

THE LINK BETWEEN HEARING LOSS, DEMENTIA AND MENTAL HEALTH: COMMUNITY CONVERSATION

Wednesday 3 April, 2019

Presented by:



Western Australian Health Translation Network



Prepared by:

DONNA M.P. JAYAKODY

ELIZABETH FOSTER

HANADI TARAWNEH

HADEEL TARAWNEH

BEN HORGAN

REPORT CONTENTS

3 / ACKNOWLEDGEMENTS

4 / WHO IS THE CONSUMER & COMMUNITY HEALTH RESEARCH NETWORK?

5 / WHAT IS A COMMUNITY CONVERSATION?

6 / THE TEAM

7 / ABOUT THE COMMUNITY CONVERSATION

8 / REPORT PREAMBLE

9 / DOTMOCRACY RESULTS

10 / THEME 1 - LIMITED ACCESS TO DEVICES

14 / THEME 2 - EDUCATION

20 / THEME 3 - SUPPORT

24 / THEME 4 - PREVENTION

28 / THEME 5 - RESEARCH

32 / THEME 6 - EVERYDAY LIFE CHALLENGES

36 / DISCUSSION

41 / ATTENDEE FEEDBACK

42 / DO YOU WANT TO KNOW MORE?

WE WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING

We acknowledge the traditional custodians throughout Western Australia and their continuing connection to the land, waters and community. We pay our respects to all members of the Aboriginal communities and their culture and to Elders past and present.

Thank you to all of the consumers and community members who attended the event. We couldn't have done this without any of you.

We'd also like to acknowledge the team from the Ear Science Institute Australia and the Consumer and Community Health Research Network (CCHRN) support team for their hard work in successfully delivering the Community Conversation. Our heartfelt thanks.

WHO IS THE CONSUMER AND COMMUNITY HEALTH RESEARCH NETWORK?

The Consumer and Community Health Research Network (CCHRN) supports consumer and community involvement across the Western Australian Health Translation Network (WAHTN) partner organisations.

CCHRN's Vision is to improve lives by ensuring the community's voice is heard and understood in health research

CCHRN's Mission is enabling consumer and community involvement in health research by supporting and connecting community with researchers, partners and policy makers

In order to achieve CCHRN's Vision we:

- Are inclusive
- Trust, respect, support and value each other and those we work with
- Work as a team
- Are relevant and sustainable so as to make a difference

WHAT IS A COMMUNITY CONVERSATION?

A community conversation is an event using an abridged version of the **World Cafe Method**, known internationally as an easy-to-use format for creating open conversations around questions of importance to a specific topic.

To effectively capture what's discussed around 6-10 community members are grouped at tables with a facilitator who directs the conversation. Specific questions relevant to the subject matter are discussed in an open and friendly environment.

All comments are written on butchers paper and used to develop a report from the conversation.

The benefits of using this method include:

- Everyone having an opportunity to answer all questions
- Community members are encouraged to engage in conversations in a comfortable space
- Having diverse perspectives which are valued and respected
- Community members are encouraged to hear and explore different ideas
- The opportunity to build a foundation of trust among community members and facilitators

WHAT IS A COMMUNITY CONVERSATION?

Sometimes the community conversation method is also used in conjunction with an additional tool known as a **Dotmocracy**

This tool is used to help community members to vote on their chosen options using a limited number of dot stickers. This is a quick and simple method for prioritising a long list of options. Community members are given a set number of stickers and asked to vote by placing the dots next to the answers or ideas they believe are the most important. Community members can spread their stickers across multiple ideas or place all of the stickers against one item.

The options with the most stickers at the end of voting 'win'. This helps the researchers identify the community members priorities relating to the community conversation subject.

