

Journal of the American Academy of Audiology

Social representation of 'hearing loss' among people with hearing loss: An exploratory cross-cultural study

Journal:	<i>Journal of the American Academy of Audiology</i>
Manuscript ID	19-087.R1
Manuscript Type:	Research Article
Date Submitted by the Author:	n/a
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Keywords:	Auditory rehabilitation, Hearing science, Hearing aids and assistive listening devices

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3 **‘Social representation of ‘hearing loss’ among people with**
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6 **hearing loss: An exploratory cross-cultural study**
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Abstract

Background: Hearing loss can have an effect on physical, psychosocial and cognitive wellbeing of an individual. Despite the research on attitudes and stigma towards hearing loss, [people with hearing loss \(PHL\)](#) continue to delay seeking help. Thus, it is vital to look at alternative theories which have been successfully used in disability research to better understand how PHL perceives hearing loss.

Purpose: The aim of the current exploratory study was to examine the social representation of 'hearing loss' in people with hearing loss (PHL) in India, Republic of Korea (ROK), United Kingdom (UK), and the United States (US).

Research Design: The study used a cross-sectional survey design

Study Sample: In this study, 424 participants were recruited using a consecutive sampling method in four countries (India, ROK, UK and US).

Data Collection and Analysis: Data collection was conducted using a questionnaire Data were analyzed using content analysis similarities analysis, prototypical analysis, and Chi-Square analysis.

Results: The free associations of the PHL were grouped into 37 categories. The most commonly reported categories were *communication difficulties, negative mental state, aging, assessment and management, causes of hearing loss, hearing ability or disability, hearing instruments, and symptoms of hearing loss*. Similarities analysis and prototypical analysis highlighted two main negative categories ([negative mental state and communication difficulties](#)) which form the central elements of [social representation \(SR\)](#) of hearing loss. PHL associated hearing loss mainly as a negative phenomenon but with some positive and neutral aspects. Respondents from ROK reported a greater number of neutral associations compared to other countries. There were cross cultural similarities and differences in terms of [PHLs](#) social representation of hearing loss, but there were more similarities than differences.

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3 **Conclusions:** The study provides an insight into how PHL collectively view their ‘hearing
4 loss’ and helps to develop our understanding of the influence of culture on the Social
5 representation of ‘hearing loss’. The results will aid the development of culturally appropriate
6 public education campaigns, marketing material and appropriate rehabilitation for PHL.
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17 **Key Words**

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19 Hearing loss, Stigma, Attitude, Social representation, Perception, Societal attitude
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24 **Abbreviations**

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27 PHL: People with Hearing Loss
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29 ROK: Republic of Korea
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31 SRT: Social Representations Theory
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33 SR: Social Representation
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36 UK: United Kingdom
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38 US: United States
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40 WHO: World Health Organization
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INTRODUCTION

According to the World Health Organization (WHO), there are 466 million people with disabling hearing loss across the globe ([World Health Organization, 2018](#)). Untreated hearing loss can have an effect on physical, psychosocial (Monzani et al, 2008) and cognitive wellbeing (Lin et al, 2013) of an individual. Despite these negative effects of hearing loss, there is a considerable delay in individuals seeking help for their hearing loss (Meyer et al, 2014). It is estimated that PHL take up to 10 years or more to seek help (Simpson et al, 2019). Some of the factors that can positively influence help seeking includes social pressure from significant others (Duijvestinn et al, 2003), motivation (Hickson et al, 1999) , self-perception of their hearing difficulties (Knudsen et al, 2010) and higher severity of hearing loss (Duijvestijn et al, 2003). Along with these factors, attitude towards hearing loss plays an important role in help seeking.

Attitudes towards hearing loss

Attitude of an individual towards hearing loss and hearing aids is one of the key factors for the delay in seeking help (Kochkin, 2010). Several factors were attributed to PHLs' attitude towards their hearing loss and these include acceptance (denial), coping with hearing loss and perceived disability. For example, PHL seek help [more quickly](#) if the perceived disability due to their hearing loss is higher or if they have accepted their hearing loss (Knudsen et al, 2010; Simpson et al, 2019).

The most commonly reported factor, which acts as a barrier for help seeking is stigma associated with hearing loss (Wallhagen, 2010). Wallhagen (2010) studied stigma towards help seeking in older adults who were not hearing aid users and concluded that the delay in [seeking help](#) was associated with “altered self-perception, aging and vanity”. [Southall et al.](#)

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3 (2010) examined the stigma relating to help seeking behaviour. They concluded that PHL go
4 through a process of denial of their hearing loss and seek help when their hearing loss
5 worsens and starts to affect their social life. Despite the research on attitudes, interestingly,
6 there has been a surprising lack of translational research that has resulted in changes in
7 outcome in terms of the PHL behaviour towards hearing loss.
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17 Attitudes focus on understanding how an individual evaluates a particular subject or object
18 (Howarth et al, 2004), but the actual practices of an individual might not be influenced by
19 their attitude towards a particular subject or object (Ajzen and Fishbein, 1977). In a study on
20 hearing protection devices (HPD) 77% of the members of a music band agreed that listening
21 to loud music could result in damage to their hearing but only 43% of the band liked to use
22 HPDs (Mendes et al, 2007). Furthermore, attitude research investigating delay in help
23 seeking may not address the issue as ‘attitudes’ do not take into consideration various
24 influencing factors such as culture, environmental and societal factors (Meyer and Hickson
25 2012). Moreover, the majority of research on stigma is descriptive and lacks a clear
26 conceptual framework to understand the stigma (David and Werner, 2016). Therefore, further
27 research on attitude towards hearing loss is needed using different theoretical models (David
28 et al, 2018) to identify various ways to reduce the problematic delay in help seeking.
29 Moreover, there has been a shift in audiology research, wherein researchers are exploring
30 other successful theories/models that are used in other health and disability research to better
31 understand the behaviour and practices of PHL (Manchaiah et al, 2012).
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54 **Social Representation Theory**

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56 In recent years, social psychologists have proposed that the use of Social Representations
57 Theory (SRT) can be fruitful in examining the societal component of issues by studying
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3 perceptions collectively (Lopes and Gaskell, 2015). SRT was proposed by Moscovici in 1961
4 and adopted into Audiology by Manchaiah et al, (2015a, 2015b). Moscovici defined **social**
5 **representations (SR)** as “the elaborating of a social object by the community for the purpose
6 of behaving and communicating” (Moscovici, 1963, p.251). The term social highlights that
7 the representations developed are social and take into consideration various aspects such as
8 cultural, historical and economic practices, political ideas and religious beliefs (Moscovici,
9 1988). **Social representations are created from our day-to-day exchanges and**
10 **communications. They define how we interact with others. SRT can be useful in**
11 **understanding a holistic perspective of disability or illness not just the negative perspective as**
12 **evident from researching stigma (Manchaiah et al, 2019). Furthermore, attitude and**
13 **stigmatization are a part of SR, therefore, SR is a more basic aspect of a community which**
14 **can influence an individual’s practices.**

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33 SRT has been used to examine social representation of ‘hearing loss’ and ‘hearing aids’
34 among the general public in different countries (Manchaiah et al, 2015a, 2015b). For hearing
35 loss, the main categories relevant to social representation were *assessment and management*
36 *(of hearing loss), causes of hearing loss, communication difficulties, disability, hearing*
37 *ability or disability, hearing instruments, negative mental state, the attitudes of others and*
38 *sound and acoustics of the environment*. The frequency in which these categories were
39 reported varied between countries highlighting cross-cultural influences. These studies
40 highlighted that hearing loss is predominantly considered as a negative phenomenon with
41 only some positive and **neutral associations**.

