue the conversation) and negative coping strategies (such as ignoring requests for repeats, or “pushing back” on assertiveness). These findings echo previous descriptions of the “give and take” required when couples adjust to life with acquired hearing loss (Hallam et al., 2008). In line with family-centred healthcare, audiologists must seek awareness of the involvement and experiences of significant others in relation to the health condition, and apply family-centred care when devising audiological rehabilitation (Singh et al., 2017; Singh et al., 2016).

Clinical implications

It is clear from prior research that adults with acquired hearing loss can experience significant emotional distress on account of their hearing loss (Jayakody et al., 2018; Pronk et al., 2013). Yet, hearing healthcare services continue to be dominated by an acute illness model of care (i.e., offering a single solution of hearing devices to address the hearing deficit). Shifting toward a chronic disease model of care, considering an individuals lived experience of the disability and the secondary emotional consequences of the underlying medical condition will likely improve client outcomes. This study elucidates the diverse social and emotional difficulties experienced by people with hearing loss, and the helpful and unhelpful coping mechanisms they employ in an attempt to handle these challenges. As a science, it now begets us to address these issues to aid clinicians in ensuring better treatment use and support clients in finding greater life fulfilment after hearing loss.

Limitations and future directions

All participants were recruited from a single hearing services organisation in Western Australian, and therefore the findings may not be transferable to the broader population. However, participants raised many similar interests and concerns previously reported in the literature, suggesting that many issues identified were reflective of the experiences of the broader population of adults with acquired hearing loss. It is important to note that study specifically recruited individuals with self-reported social challenges and emotional distress. While the majority of individuals with hearing loss experience some level of social and emotional difficulties on account of their hearing loss, the participants involved in this study likely have a much higher degree of distress than the general population of adults with hearing loss as they self-identified as individuals experiencing social challenges and emotional distress, and also volunteered to participate in this study. Targeting this specific cohort likely allowed us to canvas a broader range and great intensity of social challenges and emotional distress and to delve more deeply into these presentations and associated coping during data collection. Additionally, during the focus group sessions participants appeared comforted by the fact that everyone in the group was struggling with some aspect of social or emotional wellbeing, and this appeared to encourage them to share their own stories and be vulnerable in the sharing of their thoughts and behaviours within the retelling of these stories. It may be informative for future research to compare high distress and low distress participants to explore potential differences in cognitive and emotional representations and coping strategies within these two sub-populations. This may more clearly elucidate the targets for intervention with high distress individuals. Many participants described a lack of effective coping strategies and tended to rely on avoidance of social interaction, deepening their isolation and loneliness. Some participants indicated a desire for audiologists to support adults with hearing loss in understanding and addressing the emotional distress experienced on account of hearing loss. Future research programs should look towards developing evidence-driven low-intensity psychosocial interventions focusing on the common issues experienced by people with hearing loss, and appropriate to the skill level of audiologists.

CONCLUSIONS

Adults with hearing loss and their significant others discussed their distress in terms of social and personal consequences (social overwhelm, fatigue, loss, exclusion) and resultant emotions (frustration, grief, anxiety, loneliness, and burdensomeness). Helpful coping strategies employed to manage their distress included avoidance (selectively choosing to remove one's self from difficult situations, yet maintaining connection with communication partners during these experiences), controlling the listening environment, humour, acceptance, assertiveness, use of communication repair strategies, and accepting support from significant others. However, many participants described a lack of effective coping strategies and tended to rely on avoidance of social interaction, deepening their isolation and loneliness. Additionally, participants provided detailed descriptions of the pivotal role of significant others influencing both their experience of the distress, and their use of coping strategies. Despite the expressed need by participants, as yet there exists no formalised way for audiologists to intervene and assist with the social and emotional difficulties that occur due to hearing loss. Addressing this gap may be a promising next step in better meeting the needs of adults with hearing loss.

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Table 1. Cognitive and emotional representations of the condition, and coping strategies used to manage the condition

	Cognitive and emotional representations of the condition						Total number of representations per category	Coping strategies used to manage the condition					Total number of coping strategies per category
Categorised experiences of distressed related to hearing loss	Consequence	Identity	Cause	Timeline	Control	Emotional		Solution-focussed	Emotion venting	Coping - Avoidance	seeking support	Cognitive reprisal	
Social overwhelm	38						38	1		35			36
Frustration (grumpy & annoyance & irritability)					4	30	34	6		19		1	26
Fatigue (tiring)	21						21	7		8		1	16
Loss (missing out)	18		1				19	2		11			13
Exclusion (ignored, dismissed, rejected)	15		2				17	1		3			4
Conflict with significant others	15						15			6	1		7
Sadness & disappointment (low mood and dark days, numb)			3		3	8	14	2		3			5
Supported by significant others	11				2		13	2			7		9
Stigma (assumed to be unintelligent)		12					12	4		7			11
Anxiety (worry, scared)	2					9	11	4		6			10
Grief						11	11	2		8			10
Burdensomeness		2				9	11	2			1		3
Embarrassment	1	3				6	10	4		2			6
Loneliness						9	9	2		7			9
Perceptions of self-identity		9					9			3	2	1	6
Negative impact on Work	8						8	1		6	1		8
Cognition (confusion)	8						8	2					2
Self-confidence (self-worth)	8						8			4			4

Too hard (can't be bothered, giving up, can't cope)	7		1				8			7			7
Weighing up the cost of attending an event	4						6	4					4
Ridiculed	5						5	1		1			2
Others get embarrassed	2						2	1					1
Total number of representations per lens (based on the Self-regulation theory)	163	26	7	0	9	82	289	48	0	136	12	3	199

Figure 1. Visual representation of the self-regulation, including lenses of representation, coping strategies, and outcomes (Adapted from Haggart 2016).