THE COMMUNITY CONVERSATION TEAM

Deb Langridge, CCHRN Head: Has worked in the public health and prevention space at all levels of government - Federal, State and Local - and the not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of the community including access and inclusion, Aboriginal and Torres Strait Islander people, Culturally and Linguistically diverse communities, children and young people, mental health and community services. Deb has been the chair of Advisory Groups both in NSW and WA connecting community, government and well-being and was a member of the NSW Commission for Children and Young People's work with the NSW Parliamentary Inquiry on Children and the Built Environment. She was also a representative for WA Local Government on the recent WA Sustainable Health Review.

Dr Dona Jayakody, Lead Researcher: Is the Senior Research Audiologist at Ear Science Australia and also an Adjunct Research Fellow at the University of Western Australia (UWA). She received her PhD in Audiology at the University of Canterbury, Christchurch, New Zealand. Dr Jayakody currently leads a number of research projects including the HearCog trial which investigates the hearing loss treatment of older adults who are at risk of developing dementia. She is also a co-investigator of the West Australian Memory Study and two international research projects currently being carried out in China and Singapore. She is an associate and a review editor for the medical journal Frontiers in Neuroscience.

Thanks also to Ben Horgan, Elizabeth Foster, Hanadi Tarawneh and Hadeel Tarawneh for their support of the community conversation

ABOUT THE LINK BETWEEN HEARING LOSS, DEMENTIA AND MENTAL HEALTH COMMUNITY CONVERSATION

The aim of this event was to allow for an open discussion of views from community members. Community involvement is essential in research as it enables researchers to gain an understanding of some of the issues faced by people in certain communities. The identification of these issues allows for the development of more important research questions and encourages community members to participate in data collection

KEY QUESTIONS DISCUSSED

- What are the major challenges in everyday life for individuals, and their carers, living with hearing loss, dementia and mental health conditions?
- What gaps exist in support or care offered to people with hearing loss and dementia or mental health conditions?
- What research needs to be done to improve the lives of people living with hearing loss and dementia or mental health conditions?