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56 Although the social representations of the general public were explored, the perceptions of
57 individuals with hearing loss might be different. This is because those who have the
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3 experience of living with disability may have more personal insight about the disability
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5 (Munyi, 2012). For example, patients who were diagnosed with cancer are more likely than
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7 the general public to accept a radical treatment even if there is a negligible chance of benefit
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9 (Slevin et al, 1990). Hence, it is important to understand the PHL's SR of hearing loss. We
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11 anticipate that this knowledge will help in developing better strategies to promote help
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13 seeking for PHL.
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19 **Cultural differences**

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21 Cultural differences highlight how individual's actions and practices vary among different
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23 countries in accordance to their respective cultural values (Knafo et al, 2011). The
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25 percentage of PHL seeking help for their hearing loss varies across different countries
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27 (Kochkin, 2010; Wong and McPherson, 2008). For example, in a Eurotrak survey 48 % of
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29 PHL sought help and adopted a hearing aid as opposed to only 14% in Japan. In some
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31 developing countries like China and India the percentage has been reported between 1 and
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33 8% (Zhao et al, 2015). Various researchers have examined the contributors towards hearing
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35 aid adoption and use or lack thereof (for review see Knudsen et al 2010 and Meyer and
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37 Hickson 2012). One of the main reasons for these differences could be due to differences in
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39 how the hearing loss is perceived in various countries (Germundsson et al, 2018). There are
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41 few studies in this area of cross-cultural research (for review see Zhao et al, 2015) with cross-
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43 cultural research using social representation theory being very scarce. Therefore, it is
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45 important to understand how hearing loss is perceived among PHL across different cultures
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47 using SRT.
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56 **Study aims**

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3 The aims of the current study were to describe the PHLs' SR of hearing loss and to
4 understand the cross-cultural similarities and differences in SR of hearing loss. Data were
5 collected from participants in India, Republic of Korea (ROK), United Kingdom (UK) and
6 the United States (US).
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14 **METHOD**

15 **Ethical Considerations**

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17 Ethical approval was obtained from Universities in each country where data were collected.
18 These include: All India Institute of Speech and Hearing, University of Mysore, India;
19 Hallym University, Gangwon-do, ROK; Anglia Ruskin University, [Cambridge, UK](#); and
20 Lamar University, Beaumont, [Texas, US](#). The research adhered to the tenets of the
21 Declaration of Helsinki.
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33 **Participants**

34 The study was conducted using a cross-sectional survey design. Participants were recruited
35 using a consecutive (also termed total enumerative) sampling method. In total, 424 people
36 participated in the study across four countries. Table 1 shows the demographic details of the
37 study participants. [The mean age of participants was 58.5 years, with 62% of the study](#)
38 [sample being male](#). There was some variation in terms of the gender across countries. In the
39 UK and US, there was an [equal distribution of males and females](#), but in India and ROK there
40 were a higher number of male participants. Tertiary education was high in all countries apart
41 from [India](#), where more than half of the participants completed only secondary education.
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Procedure

Data were collected using a 'free association task' method where the participants are expected to provide free association to a stimulus ('hearing loss'). This is a popular method used to identify the elements of SR and has been used in previous studies (Danermark et al, 2014; Linton et al, 2013; Manchaiah et al, 2015a, 2015b).

The data were collected by a researcher based in each country. Researchers were given detailed orientation about the study aims, data collection method including instructions to be given and practiced data collection on a sample population (n=5), which was not included in the study. This was to make sure there was consistency in data collection across all sites. Researchers approached participants attending their local audiology clinic/s. Participants were provided with study information and those who agreed to participate gave a written consent before completing questionnaires. The participants were encouraged to ask any questions they might have before taking part in the study and during the completion of the study questionnaire.

Word Associations and Questionnaire (Appendix 1)

The questionnaire used in this study was previously used by Manchaiah et al. (2015a, 2015b) to study the social representations in 'hearing loss' in the general public. The original questionnaire was in English and was used in the UK and US. It was translated into Kannada (India) and Korean (ROK) using the forward-backward translation method (Beaton et al, 2000). The researchers in India and ROK translated the data back to English before sharing it with the primary researcher.

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3 The questionnaire was comprised of two sections. The first section required participants to
4 provide demographic information (e.g., age, socioeconomic status, education). The second
5 section required participants to list up to five words or phrases that spontaneously came into
6 their mind when they thought of the word 'hearing loss'. Subsequently, participants were
7 asked to rank these words or phrases in order of importance. Finally, the participants were
8 asked to assign a positive, neutral or negative connotation for each expression. *As the
9 questionnaire was a free association task, it helps to elicit responses spontaneously. As a
10 consequence the responses are less controlled and offer better insight into the semantic
11 universe of the 'object' that is being investigated (Abric, 1994).* Combination of the
12 frequency and rank order of the responses helps in understanding the structure and
13 organization of SR of 'hearing loss' (Abric, 2003).
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31 **Data Analysis**

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33 Initially, the number of words or phrases with positive, neutral or negative connotations were
34 counted across countries. A Chi square test was performed to examine the relationship
35 between connotations and responses. This was followed by grouping participant's responses
36 into categories using qualitative content analysis (Graneheim and Lundman, 2004). The
37 grouping was based on words or expressions with similar meaning. Examples of the
38 groupings are presented in Table 2. SC (first author) *conducted the analysis*, and it was
39 independently checked by VM (second author). The analysis was also sent to the researcher
40 who collected the data to ensure that the categorization was appropriate. The frequency of
41 each category across countries is reported in Table 2.
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56 Similarities analysis was carried out using IRaMuTeQ (Ratinaud, 2014) software
57 (<http://www.iramuteq.org/>). This similarities analysis is centered on mathematical graph
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3 theory (Flament, 1965) and presents the results in the form of a graph (i.e., matrix tree). This
4 analysis helps in understanding the frequency of each category and inter category
5 associations. The size of the node denotes the frequency of the association and is considered
6 the central part of SR. The connection between the nodes denotes inter-category associations
7 (e.g., how frequently an individual reported both categories). The thickness of the
8 connections represents the number of co-occurrences of the categories. By creating this
9 matrix tree, it is easy to visualize graphically, the main elements and the connections of social
10 representation.

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13 Finally, prototypical analysis was conducted which involved placing categories into
14 frequency and rank. The results are presented in a 2x2 table (see Table 2). In terms of the
15 rank, a high rank number (rank > mean of ranks) represents a less important category. The
16 ‘central zone’ represents categories that were more frequent and most important (i.e. low
17 number rank). The ‘first peripheral cell’ represents the most frequently reported but least
18 important categories (high number rank). The ‘second peripheral’ consists of categories that
19 are both less frequently reported and least important (lower number rank), and finally
20 ‘contrasted elements’ consists of the less frequently reported but most important (higher
21 number rank) categories. Any SR includes central elements which are steady and offers the
22 meaning of representation (Abric, 2003). The peripheral elements are less stable and can vary
23 between individuals and situations.

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Results

Content Analysis

Content analysis was performed to group expressions into a smaller number of meaningful categories. In total, 37 categories were identified although not all categories were present in each country (see Table 3). The two most frequently reported categories were *negative mental state* (14.0%) and *communication difficulties* (10.2%). Some categories were reported at a similar frequency across countries (e.g., *causes of hearing loss*, *communication difficulties*, *negative mental state*) whereas others differed in frequency (e.g. the category *deafness* was reported more by participants from ROK and UK than from India and US).

