

Adult Cochlear Implantation: The Belgian experience

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Executive summary

Belgium was at the forefront of developments in cochlear implantation, but today lags behind other countries in its provision of implants for adults. We know that hearing loss in adulthood is linked to a greater likelihood of unemployment, as well as an increased risk of poor health, depression and other conditions, including dementia. Despite this, there is little recognition of the impact of hearing loss or of the latest hearing technologies which could improve hearing. This failure to address the consequences of hearing loss is exemplified, above all, by the low level of provision of cochlear implantation for adults in Belgium.

This report reviews the current evidence on the impact of deafness in adulthood and the recent evidence of the impact of cochlear implantation in adulthood. It utilises international data, particularly that from the UK, where extensive work has been done, and gives the Belgian perspective discussing the provision of cochlear implantation in a changing health context. Reports on new research detailing the experience of adults who have been refused implantation are also looked at. The report recommends:

1. An updated review of CI criteria

A review of cochlear implantation criteria concerning both unilateral and bilateral cochlear implantation for adults and for the elderly.

2. Real impact of hearing loss

Greater emphasis should be given to the real world impact of hearing loss and the use of more relevant Quality of Life measures. This includes better models for assessing patient perception of benefits.

3. Co-existence of hearing loss and other health problems

In respect of the cost effectiveness for cochlear implants, greater account needs to be taken in assessing the cost benefit ratios for cochlear implantation of the growing evidence between hearing loss and the existence of other conditions in older people, particularly dementia.

4. Models for considering the wider health costs

There is the need for models used for funding to look at the wider health costs in decision making. This would avoid transferring costs to the health and care systems due to the fact that the issue of hearing loss has not been addressed earlier. It is not only a question of hearing, it is also about the quality of life and of quality of health.

5. Preparation of doctors and audiologists

Better preparation of doctors and audiologists concerning the potential benefits of cochlear implantation for adults, including the elderly, when a hearing aid proves insufficient.

6. Encourage public health authorities to take action

Greater action of Public Health authorities in providing information on the benefits for people who are trying to cope with their hearing loss and in reducing the potential stigma associated with hearing loss, so people are encouraged to take action.

A doctor with a cochlear implant says:

“I would like to think that I was always sympathetic of patients suffering from loss of hearing but now I actually know how it feels. I am passionate about encouraging and promoting the possibilities of cochlear implantation - I think there is an “iceberg of unmet need” out here. I feel doctors need more information about the procedure, and more patients should be referred to ENT consultants and audiologists who have experience and understanding of the role that cochlear implants can have in transforming lives.”

SECTION 1:

Introduction

To be able to communicate is to be part of our society. Losing your hearing is not simply the absence of sound. If not addressed, hearing loss becomes the loss of our capacity to participate in social life and it cuts us off from our family, friends, social contact and work. Deafness in adulthood is linked to depression, the increased risk of unemployment, poor health¹, a deterioration in mental health and the increased risk of other conditions, including dementia.² This results in a social burden on individuals³ and families as well as a huge economic burden on society. This burden often goes unrecognised. A study in the United States suggests that the failure to tackle the effects of hearing loss costs between “\$154 billion and \$186 billion per year (based on prices in 2000), which is equal to 2.5% to 3% of the Gross National Product.”⁴ Similar estimates in the UK estimate the loss to the UK economy every year due to unemployment related to hearing loss at £13 billion each year (2006 prices).⁵

The loss to individuals is more difficult to calculate but quite clear in principle. The Global Burden of Disease study shows that across the UK, in people over 70 years, age-related hearing loss is the eighth most important contributor to the years of life lost due to the presence of a disability.⁶ The 2012 General Practitioner survey in England shows that 83% of those with severe hearing impairment have an additional long term condition and 33% have more than two additional long term conditions. Of the 300,000 people of working age with severe hearing impairment, 20% reported being unemployed (and seeking work), with an additional 10% reporting that they cannot (seek) work due to an illness or health condition.

In the absence of much needed studies in Belgium, we use data from elsewhere to make the case here.

The consequences of not working due to hearing loss is independent of other long term conditions and dramatically higher than the national average. It is also important to note that the nature of work is changing, with many more jobs dependant communication skills, which leaves those with an unaddressed hearing loss more vulnerable to unemployment.⁷ The impact of hearing loss on the individual is compounded by the stigma attached to this by society. People fear to take action when they lose their hearing because they, quite rightly, perceive they will be treated differently.⁸ Possibly this is the reason why, on average, there is a ten year delay in seeking help for hearing loss.

Furthermore, the consequences of hearing loss are insufficiently understood and not taken into account or prioritised by the medical profession or the Health Services.

The reports on health expenditure on hearing loss show that this has remained essentially static or at best experienced a marginal increase. Thus expenditure will not have accounted for improvements in technology and the evidence of an increase in unmet need⁹ in the UK. In the UK, of those who do consult their doctor concerning their hearing loss, 45% are not referred to a specialist for an audiological assessment. In Belgium the Standard CI criteria have not changed despite improvements in technology.