REPORT PREAMBLE

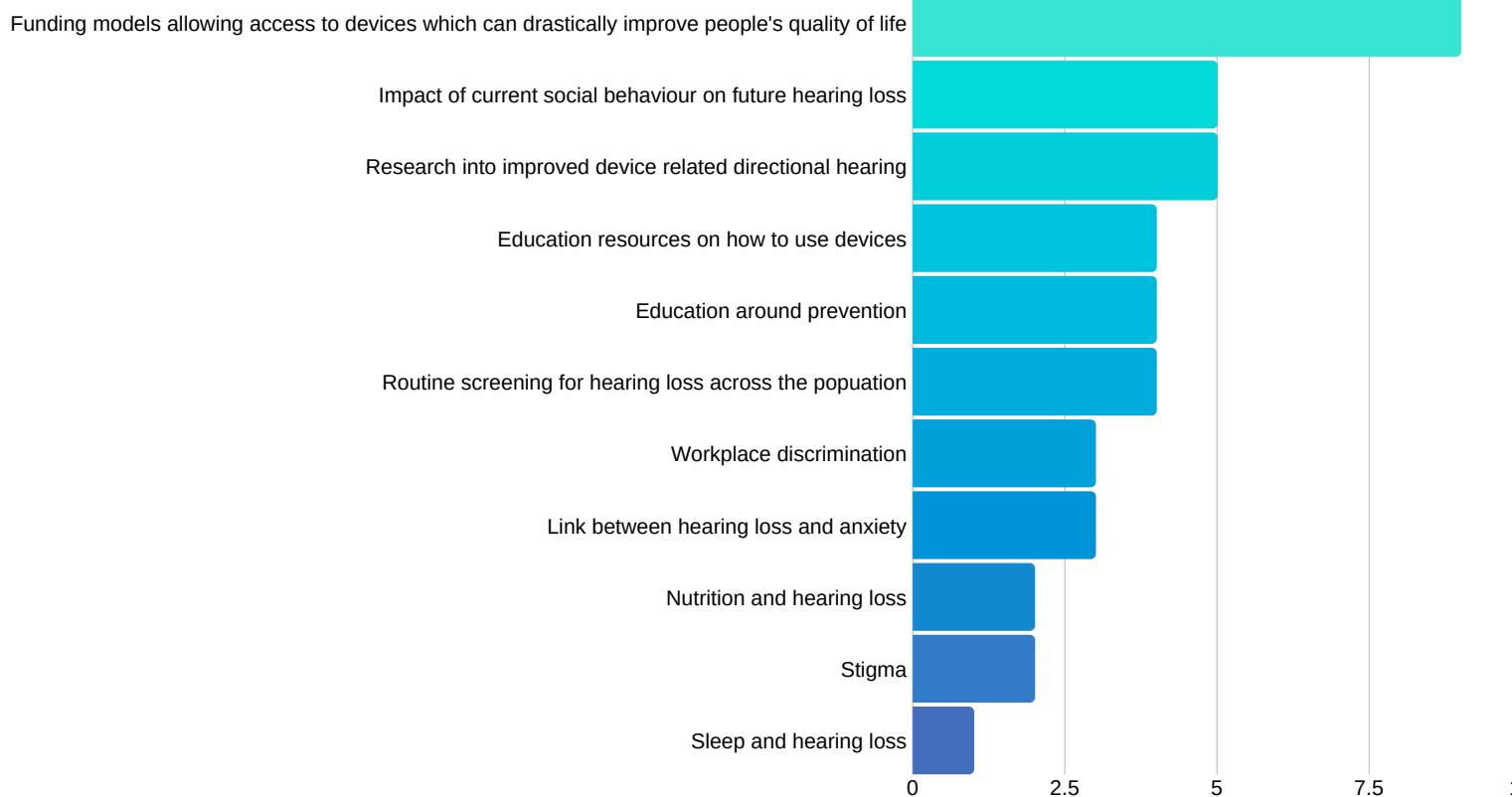
In total 15 consumers and carers attended the discussion. Attendees were divided onto three tables with a Table Facilitator, who was also the scribe. The three key questions were asked during the discussion, with attendees given 20 minutes to discuss the first two questions and 15 minutes for the third question.

After the table feedback, the Table Facilitators worked together to determine the key pieces of research identified across the tables.

Once the key themes were properly identified attendees were given three coloured dots and asked to vote in a "Dotmocracy" process by placing dots next to the research piece(s) they saw being the most important. They could spread their dots across multiple ideas or place their dots all in one place. The results of the Dotmocracy are presented in the following report.

DOTMOCRACY RESULTS

What issues were of a priority to our Participants?



The Dotmocracy results show the research priority areas with the greatest number of votes was to "Develop funding models allowing access to devices which can drastically improve people's quality of life" followed by the "Impact of current social behaviour on future hearing loss" and "Research into improved device related directional hearing".

The Community Conversation event revealed six major themes, including access to devices, education, support, prevention, research and everyday life challenges. These themes frequently appeared when participants were answering each of the three Conversation questions and were also shown in the Dotmocracy results. As the data is qualitative, the presentation of these results are descriptive.

THEME 1

Limited access to devices

DEVELOP FUNDING MODELS ALLOWING ACCESS TO DEVICES WHICH CAN DRASTICALLY IMPROVE PEOPLE'S QUALITY OF LIFE

The most common theme to emerge was the need for funding models to allow people access to devices which can drastically improve their quality of life. Attendees also identified the following:

- Cost of hearing aids and auditory care is not supported by federal or state governments or other organisations
- Cochlear Implants are the only funded device
- Private health costs and limitations
- Costs of maintaining devices (as devices need replacing every few years)
- How to manage the costs of devices when on a pension



DEVELOP FUNDING MODELS ALLOWING ACCESS TO DEVICES WHICH CAN DRASTICALLY IMPROVE PEOPLE'S QUALITY OF LIFE

The cost of hearing aids and auditory care was a major problem for people with hearing loss, as there is little to no support from organisations for people who require financial aid for treating their hearing loss. Cochlear Implants are funded by the government or health-care providers, however hearing aids are not. Attendees implied the it's not necessary to get help for your hearing loss until it gets to the point where a Cochlear Implant is needed. Attendees were worried about the flow on effect the above can have on the mental health and quality of life of hearing affected individuals.