[Table 3 near here]

Positive, Neutral and Negative Connotations of Hearing Loss Categories

Figure 1 shows the percentage of responses associated with positive, neutral and negative connotations by participants from the four countries. Significant differences were noted among PHLs responses in relation to positive, neutral and negative connotations (Chi square=82.1488, $p < 0.00001$). In general, there was a high percentage of negative connotations with nearly 80% of all responses carrying negative connotations. Along with negative connotations, there were also neutral (11.6%) and positive (8.9%) connotations. There were some cross-cultural differences in reported connotations. A higher percentage of positive connotations was noted in responses from the Indian sample (15.61%), a higher percentage of negative connotations was noted in responses from the US sample (84.04%), and a higher percentage of neutral connotations was seen in responses from ROK (23.04%).

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[Figure 1 near here]

Similarities Analysis

The similarities analysis of the categories is presented in the form of a matrix tree. Here, the size of the circle represents how frequently each category was reported (bigger size = higher frequency) and the connection between the circles represent the relation between the categories. The numbers on the lines between the circles indicate the frequency of respondents associated to both categories. The direction of the connections does not have any meaning.

[Figure 2 near here]

Figure 2 shows the matrix tree index for all four countries together. There are two main nodes, *communication difficulties* and *negative mental state* as the central elements of SR. Both these categories were predominantly associated with negative connotation. These two nodes also had a very strong link (70). In other words, 70 individuals who listed expressions about the *communication difficulties* category also reported expressions about *negative mental state*. Associations between different categories are shown in Figure 2.

[Figure 3 near here]

The similarities analysis of responses from the Indian sample (see Figure 3) highlight three main categories: *negative mental state*, *hearing ability or disability* and *symptoms of hearing loss*. These are considered as the dominant parts of the SR of hearing loss in India. The inter-relations were stronger between the categories: *negative mental state* and *hearing ability or*

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3 *disability* (22), *negative mental state and others actions and attitudes* (21), *hearing ability or*
4 *disability and symptoms of hearing loss* (24), and *symptoms of hearing loss and causes of*
5 *hearing loss* (21). All the three main nodes were associated with negative connotations.
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12 **[Figure 4 near here]**
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15 Figure 4 shows the similarities analysis results of the ROK sample. In the ROK, there were
16 three main nodes: *hearing instruments*, *communication difficulties* and *negative mental state*.
17 Inter category associations were predominant between the categories: *negative mental state*
18 and *communication difficulties* (18) and *hearing instruments* and *communication difficulties*
19 (17). 'Hearing instruments' were predominantly associated with neutral and positive
20 connotation suggesting that the respondents from ROK view hearing loss as a condition that
21 is manageable using hearing instruments.
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33 **[Figure 5 near here]**
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35 The matrix tree index of the UK (see Figure 5) represents one bigger node, *negative mental*
36 *state* followed by three medium-sized nodes: *aging*, *isolation* and *communication difficulties*.
37 These three nodes *aging* (17), *isolation* (23) and *communication difficulties* (17) have links to
38 the category *negative mental state*. All the categories were associated predominantly with
39 *negative connotations, suggesting* that the PHL from the UK view hearing loss negatively.
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53 Figure 6 represents the matrix tree index of the US. The similarities analysis identified two
54 main nodes *negative mental state* and *communication difficulties*. Both these categories are
55 linked to each other (18), suggesting that 18 individuals who reported *communication*
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3 *difficulties* also reported *negative mental state*. These two main categories were
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5 predominantly associated with negative connotations.
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10 [Figures 3 to 6](#) shows the matrix tree indices of India, ROK, UK and the US
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12 respectively. These show the cross-cultural similarities and differences of the representations
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14 of PHL. The biggest category that was reported across all countries was *negative mental*
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16 *state*. [Across all countries, there were at least two categories that were reported most](#)
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18 [frequently \(i.e., bigger nodes\)](#).
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24 **Prototypical Analysis**

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26 The data were further analyzed to understand the most important associations based on their
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28 rank and frequency. The results of prototypical analysis for all countries together are
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30 presented in Table 4. In addition, the elements in the central zone for each of the four
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32 countries are presented in Table 5. The element *negative mental state* was the most important
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34 component of the central zone based on frequency and rank followed by *communications*
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36 *difficulties*, *hearing ability or disability*, *hearing instrument*, *isolation*, *aging*, *discomfort* and
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38 *deafness*. There were some differences noted in the central zone elements across countries.
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41 For example, the element *communication difficulties* was represented in the central zone in all
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43 four countries. The element *negative mental state* was represented in the central zones of only
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45 India and the UK.
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Discussion

This study examined PHLs social representations of 'hearing loss' and also the cross-cultural similarities and differences in the content and structure of social representations in India, ROK, UK and US.

The SRT was used to model the societal similarities and differences of the phenomenon 'hearing loss'. The aspect of culture plays an important role in forming the structure and organization of SR of 'hearing loss'. There is limited work done in this area other than the work done by Manchaiah et al. (2015a) where they conducted research to understand the social representation of hearing loss in the general public. By studying the SR of hearing loss among PHL, we highlight that their understanding and knowledge of hearing loss may influence their social representation as it is very different to social representations of hearing loss reported by the general public (Manchaiah et al, 2015a). This difference in social representation in PHL may have bearing towards their actions (Howarth et al, 2004).

Research has shown that the working on individual's attitude in relation to seeking help has not yielded positive results. Therefore, developing public education strategies that focus on modifying societal norms could help in reducing the delay in seeking help. Thus, understanding SR of hearing loss across different cultures is needed.

PHL consider 'hearing loss' to be predominantly negative with more than 70% of the free associations linked to negative connotations. This was true across all four countries and was similar to connotations of the general public which were predominantly negative (Manchaiah et al, 2015a). In a study by Heffernan et al (2016) using 25 adults with hearing loss, the majority of respondents associated hearing loss to negative aspects, with the most common being related to being labelled as 'old' and to a lesser extent being associated with

