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Severe hearing loss as a disability: how to ensure equal access to optimal treatment

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Declaration of Interest

Patrick D'Haese is an employee of MED-EL GmbH, Innsbruck, Austria. Prof. Van de Heyning receives grants to the institution from MED-EL and Cochlear.

Abstract

With 25% of people experiencing disabling hearing loss by the age of 70, Europe cannot afford to ignore what this would mean for its ageing population. Untreated hearing loss could result in an annual cost of 213 billion euros to Europe's economies. In addition to depriving an individual of a sense, hearing loss adversely affects the mental health, cognitive functioning, mortality and employment of an individual, while also being linked with comorbidities such as stroke, diabetes and dementia. Although cochlear implants (CIs) are recognised as cost-effective solutions for adults and children with severe to profound hearing loss, less than 10% of adults who could benefit receive a CI. Additionally, the provision varies hugely across Europe and around the world. CIs could potentially have an enormous impact on quality of life as well as providing long term savings to national health systems. However, referral guidelines for CIs across European member states lack consistency and clear referral pathways and guidelines need to be developed. The sharing of best practice and strategies for the prevention, screening, diagnosis and treatment of severe hearing loss with innovative solutions, such as cochlear implants, have the potential to maximise hearing health for all European citizens.

Key Words: access, cochlear implant, uptake, severe hearing loss, disability

Introduction

Disabling hearing loss as defined by the World Health Organisation (WHO), affects 6% of the world's population, with the majority of this group being adults over the age of 65 (WHO, 2013). This represents a staggering number of people of more than 80 million over 65 and, as we know that the prevalence of hearing impairment increases with age, it is only set to grow as the population ages. Currently within Europe, 20% of women and 30% of men have some degree of hearing loss by the age of 70 (Roth, Hanebuth, & Probst, 2011).

The full extent of how hearing loss affects an individual's well-being and quality of life should not be underestimated. It adversely affects an individual's overall health, mental health, cognitive functioning, mortality social life and employment (Archbold, Lamb, O'Neill, & Atkins, 2014). It is linked with many comorbidities including stroke, diabetes, increased mortality, and dementia (Claes, Van de Heyning, Gilles, Hofkens-Van den Brandt, et al., 2018; Claes, Van de Heyning, Gilles, Van Rompaey, & Mertens, 2018; Feeny et al., 2012; Gopinath, Schneider, Rochtchina, Leeder, & Mitchell, 2009; Lin et al., 2011; Mitchell et al., 2009). Those with severe hearing loss also have higher unemployment rates and often suffer from social isolation and depression ((Kochkin, 2010; B Shield, 2018). The number of people affected and the severity of the health consequences of hearing loss are reflected in the World Health Organisation's (WHO) assessment of global disease burden reports, which consistently place hearing loss in the top 10 disease burdens for high income countries, above diabetes, , osteoarthritis and chronic obstructive pulmonary disease (COPD)(GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, 2018). .

If left unaddressed, the impact of untreated hearing loss on lost productivity due to unemployment or early retirement and increased healthcare and social care service use could

cost Europe's economies as much as 213 billion euros, at a time when budgets are already strained to the maximum extent (Roth et al., 2011; B. Shield, 2006; World Health Organisation, 2013). There is considerable variation in hearing device access across Europe, uptake rates vary by country and ensuring equal access to treatment is becoming ever more important. Addressing the inequalities in hearing healthcare that exist across EU member states must be a priority for the future.

Hearing loss treatment

For most people with hearing loss, the severity is mild to moderate and can be addressed successfully with well fitted hearing aids (Stevens et al., 2013). However, for those with more severe loss, a hearing aid sometimes does not provide sufficient benefit due to the processing limitations of both the hearing aid and hearing pathway. A hearing aid works by delivering amplified sound to the ear, but this sound must still be processed by the inner ear, which not only loses its sensitivity to sound but also its ability to filter it. A cochlear implant (CI) bypasses the middle ear and damaged inner ear hair cells by providing electrical stimulation directly to the hearing nerve via an electrode array, which is surgically inserted into the cochlea. The acoustic input received by the speech processor microphone is changed into a series of electrical pulses which are delivered as electrical stimulation to the nerve via the electrode array. For those who do not get sufficient benefit from a hearing aid, a CI offers improved sound detection and better speech perception for the majority of patients (Gifford, Dorman, Shallop, & Sydlowki, 2010). It is recognised as a cost-effective solution for adults and children with severe to profound hearing loss (Bond et al., 2010).

Hearing loss is the number one cause of years lost to disability in the over 70s age group, with 7% of these cases being severe or profound loss (Davis, 1995). However, uptake rates

for hearing aids and cochlear implants are surprisingly low. The average European uptake rate for hearing aids is 59% for people who are referred for hearing care, but within this there is considerable variation across countries (Laureyns, Best, Bisgaard, & Hougaard, 2016). When considering self-reported hearing loss, this falls even further to 30% (Laureyns, Best, Bisgaard, & Hougaard, 2016). For CIs the global uptake rate is less than 10% for adults with severe to profound loss and as low as 50% for children in some countries and also varies hugely across Europe (Sorkin & Buchman, 2016). Europe faces huge challenges in managing untreated hearing loss in its aging population and appropriate referral for CIs can play a key role in providing necessary solutions (D'Haese, 2016; D'Haese et al., 2019).