Other attendees raised that private health insurance can help with hearing aid costs, however there are very strict and limited criteria which you must fit before being able to receive aid and it can be very expensive, especially for people on a pension. The cost of maintaining hearing devices was considered an ongoing issue, with devices needing replacement every few years

A number of attendees also felt the prohibitive costs of hearing devices are causing people to opt for cheaper options, which are often of poor quality and a less appropriate treatment option, which can impact people's mental health and quality of life.

DEVELOP FUNDING MODELS ALLOWING ACCESS TO DEVICES WHICH CAN DRASTICALLY IMPROVE PEOPLE'S QUALITY OF LIFE

Access to care

There is high demand on the Ear Science Institute Australian staff and attendees felt if they're not proactive they can fall through the gaps in the system.

Attendees mentioned there's a massive difference between knowledge in Audiologists and would like a publicly accessible list of trusted hearing loss professionals to be developed so there's a clear pathway for clinicians and patients. Attendees also felt that access to specialist help and other facilities plays a role in how well you're able to get help so, therefore, facilities need to be more accessible and more direct.

A lack of access for hearing loss affected people in rural areas and unmanageable travel distances to access services was also mentioned as something which needs improvement.



THEME 2

Education

EDUCATION

There were four sub themes in this grouping:

- Education resources on how to use devices
- Education in the wider community
- Education of health professionals
- Education of carers



EDUCATION

Education resources on how to use devices

Attendees felt they're not taught how to use implants and devices properly, impacting on their use of the device. Cochlear Implants need constant adjusting and attendees said they find it difficult to learn how to use the device and know if the device is actually working properly.

The challenge of learning to hear with an implant was also mentioned with the suggestion of home services being ideal as the user would be able to be in their own environment and use their own computer without the feeling of "am I doing this right?"

Attendees also said hearing aids are tougher for older people who aren't familiar with modern technology so there needs to be more training and support for them on how to use the device correctly. It was agreed there needs to be more emphasis on the rehabilitation aspects of hearing loss management as education and support around problems associated with hearing loss are very limited for both carers and patients.

EDUCATION

Education in the wider community

A major concern amongst attendees was the lack of awareness of hearing loss amongst the community, healthcare professionals, and employees. Attendees felt as though there's a need for more information on hearing loss in the wider community as their hearing loss is not being taken seriously as it's not seen as an impactful disability.

Some suggested the creation of software or a virtual reality experience which can give the wider community an understanding of what it's like to live with hearing loss.

Attendees also mentioned there needs to be wider community education on how to communicate with people with hearing loss as there's a sense of frustration from hearing enabled people when trying to communicate with people affected by hearing loss.



EDUCATION

Education of health professionals

Attendees felt there's a lack of "industry knowledge" and it was agreed healthcare professionals seem to have no clear line of action when it comes to two things:

- Diagnosing symptoms
- Direction to take to manage symptoms (pre and post diagnosis)

Attendees also felt that it can take "some time" before their symptoms are taken seriously by health care professionals. Some attendees said they were told that it's not "that bad" and to "just live with it".

Some attendees have a lack of trust in the product and healthcare providers, as they felt they're oversold on products and asked to buy things they don't need. This also ties into patients needing more education on why they need certain products, and how to use them.

EDUCATION

Education of carers

A number of attendees thought the education given to carers is lacking and there's no support for people looking after loved ones with hearing impairment.