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3 stereotypes such as ‘stupid’ and ‘silly’. The negative perception of hearing loss may be due to
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5 hearing being an important aspect of everyday interaction and any hindrance to this
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7 interaction could lead to negative emotions (Danemark, 1998). Moreover, the cognition or
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9 thoughts of humans are negatively biased towards a disability (Wright, 1988).
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15 Along with negative connotations PHL have reported positive and neutral associations to
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17 their [hearing loss \(about 20%\)](#), [although the negative connotations](#) greatly outweigh positive
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19 aspects. Interestingly, SR of ‘hearing loss’ in the general public produced more positive and
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21 neutral connotations (around 43%) (Manchaiah et al, 2015a). This discordance may be due to
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23 PHL’s better understanding hearing loss and its impact on their everyday life. Furthermore,
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25 the participants used by Manchaiah et al (2015a) had a mean age of 41 years as opposed to a
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27 mean age of 58 years in the current study. The difference in age of the respondents could
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29 [influence the outcomes](#), as hearing loss is usually mild in a younger age group and may not
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31 affect their daily communication.
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38 PHL considered *assessment and management* as either a positive or a neutral association
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40 highlighting the importance of managing the hearing loss rather than the consequences of
41
42 hearing loss. This is similar to a study by Heffernan et al (2016), where participants
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44 positively reacted to the prospect of having help to manage their hearing loss. Furthermore,
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46 the category *positive mental state*, which included free associations such as ‘useful in noisy
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48 environments’, [‘silence’](#), [‘peaceful’](#), was predominantly a positive association highlighting
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50 the importance of looking at the positive aspects of hearing loss. This is in line with research
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52 which has showed some positive aspects [of hearing loss](#), and these include ‘reduced
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54 disturbance by unwanted sounds’ (Kerr and Stephens 2000; Manchaiah et al, 2015c).
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3 Developing an understanding of positive and neutral aspects of hearing loss will help in the
4 creation of an individualized management plan.
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10 Content analysis highlighted 37 unique categories, suggesting diverse representations towards
11 hearing loss. The most frequently occurring category across all countries was *negative mental*
12 *state*. It does not correlate well with the SR of the general public where *disability* was the
13 main category (Manchaiah et al, 2015a). This is noteworthy, as PHL develop coping
14 strategies to deal with the challenges of hearing loss (Danermark, 1998) and may not consider
15 hearing loss as a disability.
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26 Similarities analysis revealed a predominant inter-category association between categories
27 *communication difficulties* and *negative mental state*, suggesting the SR of 'hearing loss' was
28 mainly related to the impact of an uncorrected hearing loss (Arlinger, 2003). This is
29 consistent with research on hearing loss linked to negative mental state causing poor general
30 health, depression and anxiety (Gopinath et al, 2009). The category *negative mental state* was
31 linked to *aging*, *hearing ability or disability* and *hearing instruments*. Hearing loss has
32 traditionally been linked to being old and hearing aids considered mainly for the elderly.
33 Ageism and negative associations of being disabled in a society focused on a youthful
34 appearance were considered as factors in delaying seeking help (Wallahagen, 2010). The
35 category *communication difficulties* was also linked with *activity limitations*, suggesting that
36 hearing loss has an impact on everyday communication which in turn impacts quality of life.
37 Hearing loss affects communication and hinders everyday activities such as watching TV
38 with others, *retrieving phone messages*, involvement in conversations (Grenness et al, 2016).
39 Another important finding was hearing loss leading to *isolation*. It has been suggested that in
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3 older adults, hearing loss may be naturally linked to cognitive decline, perhaps through social
4 isolation (Lin et al, 2013).
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7 When frequency of the category and rank were combined, the most important elements were
8 *negative mental state* followed by *communication difficulties*. These elements in the central
9 zone are in agreement with the literature on *acquired hearing loss*, where the consequence of
10 hearing loss were communication difficulties (Dalton et al, 2003) and impact on mental state
11 leading to depression (Gopinath et al, 2009). Some other elements in the central zone were
12 mainly negative and related to known associations of hearing loss such as ‘isolation’ and
13 ‘aging’. The only positive connotation in the central zone was *hearing instruments*,
14 suggestive that PHL are aware that hearing aids may be a solution for their hearing loss.
15 Similar results to our prototypical analysis were found in a study on disability prototypes in
16 the US and Russia by Martz et al. (2009). The important elements relating to hearing
17 impairment included *communication limitations*, *cognitive impairment* and *isolation*. In the
18 current study, the central zone of the UK and ROK had more elements than the central zones
19 of the US and India. Moreover, the element *aging* was represented in the central zone of three
20 *countries (not India)*, emphasizing the fact that hearing loss is associated with aging. The
21 prototypical analysis offered insight into information that was not evident from the
22 frequencies and similarities analyses. Although *negative mental state* was the most frequently
23 reported category in the ROK and US, the prototypical analysis (that looks at rank as well as
24 frequency) indicated that it was not a priority (by not being located in the central zone).
25 *Symptoms of hearing loss* was also not represented in the central zone of *India*, although it
26 was one of the most frequently reported categories.
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56 There were both similarities and differences seen in the social representation of hearing loss
57 from different countries. The category *isolation* was the main representation from the UK.
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3 This is interesting considering the advanced healthcare system in the UK and the free
4 provision of services through the National Health Service. *Isolation* could be a result of PHL
5 not seeking help for their hearing loss (Bucks et al, 2016). The category *others' actions and*
6 *attitude* has a stronger representation in India. The attitudes of others can negatively influence
7 PHL help seeking. PHL were stereotyped as 'old', 'stupid' and 'crippled', and this obviously
8 had a negative effect on help seeking (David et al, 2018). The category *aging* was strongly
9 represented in all countries except India. Perception of aging is dependent on culture and can
10 be linked to help seeking (Knudsen et al, 2010). In some Asian cultures, hearing loss is
11 considered as a natural part of aging, and the focus is on the society adjusting to the needs of
12 PHL rather than PHL adjusting to society (Wong and McPherson, 2008). The category
13 *hearing instruments* was mainly represented as a positively reported category in ROK and
14 US. These similarities and differences in the representations of hearing loss may be attributed
15 to cultural differences (Zhao et al, 2015). The study did not take into account factors such as
16 media exposure, ethnic group, social structure, laws and traditions of different countries and
17 access to hearing healthcare (e.g., public vs private, professional availability) which all can
18 influence the formation of SR (Manchaiah et al, 2015a). Furthermore, the differences in the
19 SR may not solely be based on the cultural differences, as there are differences in
20 demographics of the samples from each country. Germundsson et al. (2018) researched the
21 impact of demographics including age, gender, education and country of origin on the
22 response patterns of the general public. They concluded that, the country of origin
23 significantly influenced the response patterns, highlighting the cross-cultural differences
24 regarding hearing loss. The impact of demographics on the response patterns of PHL
25 regarding hearing loss would need to be explored in future research.

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56 This research has highlighted that the consequences of hearing loss (e.g., *communication*
57 *difficulties, negative mental state, isolation* etc) need to be addressed. Furthermore, views on
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3 hearing loss were culturally dependent. Further work in this area should concentrate on: (1)
4 development of culturally sensitive and linguistically appropriate marketing and education
5 material regarding hearing loss (2) using the findings from this study to develop public health
6 campaigns and policy development and finally (3) educating clinicians to view hearing loss
7 holistically and to address both the biological and social aspects of hearing loss. Social
8 representations seem to have a stronger influence on individual behaviour than attitudes.
9 Hence, examining disabilities such as hearing loss using SRT as an alternative model is
10 suggested.
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24 **Limitations**

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26 The current study had a few limitations which limit its generalizability. The categorization of
27 the free associations may have been influenced by researcher bias. We did try to minimize
28 this by having two researchers independently categorizing the free associations. Additionally,
29 there were some free associations, which were ambiguous and could be categorized into more
30 than one category. However, there was an in-depth discussion between the researchers in
31 these cases with factors relating to translation considered very carefully before a final
32 agreement was reached. There were some associations which were ambiguous and would not
33 fit into any of the categories and do not relate to the phenomenon that was being investigated.
34 They made up less than 1% of all the responses and were discarded from the analysis. The
35 other potential limitation of this study is the participant recruitment and sampling, which
36 involved recruiting patients mainly from a few clinics in one city in each country. The sample
37 size was also relatively small. In view of this, the findings of this study should be viewed
38 with caution and may not be generalized to all PHL. However, one of the main strengths of
39 this study was exploring the cross-cultural aspects of 'hearing loss', as there is limited
40 literature on this topic (Zhao et al, 2015).
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Conclusions

This exploratory study examined the social representation of hearing loss among PHL in four separate countries with different cultures. Content analysis of free associations produced 37 categories, with the most frequently occurring categories being *negative mental state* and *communication difficulties*. PHL tended to associate negative representations towards hearing loss, although some positive and neutral aspects were also reported. The chi-square analysis revealed that there are cultural differences in SR of hearing loss. Similarities analysis revealed the structure of SR. There were two main nodes, *communication difficulties* and *negative mental state*. These nodes were strongly linked, indicating a strong association. The category *negative mental state* was linked to *aging, hearing ability or disability* and *hearing instruments*. The category *communication difficulties* was linked to *activity limitations*. The categories *negative mental state, communications difficulties, aging, discomfort* and *deafness* formed the core elements of SR, and these elements were similar to the larger nodes of similarities analysis. In addition, the study found similarities and differences in SR across different countries, although the similarities outweigh the differences. The results of the study will be helpful in developing strategies that focus on addressing the societal norms and thus potentially influencing the help-seeking behaviors of PHL.