The Current Situation

There is currently a lack of reliable epidemiological studies in the field of hearing loss, especially for the severe to profound range. Specifically, the prevalence of severe or greater hearing loss is not well documented (Rapport et al., 2018; Stevens et al., 2013). Data from studies reporting the number of people who are seeking help for their hearing loss provides some confidence but this still makes it difficult to be sure that estimates of CI uptake rates are accurate for the situation today (Rapport et al., 2018).

One of the most comprehensive studies to date was conducted by Davis (1995), estimating that the prevalence lies around 4,000 people in a million who would have a profound hearing loss, although numbers of those with profound hearing loss in their sample were small. None the less, this provides a conservative estimate of the numbers per million who have a hearing loss well within the criteria to benefit from a cochlear implant.

However, the highest rates of implantation in Europe are only 300 implanted persons per million of population for Germany and Austria, falling to less than 150 per million in Italy and France (De Raeve & Van Hardeveldt, 2014).

Current access varies significantly both globally and across EU member states. The data from the EURO-CI users group reported by De Raeve and Van Hardeveldt (2014) demonstrates the considerable variation in the number of people receiving a CI within Europe and highlights the huge disparity between those who could benefit from a CI and those who are getting implanted and fitted. Western European nations implant about 200 people per million (children and adults), out of the estimated 300 people per million who would benefit, whilst in Eastern Europe only 50-75 per million (children and adults) are performed. Data is available for CI uptake rates in Belgium (6.6%), Netherlands (8.4%) and the UK (5%) (L. De Raeve, 2016; L De Raeve & Van Hardeveldt, 2014; Raine, 2013). Poor adult uptake of CIs derives from lack of referrals for CI assessment and seems to be independent from how healthcare is funded and even in the insurance-based system of the USA, estimated uptake rates in adults is only around 8% (Holder, Reynolds, Sunderhaus, & Gifford, 2018). The picture for hearing aids is better, but similar variations exist across Europe. For example, Spain has 2.8 hearing aids per 1,000 of the population, while Denmark has 22.4 per 1,000 (Lamb, 2016). Despite efforts of many professionals to improve awareness, there is little evidence that rates of implantation for adults have changed over the past few years or that the situation is improving (L. De Raeve, Archbold, Lehnhardt-Gorjany, & Kemp, 2020).

The situation is more consistent across Europe for children than adults with one implant per 1,000 new-borns and uptake rates between 80 and 90 % (L. De Raeve et al., 2020). This is due in some parts to the widespread use of neonatal screening programs in most European countries. These programs are conducted at or within a few weeks of birth and ensure prompt

referral for hearing aids or CI assessments for those with hearing loss. However, variation in uptake of CIs still exists both across countries and within regions. In Belgium the country wide rate of implantation is 78%, but in Flanders it is 90-94%, implying lower rates in other regions in the country (L. De Raeve, 2016). Even in the USA overall utilization is only 50%, but reaches as high as 86% in some states (Sorkin & Buchman, 2016).

So, what can be done?

What are the barriers to achieving equal access to cochlear implants across the EU? The answer is complex and varied. Comprehensive descriptions are given for the USA, UK and Australia and include issues such as lack of awareness, funding, social and racial barriers and fears and concerns over surgery (Bierbaum et al., 2020; Rapport et al., 2020; Sorkin, 2013; Tampio, Schroeder Ii, Wang, Boyle, & Nicholas, 2018). Hearing aid uptake in the severely to profoundly deaf is relatively high, raising the question; why are not more qualifying individuals receiving CI's (Shield, 2018)? General awareness of CIs in the population and even amongst hearing healthcare professionals is poor and referral networks are not effective (D'Haese et al, 2019; D'Haese et al, 2018; D'Haese et al, 2020). Poor awareness among primary healthcare physicians has been highlighted as a contributing factor to the under identification of potential CI candidates in both the US and Europe (Mahboubi, Lin, & Bhattacharyya, 2017). This partly results from a lack of a standard of care with no widely accepted clinical guidelines across Europe and globally. Clinicians report that confusion commonly arises on who is a candidate for CIs and what the benefits are (Mahboubi, Lin, & Bhattacharyya, 2017).