Attendees want carers to be careful not to take over as this can have a big effect on the person with hearing loss and dementia. Attendees mentioned that getting special treatment is not always a good thing, as it can actually lead to you feeling inferior, and can cause frustration.

THEME 3

Support

SUPPORT

Hearing loss

Attendees raised the point they find older people tend to struggle more with managing their hearing loss disability than younger people. They feel older people get more socially withdrawn whereas younger people would still like to participate in social events.

Attendees emphasised there's a need for more support from government services, health professionals, and the wider community, especially for older people who find it harder to manage their hearing loss. They feel more information is needed after the diagnosis of hearing loss from a specialist as there's no documentation available for the processes around education and support for hearing loss affected individuals.

A number of attendees mentioned hearing loss is not supported under the National Disability Insurance Scheme (NDIS), something which could potentially support them and help them maintain their independence.



SUPPORT

Mental health

Attendees discussed the trauma when first diagnosed with hearing loss and some people will ignore their hearing loss until they can't cope anymore. Attendees said they feel embarrassed by their hearing loss and it affects their self-esteem as it impacts their ability to communicate and they often don't have the confidence to speak up if they don't understand something.

Other issues identified:

- Long waiting lists for Cochlear Implants (18 months)
- Lack of support for maintaining good mental health
- Lacking the correct definitions to qualify for mental health support, and rehabilitation groups
- Other support services are very limited

All of the above issues have a flow on effects on the person's health such as depression, and the worsening of dementia. It was also mentioned hearing loss can be stressful and this can lead to cognitive impairment.

SUPPORT

Dementia

Attendees spoke about how dementia affects all aspects of life and there's a shock when diagnosed, with patients often left thinking, "why was I diagnosed with dementia?"

It was agreed there are positives and negatives of being diagnosed; a diagnosis can be helpful to be aware of why things are happening and it can cause you to live in the moment, but attendees still have concerns around the care they'll receive in the later stages of dementia, especially for their hearing loss.



THEME 4

Prevention

PREVENTION

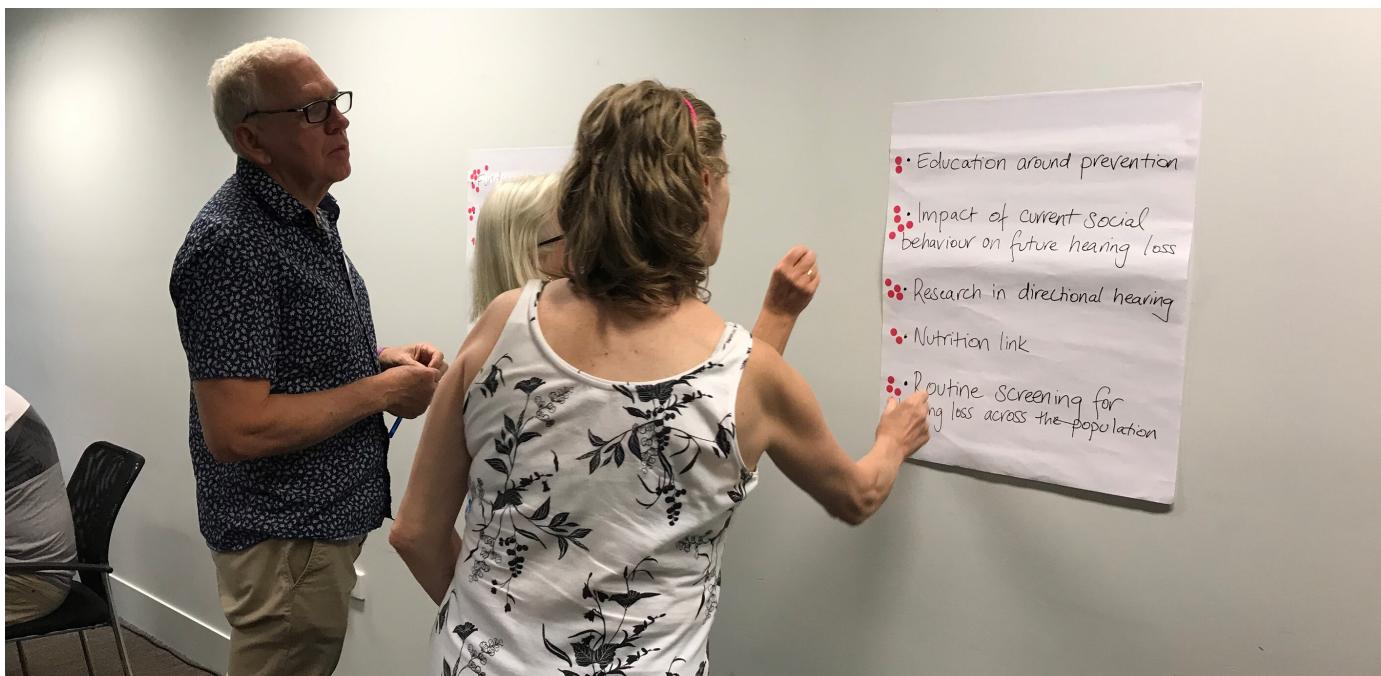
Impact of current social behaviour on future hearing loss