Acknowledgements

Data collection in ROK was supported by the Ministry of Education of the Republic of Korea and the National Research Foundation of Korea (NRF2018S1A3A2074932).

Conflict of Interest

None to declare

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Table 1: Demographic details

	All Countries (n= 424)	India (n= 111)	ROK (n= 113)	UK (n=100)	US (n=100)
Mean age in years (S.D)	58.5 (19.2)	52.9 (18.9)	50.2 (17.2)	68.7 (15.5)	63.8 (18.9)
Gender (% Male)	61.5	72	63.7	57	52
Hearing aid use (% yes)	49.6	18	43.4	65.1	76
Family and friends with hearing loss? (% Yes)	48	34.2	31.8	68.5	63
Education (%)					
▪ Primary	13.4	20.7	11.5	16	5
▪ Secondary	41.1	57.7	36.3	38	31
▪ Tertiary	45.5	21.6	52.2	46	64
Socioeconomic status (%)					
▪ Low	8.7	12.7	11.4	7	3
▪ Middle	73	60.3	84.1	71	76
▪ High	18.3	27	4.4	22	21

Table 2: Prototypical analysis 2x2 table

	Ranks < mean of ranks	Ranks > mean of ranks
Frequency > mean of frequency	Central Zone	First peripheral
Frequency < mean of frequency	Contrasted elements	Second peripheral

For Peer Review

Table 3: Percentage of hearing loss categories reported in different countries

Categories	Number of responses (% responses)				
	All (n=2096)	India (n=551)	ROK (n=560)	UK (n= 490)	USA (n= 495)
Acceptance of hearing loss (e.g., accepting the problem, have it, have to accept)	0.8	0.7	-	-	2.6
Activity limitations (e.g., hard to watch TV, church, cinema)	3.87	3.3	2.5	4.5	5.5
Aging (e.g., old, age, Aging)	4.7	1.6	4.1	7.4	6.3
Alternative modes of communication (e.g., Sign language, text messaging, ASL)	0.7	0.2	1.1	0.8	0.8
Assessment and management (e.g., hearing test, surgery, doctor)	4.2	5.3	5.2	1.8	4.0
Attitude of the individual (e.g., don't care, don't like, patience)	2.6	1.8	0.5	3.7	4.7
Body structure (e.g., ear, part of body, inner ear)	1.3	0.2	1.4	1.0	2.6
Causes of hearing loss (e.g., genetics, noise exposure, hereditary)	5.5	9.1	5.5	3.1	4.0
Challenging (e.g., difficulty, challenge, hard)	1.8	0.7	1.8	2.2	2.6
Communication difficulties (e.g., mumbles, repetitions, can't understand, misinterpretation)	10.2	8.7	11.6	9.0	11.3
Coping strategies (e.g., avoidance, lip reading, reading facial expression)	1.8	1.8	2.0	2.2	1.2
Cost and time (e.g., Cost, Money, Time)	0.8	0.6	0.4	1.0	1.2
Deafness (e.g., deafness, hearing loss, hearing impairment)	2.7	0.2	4.1	4.1	2.6
Dependence on others (e.g., dependent, dependent on others, feeling of being dependent)	0.3	0.6	-	0.2	0.6
Disability (e.g., disability, invisible, handicap)	1.9	0.6	4.5	1.6	0.6
Discomfort (e.g., irritable, itchy, discomfort)	3.1	1.5	6.3	2.5	1.8
Education, employment and career issues (e.g., hinders work, difficulty in college, difficulties in business)	1.9	2.4	1.8	0.8	2.4
Friends and family members (e.g., grandparents, parents, wife)	1.0	0.4	0.4	1.0	2.2
Health condition (e.g., ill health, another health condition, poor health)	0.8	0.2	1.3	1.2	0.4
Hearing ability or disability (e.g., cannot hear, not hearing, going deaf)	5.4	10.2	3.2	2.9	5.3
Hearing instruments (e.g., hearing aids, cochlear implants, having hearing aids)	5.2	0.7	9.5	3.5	6.9

1	Isolation (e.g., isolated, lonely, not involved)	5.0	2.2	3.9	11.4	3.0
2	Lifestyle and relationship changes (e.g., marriage problems, arguments in family, can't lead normal life)	1.9	1.8	2.3	1.2	2.0
3	Need for support (e.g., need help, help, need caregiver)	0.7	0.4	0.5	0.6	1.2
4	Negative mental state (e.g., sad, fear, worry, depression, sorrow)	14.0	12.6	10.7	17.6	16.0
5	Others' actions and attitude (e.g., others tease, others make fun, others laugh)	2.7	8.2	0.5	1.6	0.2
6	Positive mental state (e.g., useful in noisy environments, silence, peaceful)	1.3	1.3	0.2	2.9	1.0
7	Problem for others (e.g., other people frustrated, other people has to speak loud, communication partners disadvantaged)	0.7	1.6	0.5	0.6	-
8	Recognizing importance of hearing (e.g., hearing is important for speaking, receiving information, ears important)	0.5	1.8	-	-	-
9	Reduced ability (e.g., obstacle to success, decreased concentration, lack of confidence)	2.1	2.6	2.1	2.9	0.8
10	Seasonal and diet (e.g., weather, not to eat certain foods, eat nutritious food)	0.2	0.7	-	0.2	-
11	Sound and acoustics of the environment (e.g., noisy, background noise, loud sounds)	1.8	0.2	5.0	0.4	1.4
12	Stress and exhaustion (e.g., stress, tiring, tiredness)	1.6	-	3.4	0.6	2.4
13	Symptoms of hearing loss (e.g., pain, tinnitus, ear discharge)	4.9	13.1	3.0	1.0	1.8
14	Uncertainty (e.g., loss in life, worry about future, future becomes difficult)	0.6	2.2	-	-	-
15	Voice and speech functions (e.g., people shout, raise voice, people mumble)	1.0	0.2	0.4		
16	Vulnerable (e.g., unsafe, danger, road accidents)	0.6	0.7	0.4	1.4	-
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58						
59						
60						

Table 4: Prototypical analysis of hearing loss data from all countries

	Ranks < Mean of Ranks	Ranks > Mean of ranks
Frequencies > Mean of frequencies	Central Zone Negative mental state Communication difficulties Hearing ability and disability Hearing instrument Isolation Aging Discomfort Deafness	First periphery Causes of hearing loss Symptoms of hearing loss Assessment and management Activity limitations Others' actions and attitude
Frequencies < Mean of frequencies	Contrasted elements Attitude of the individual Education, employment and career issues Stress and exhaustion Acceptance of hearing loss Vulnerable Uncertainty Recognizing the importance of hearing Dependence on others	Second periphery Body structure Friends and family members Health condition Positive mental state Disability Reduced ability Coping strategies Lifestyle and relationship changes Sound and acoustics of the environment Cost and time Challenging Voice and speech functions Problem for others Need for support Alternative modes of communication Seasonal and diet