Referral guidelines across European member states vary dramatically (Vickers, De Raeve, & Graham, 2016). Considering that the benefits of cochlear implantation do not vary by nationality, there must be other drivers for this variation. Hearing function is measured with an unaided pure tone audiogram (PTA) and ideally with a test of speech recognition with well fit hearing aids. Criteria for treatment with a CI are usually based on a combination of the results from these two tests. However, in Germany and Austria there are no defined criteria for adults and the decision is made by the implanting surgeon. In other countries the degree of hearing loss and speech test scores required are fixed (Table 1). In Germany and Italy, teams have flexibility in deciding if an individual who falls outside the defined criteria may benefit, whereas in other countries criteria are far more strict. Issues of heterogeneity across Europe exist due to different languages and linguistic structures, meaning that percentages across tests cannot be compared. However, testing levels, which also vary across country, could be fixed at an agreed conversational level. Large discrepancies in the provision of CIs are also apparent with bilateral implants for adults not funded in some EU states, but available in others while single sided profound deafness is only funded in Germany, Austria and Italy.

Country	Pure tone threshold	Aided speech reception (quiet, unless stated)
Austria	No specific tests ≥65 dB HL bilaterally	Presentation level: 65 dBHL Monosyllabic: ≤50% Adults; ≤40% Paediatric (word appropriate)

Belgium	<p>≥ 70 dB HL in better ear</p> <p>in at least 3 out of 4 frequencies (0.5, 1.0, 2.0 and 4.0 kHz)</p>	Phoneme score $\leq 50\%$ at 70 dB SPL (unaided)
Finland	<p>Pure tone average >75 dBHL unaided, aided 4 kHz >45 dBHL</p>	<p>Bisyllables $<70\%$ at 65-75 dB SPL</p> <p>Sentences in noise > -1 dB SNR at 65 dB SPL</p>
France	<p>No specific tests as there are no pure tone thresholds criteria defined in France</p>	<p>Presentation level: 60 dB SPL</p> <p>Adults; Bisyllabic (Fournier list) score $\leq 50\%$</p> <p>Children same score $\leq 50\%$ (word appropriate)</p>
Germany	<p>Pure tone average ≥ 70 dBHL unaided</p>	<p>Presentation level: 65 dBHL</p> <p>Sentence score in noise: $\leq 60\%$</p>
Italy	<p>80 – 90 dBHL</p>	<p>$\leq 50\%$ bisyllables.</p> <p>For sloping loss $<20\%$ bisyllables at SNR +10</p>
Netherlands	<p>> 80 dB HL on the better ear</p>	<p>Presentation level: 65 dBHL</p> <p>Monosyllabic score in quiet: $\leq 50\%$</p>
Portugal	<p>Severe to profound loss</p>	<p>None</p>
Spain	<p>No specific tests</p>	<p>Presentation level: 65 dBHL</p> <p>Monosyllabic score in quiet: $\leq 50\%$</p> <p>Bisyllabic (Disyllabic) score in quiet: $\leq 50\%$</p>

Ensuring equal access to CI's needs to begin with agreeing on a set of clear guidelines for implantation within the different member states of the EU. This approach is being explored by clinical groups such as the HEARRING Network. There is an argument that the use of any fixed speech perception based criteria, measured in an artificial setting, may lead to inequalities as these measures are not a reliable way to evaluate cochlear function (Govaerts, 2016).

The introduction of National Adult Hearing Screening Programmes would raise awareness of hearing loss and encourage people to take early action rather than waiting a number of years before seeking help (Lamb & Archbold, 2016; Laureyns et al., 2016). However, while adult hearing screening is recommended in the USA, current evidence is inadequate to assess the benefits of screening in an asymptomatic population (Chou, Dana, Bougatsos, Fleming, & Beil, 2011). Targeted programs of screening tend to focus on those with existing long-term conditions known to be associated with hearing loss who are already accessing clinical services. It's worth considering that if we have our eyes routinely checked, why wouldn't we encourage the same routine for our hearing? Even if adult hearing screening was in place, there is a need for clear referral pathways including hearing aids to CIs for those in need, in addition to accurate information within medical and audiology services. Too often the request to be considered for a CI comes from the patient themselves after reading a news article or seeing a TV program rather than a health care professional (personal communication).

Considering the currently low access rates to this life changing treatment and the high number of people with severe hearing loss, any uptick in the numbers of implants would have a strong positive impact on both financial and clinical resources. The need to effectively

manage health budgets is even more pressing since the COVID-19 pandemic. Further improving efficiency, the use of remote screening, programming and follow up can greatly reduce the pressure on clinics (Slager et al., 2019). Innovative techniques such as day surgery and same day patient consultation can also greatly reduce hospital bed use and streamline the process (Nassiri et al., 2020). Whilst the costs may seem unsustainable, they must be considered in the context of the total estimated cost of hearing loss to the European Union, which is €213 billion per year. Hearing loss particularly affects the elderly as it is a consequence of the aging process. However, living with hearing loss does not have to be an accepted part of the ageing process. With an ageing population, Europe cannot afford to ignore hearing loss and addressing it effectively is a key part in supporting its active ageing agenda (D'Haese et al., 2019).

Summary

Cost-effective treatment options for moderate to severe hearing loss, such as cochlear implants, have the potential to enormously impact quality of life, as well as providing long term savings to national health systems. However, there is a need to promote the development of clear referral pathways and guidelines, the sharing of best practice and strategies for the prevention of hearing loss in order to preserve and maximise hearing health for all European citizens.

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