Attendees expressed their concern about young people and their hearing as they often listen to very loud music. They feel as though young people aren't fully aware of the consequences of hearing loss, for example, for people with hearing loss entertainment becomes another aspect of daily living which is difficult as they can no longer go to the theatre or movies. For this reason, attendees think health promotion campaigns targeted towards young generations would help to increase knowledge and understanding about the consequences of hearing loss.

PREVENTION

Education around prevention

Attendees mentioned there's often a delay in seeking help; either the person doesn't realise they have a problem, they're too stubborn or in denial, or they're not ready to deal with a diagnosis or treatment yet. They feel there needs to be more education around the importance of early diagnosis and prevention.



PREVENTION

Routine screening for hearing loss across the population

Attendees believe there should be more comprehensive hearing tests and routine screening for hearing loss in the general population across the lifespan for early detection. Routine screening for cognitive function in people with hearing loss was also seen as something which would be beneficial.

THEME 5

Research

RESEARCH

Research on prevention

Attendees addressed the need for more research on hearing loss prevention and they believe researching the causes of hearing loss is more important than the treatment. It was suggested there should be longitudinal studies which look at every aspect of life (diet, education, financial status, family dynamic etc.) to investigate how these aspects may be connected to hearing loss and / or dementia. Another attendee mentioned it would be interesting to look at the impact of congenitally hearing impairment vs post-lingually hearing impairment and if this has an effect on dementia.

Attendees believe hearing loss, mental health and dementia should be further researched to establish firm links between them as well as the incidence of hearing vs hearing loss in people with dementia.

Attendees wanted to know more about what could possibly cause or worsen hearing loss or dementia such as a connection with anaesthesia, medication, chemicals in the environment, sleep apnoea, the sound of water or glue ear. Another attendee wanted to know if industrial hearing impairment worsens after you retire.

RESEARCH

Research into improved device related directional hearing

Attendees agreed when there's background noise it becomes really hard for them to do everyday things. For example, when they go out shopping and the shopping centre has music playing, they find it harder to hear and understand the shopkeeper, causing them to feel as though they don't want to go out and do things which otherwise are necessary.

Attendees think if devices had improved directional hearing it would help them in these types of situations.



RESEARCH

Nutrition and hearing loss

It was mentioned it might be interesting to look at the role of diet / nutrition and the connection it has to hearing loss, dementia or mental health.

Tinnitus

Attendees think there should be more research on how to better manage and treat tinnitus, and to apply a method to alleviate the symptoms which can be used in any setting or during any daily task.