Table 5: Elements of the central zone in hearing loss data in each country based on prototype analysis

India	Negative mental state Hearing ability or disability Communication difficulties
Republic of Korea	Communication difficulties Hearing instruments Discomfort Causes of hearing loss Disability Aging Deafness Stress and exhaustion
United Kingdom	Negative mental state Isolation Communication difficulties Aging Deafness Causes of hearing loss Attitude of the individual Hearing instruments
United States	Communication difficulties Aging Hearing ability of disability Attitude of the individual

Figure 1: Percentages of hearing loss categories ranked positive, neutral and negative among participant groups

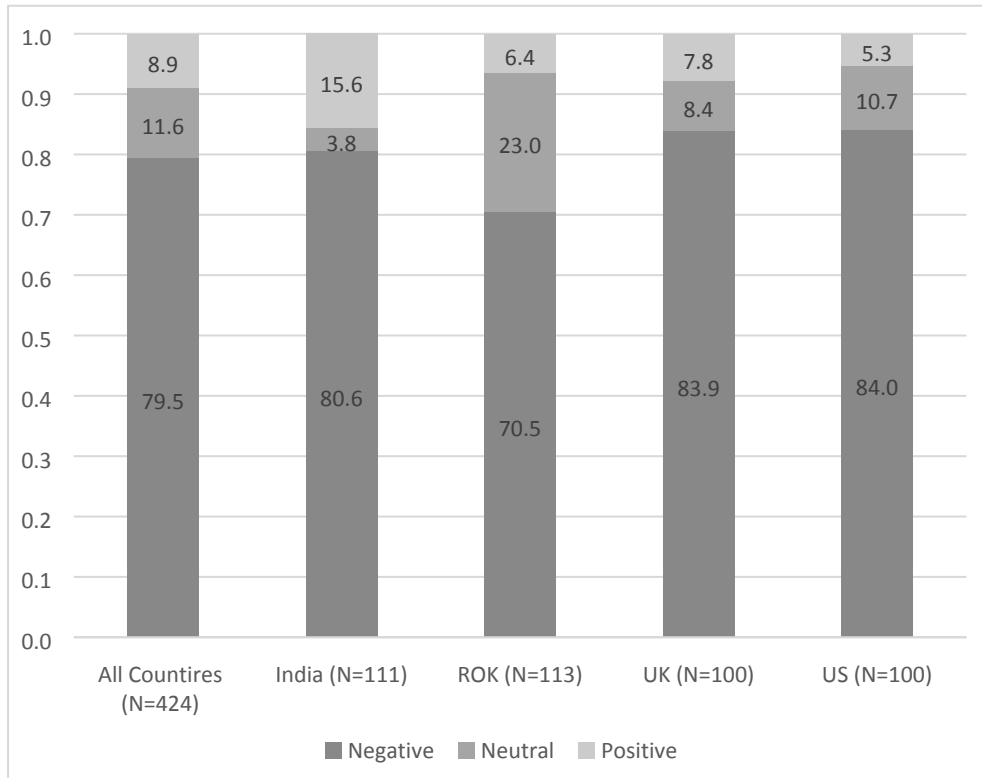


Figure 2: Maximum tree index based on similarities analysis for all countries (n= 424)

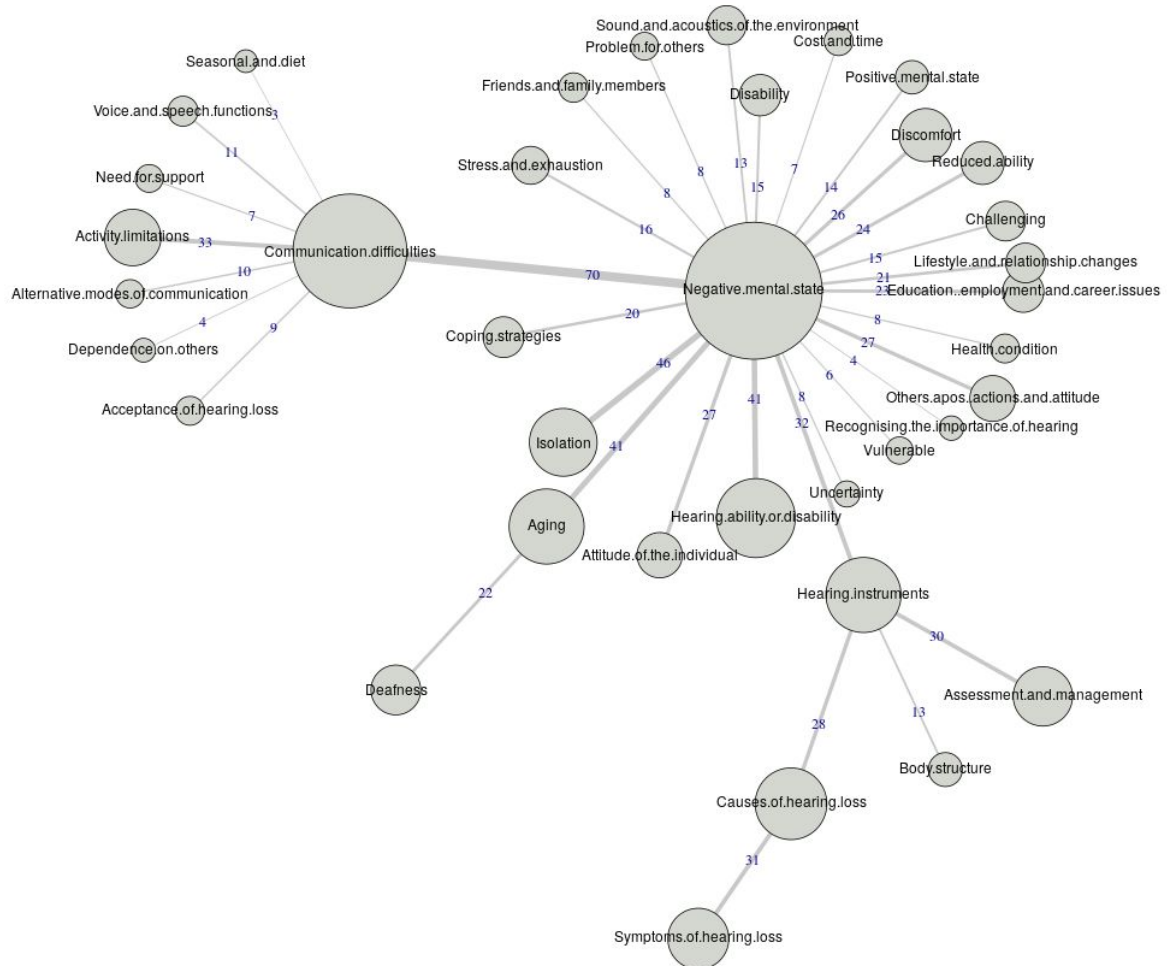


Figure 3: Maximum tree index based on similarities analysis for India (n= 111)

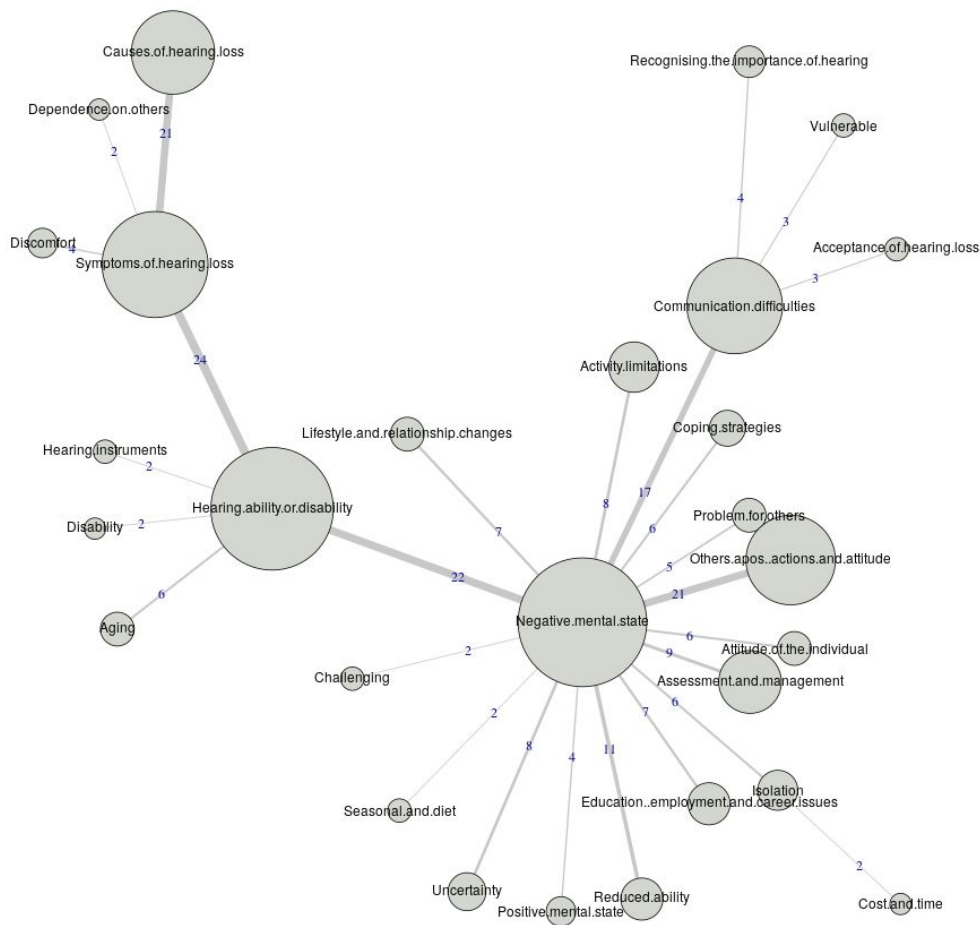


Figure 4: Maximum tree index based on similarities analysis for Republic of Korea (n=113)

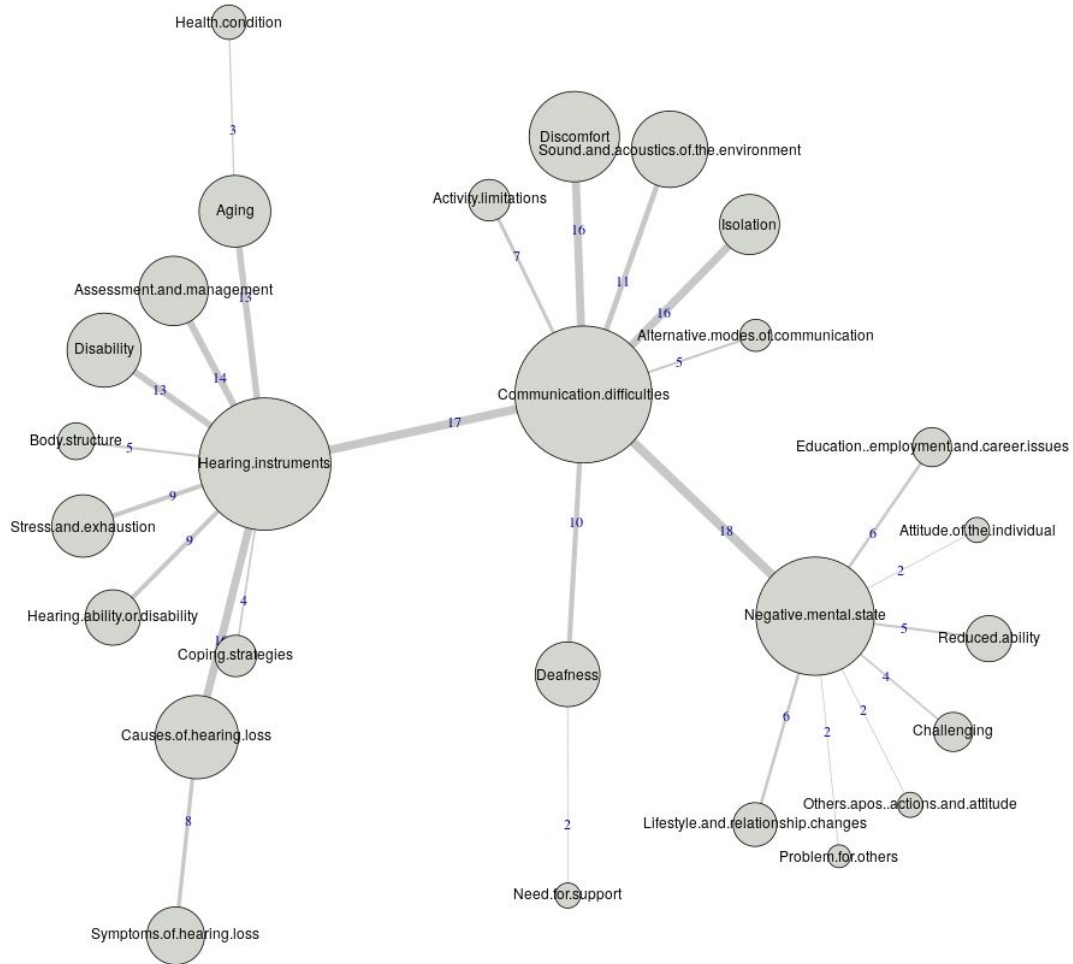


Figure 5: Maximum tree index based on similarities analysis for the United Kingdom (n= 100)