THEME 6

Everyday life challenges

EVERYDAY LIFE CHALLENGES

Everyday life

Attendees agreed what challenged them the most in everyday life was their inability to communicate efficiently. For example, they found it was hard for them to continually ask people to repeat themselves when they couldn't hear them. This caused the attendees to feel high levels of embarrassment, low self-esteem and the feeling of "inability to function."

Attendees think there's an underestimation of the effects of hearing loss when in reality you need hearing to participate fully in life. Attendees discussed how simply just the background noise in shopping centres can be disruptive and one attendee mentioned having to do grocery shopping for their friend as they cannot cope with shopping centres.

Attendees feel entertainment is another aspect of daily living which is difficult with hearing loss and they would like there to be a higher requirement for TV channels to have subtitles and other aids in order to help people with hearing loss because they "also want to be entertained."

Those with bone anchored hearing aids also discussed the challenges of everyday life involved with the device as they need a card to get through airports, they have issues with having MRI's and they're unable to be cremated due to the device exploding

EVERYDAY LIFE CHALLENGES

Workplace discrimination

A number of attendees addressed the need for better employer support to cater for the needs of staff members with hearing loss. One attendee mentioned she's a nurse with significant hearing loss and is unable to work in the birthing suite as she can only hear when facing the person speaking to her, but is continuously rostered to work in that area.

Other attendees experience misunderstandings around what is being said and have a fear of answering someone incorrectly, affecting their confidence and impacting their ability to work efficiently with others.

Attendees say job opportunities are limited due to hearing loss and getting a job can be difficult as hearing plays a big role in how well you can do a job. Attendees also mentioned "when deciding which job to apply for, there is a need to think about how having hearing loss will impact your ability to do the duties which are associated with that job."

EVERYDAY LIFE CHALLENGES

Link between hearing loss and anxiety

Attendees mentioned it's challenging to leave the house as they're afraid and suffer anxiety when in unfamiliar environments, often leading to withdrawal and this behaviour becoming a cycle. The importance of routines was raised as a method to give a sense of safety as high levels of anxiety occur in "new situations."

Stigma

Attendees felt that there's a stigma around hearing loss and people are labelled as a "condition" rather than as a whole person. It was also mentioned people with hearing loss are treated differently and are often branded "a dope." Attendees say these negative experiences can drive isolation and further affect the person's mental health and quality of life.

This issue was also mentioned when discussing the need for education about hearing loss in the wider community and that people need to be educated on how to communicate with hearing affected people.

Sleep and hearing loss

One attendee mentioned working hard to hear all the time is tiring and that a good sleep is very important.

DISCUSSION

DISCUSSION

The most common theme during the Community Conversation was limited access to devices due to cost. Attendees felt as though the support for the cost of hearing aids was lacking, forcing many to opt for cheaper devices, which are poor quality, impacting their mental health and quality of life.

The development of funding models allowing access to devices which can drastically improve people's quality of life was seen as a necessity as it would allow people to afford hearing aid options which properly suited their needs.

Many attendees complained of problems with the directional hearing of their device, with them frequently struggling to hear when there's background noise. The Community Conversation suggests attendees often try to avoid loud environments so they're limited on where they can go and this leads to isolation. It was also mentioned they suffer anxiety when in unfamiliar environments, impacting their self-esteem and causing them to become introverted.

As many people are forced onto cheaper devices of poorer quality due to cost, their hearing needs are not always met. As some devices having better directional hearing settings than others. The development of funding models allowing access to devices along with increased research into improved device related directional hearing would help solve these issues and improve quality of life.

DISCUSSION

The Community Conversation results also showed attendees feel they're not taught how to use their device properly, leaving many wondering if they are using it correctly. The lack of education and support seems to be a problem particularly for older adults who lack the confidence to learn the technology with hearing aids, putting them off wearing them, or using them at all.

Those with Cochlear Implants appeared to have the most trouble with learning how to adjust the device, and use it in their own home environment, with home visits being suggested as beneficial.