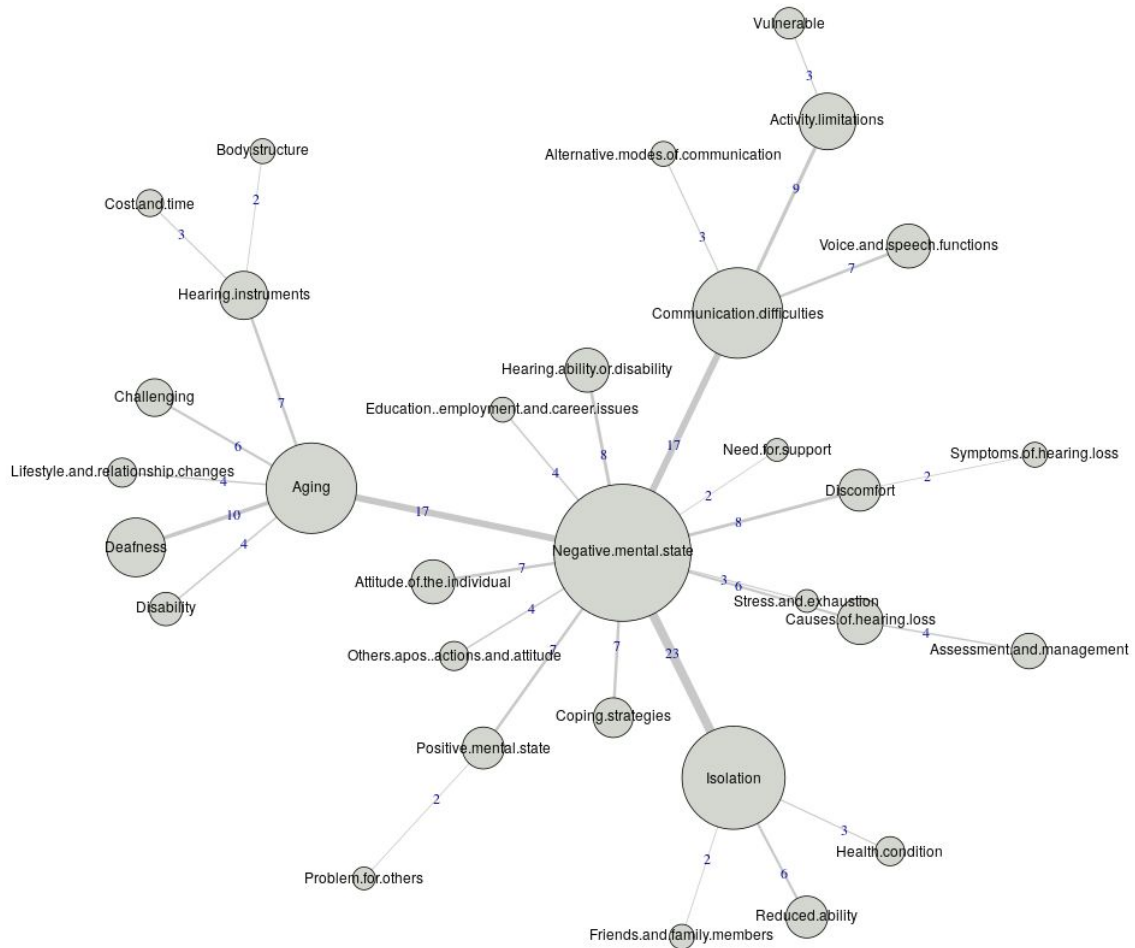
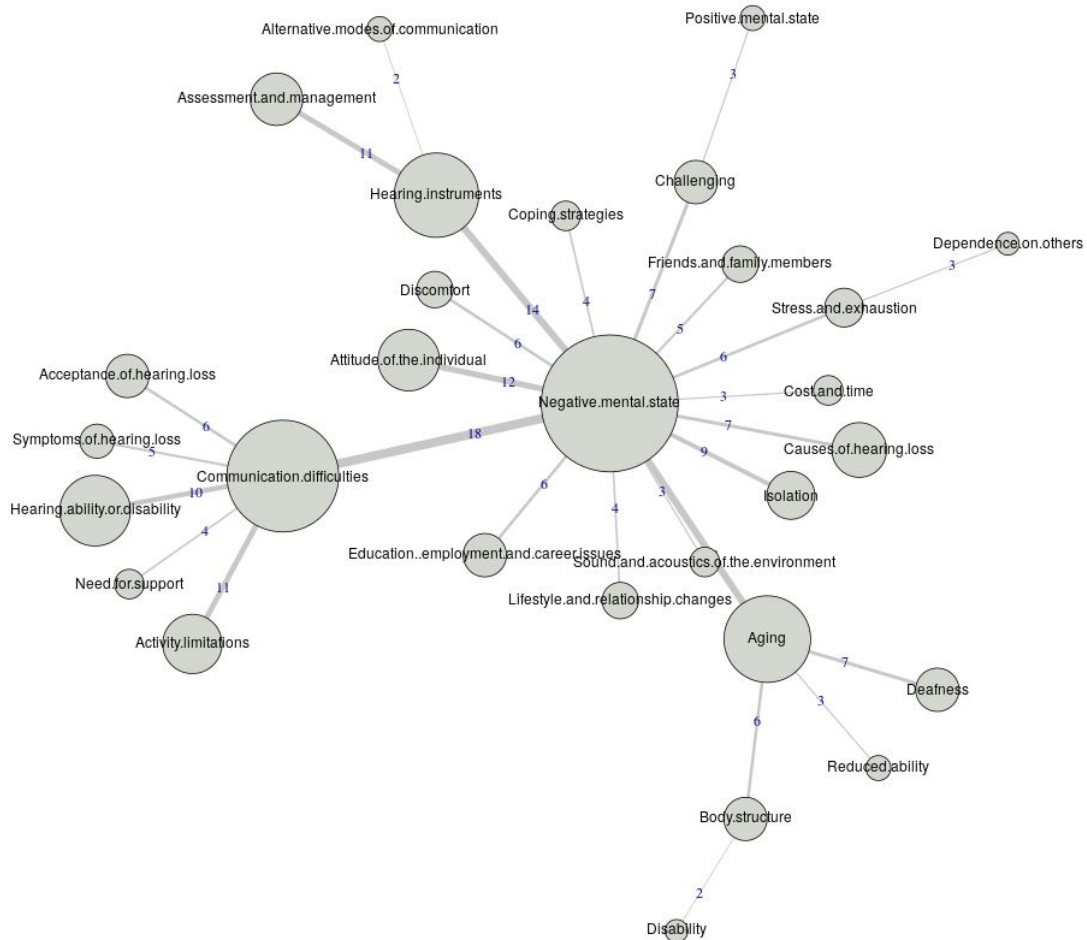


Figure 6: Maximum tree index based on similarities analysis index for the United States (n= 100)



Appendix 1

Social Representation of 'Hearing Loss'

The intention of the study is for you to think of the five words/expressions linked to the topic above, then you decide how important each word/expression is and whether you feel the word has a positive/neutral/negative connotation. Please follow the instructions below.

Instructions

In section one please complete the demographic details.

For the second section, first please think of five words and/or expressions that spontaneously come into your mind when you think 'hearing loss'.

Second, in the "Rank" column please rank the importance of your word/expression by assigning a number (between 1 and 5) against your word/expression. 1 is the most important word/expression and 5 is the least important word/expression and finally,

In the 'Negative – Positive' column, please enter a tick (✓) in the appropriate cell if you feel your word / expressions has a negative or positive connotation associated with it (one tick per word/expression). The "0" cell indicates that the word / expression is neither negative nor positive. The "+" cell has the positive association rating while the "-" cell has the negative association rating.

Section 1: Demographic details

Age:	Gender:
Do you use hearing aids?: Yes/No	Socioeconomic status: Low/Middle/High
Does someone in your family/friends have hearing loss?: Yes/NO	*Education: Primary/Secondary/Tertiary

**Primary - (Class 1-7)/Secondary - (Class 8-10)/Tertiary - Under Graduate/ Graduate /Post Graduate (General)/ Professional (Doctor, Engg, lawyer, etc)*

Section 2: "Hearing Loss"

- *Stage 1:* Under the column words or expression, please write five words or expression that come spontaneously into your mind when you think about the term 'hearing loss'.
- *Stage 2:* Under the column Rank please suggest the order of importance of the words/expressions by tagging "1" as the most important answer down to "5" as the least important.
- *Stage 3:* Please rate the negative/positive association of your word/expression by ticking the appropriate cell (-, 0, +).

Words or expressions	Rank order	(Negative) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> (Positive)		
		-	0	+