Attendees also want more emphasis on the rehabilitation aspect of hearing loss, as they find it challenging to learn and train themselves how to hear with an implant.

There's a lack of support for the maintenance of good mental health and the definitions to qualify for mental health support, rehabilitation groups and other support services is very limited. This causes concern about the flow on effects such as depression, and the worsening of dementia for people who are waiting 18 months for a Cochlear Implant or are struggling with the device after implantation.

Education, especially in the wider community, was thought of as necessary for improving how people with hearing loss are treated within the community. The Community Conversation shows hearing loss causes people to feel high levels of embarrassment and low self-esteem, which is often worsened by others treating them differently.

DISCUSSION

There's a need to educate the wider community on how to communicate properly with people with hearing loss as attendees felt there's a sense of frustration from hearing enabled people when trying to communicate with them. In contrast, attendees also felt too much care and special treatment had similar effects on how they felt, as it can lead to feeling inferior, making them frustrated.

By increasing education and awareness of hearing loss in the wider community the stigma associated with hearing loss can be reduced and people with hearing impaired will feel more accepted within the community, improving quality of life and overall self-esteem.

The Community Conversation also demonstrated people who are hearing impaired feel their hearing loss is not taken seriously by the community, healthcare professionals, and employers. Attendees think that people need to be educated about the impact of hearing loss. This can be seen through healthcare professionals telling them it's not "that bad" and to "just live with it", which can impact how the rest of the community views hearing loss.

To reduce this, there needs to be a clear path of action developed when it comes to two main things:

- Diagnosing symptoms
- Direction to manage symptoms (pre and post diagnosis)

The underestimation of the effects of hearing loss on someone's quality of life can also be seen in the workplace. Many attendees highlighted the difficulties of working with a hearing impairment and feel employers need to be better educated on how hearing loss can affect someone's ability to work.

DISCUSSION

Attendees experience fears around misunderstandings as they don't want to keep asking people to repeat themselves but also don't want to answer incorrectly and appear to be incompetent. This highlights the importance of more support in the workplaces for those with hearing loss so they don't feel the pressure of being expected to cope and adapt in situations where it isn't possible.

There were also concerns regarding young people listening to loud music as attendees feel young people aren't fully aware of the consequences of hearing loss. The Community Conversation showed attendees placed high importance on the development of more health promotion campaigns targeted towards younger generations to increase knowledge and understanding of hearing loss.

More research on the causes of hearing loss and the possible prevention methods was considered more important than research on treatments. Attendees suggested longitudinal studies which look at every aspect of life (diet, education, financial status, family dynamic etc) to investigate how these aspects may be connected to hearing loss and / or dementia.



ATTENDEE FEEDBACK

Overall attendee feedback tended to be positive about how useful, informative and participative the Community Conversation was. A small number of people indicated a low level of satisfaction around how useful the event was and some indicated that others talked too much during the event.

The variety of people, views, and diversity of opinions were all seen as healthy and positive overall. The educational presentations and hearing the diversity of opinions and ideas were also seen as the best things about the event. Attendees rated having all of their questions answered and being able to put forward their ideas as very high.

Other points of feedback included thanking the researchers for caring about the community voice in their research, and hearing the stories of other attendees - a community feeling within the Community Conversation. The Dotmocracy function was also pointed out to be a great visual tool.

The areas the Community Conversation could be improved is similar to feedback we've had from similar sessions - pre-reading would be appreciated, the session being longer, with more time on the questions, and including a younger generation of people for their views.

Overall the attendee feedback was positive and it's good to see each time we engage with a specific community group that a Community Conversation continues to be a worthwhile and impactful event which resonates with the attendees.

DO YOU WANT TO KNOW MORE?

Visit the Consumer and Community Health Research Network at

<https://www.involvingpeopleinresearch.org.au>

Where you can find us on social media:



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