We know from studies that hearing aids improve the health-related quality of life of adults by reducing the psychological, social and emotional effects of hearing loss.¹⁰ For those who are severely/profoundly deaf, and for whom hearing aids provider little benefit, cochlear implants (CI) offer the possibility of useful hearing. Despite the digital revolution in which high quality digital hearing aids are now routinely fitted with greater patient benefit, there remains a huge underutilisation of implants for adults.

“Blindness cuts one off from things, but deafness cuts one off from people.”
Helen Keller.

“For me there can be no relaxation in human society; no refined conversations, no mutual confidences. I must live quite alone and may creep into society only as often as sheer necessity demands.”
Ludwig Van Beethoven, in a letter to his brother reflecting on the impact of his deafness.

“I don’t know why but people are very loath to engage with a deaf person and I think it is self-consciousness because they must be afraid because they think that a deaf person won’t be able to understand what they are saying and what do they do then. They take fright and I battle with that.”
Research Respondent.

Cochlear Implants

A cochlear implant consists of parts that are worn externally (microphone, sound processor and transmitter coil) and parts that are placed under the skin behind the ear (receiver-stimulator) and in the inner ear (electrodes) by means of an operation. The microphone is often worn behind the ear like a hearing aid. It picks up sounds which are transformed into electrical signals by the receiver-stimulator and sent to the brain by the electrodes placed in the inner ear (cochlea). Sounds heard with a cochlear implant are not the same as those heard with the human ear. With an appropriately programmed system and support, the person with a cochlear implant becomes able to use their implant to understand speech and other sounds.



This failure to address the consequences of hearing loss are clearly exemplified by the way we are failing to capitalise on the potential benefits for adults by extending both the provision and the choice for cochlear implantation.

In February 2013, the World Health Organisation (WHO)¹¹ reported that about 5% of the world's population has a disabling hearing loss and approximately one-third of people over 65 years of age are affected by a disabling hearing loss.

Concerning the prevalence of permanent adult hearing loss in Western Europe, a national survey in the UK conducted by Davis¹² is still the best and most detailed study. It shows that among 18-80 year olds, 0.7% had a severe hearing loss (70-94 dB HL) and 0.2% a profound hearing loss (>95 dB HL).

With a population of nearly 9 million over 18 years of age in Belgium¹³ there are an estimated 63,000 people with a profound hearing loss and 18,000 with a severe loss.

Although it is difficult to determine the exact number of adults who may have a clinical need for an implant, Raine¹⁴ concluded that according to the current measures of profound deafness, the level of provision for cochlear implantation in the UK "would appear to be significantly below any predictions of the need."

According to the data, there has been a steady annual growth in the number of adults receiv-

ing implants since the reimbursement of CIs in Belgium between 1994 and 2002. Since then, however, there has been no further growth.¹⁵ Today, only 2400 of the 36,000 CI candidates with a profound to severe hearing loss, i.e. only 6.6% of the adults who might have benefitted from an implant are in fact getting one.¹⁶

Although the rate of underutilisation is similar to that seen in the USA,¹⁷ and the Netherlands¹⁸, it represents only half the number of implants in adults in Germany and Austria.¹⁹ The percentage of CI users in these countries is comparable to the percentage of hearing aid users in Belgium, namely one third of the candidates is wearing a hearing aid.

NICE²⁰, a well-known UK authority, has reviewed the effectiveness of cochlear implantation and has issued a positive, but restrictive, assessment of the criteria to be used for fitting cochlear implants in adults. Since then and the review of 2011, there has however been significant additional research, as well as meta-analyses and technical assessments, which have strengthened the case for a broadening of criteria for adults.

Furthermore, there have been significant developments in the technology. This changes our understanding of the costs and benefits of cochlear implantation. The relative costs of the actual implant have fallen, thus reducing the health costs of providing cochlear implantation.

Related to this we are also getting a clearer understanding of the costs involved in neglecting to take action, concerning both individuals and society. This refers to lost employment opportunities, a rise in health-related problems and the costs of addressing these issues.

The weight of this evidence points to:

- Cochlear implantation in adults is an effective intervention for a much wider group of candidates than had previously been thought.
- 7% with a severe (70-94 dB) and 0.2% with a profound (> 95 dB) hearing loss would give an estimated 36,000 CI candidates in Belgium.
- one third of hearing aid candidates has a hearing aid, but only one in twenty CI candidates has a CI.
- The benefit of cochlear implantation needs reviewing in the light of reduced costs, more effective technology and more evidence concerning a positive outcome.
- The need for a better assessment and funding framework to ensure equitable access for those who could benefit.
- Ensuring greater awareness of doctors, audiologists and the public concerning cochlear implantation.



SECTION 2:

Current knowledge

In England, the NICE Guidance of 2009, reviewed in 2011, concluded that fitting cochlear implants was effective in adults, subject to the following criterion:

“The Committee concluded that unilateral cochlear implantation for adults and children with severe to profound deafness who did not derive adequate benefit from acoustic hearing aids would be a cost-effective use of NHS resources”.

Clinical Criteria

Cochlear implants have been reimbursed in Belgium for children and adults since October 1994 and initially only in patients with a bilateral total sensory deafness. In March 2006²¹, the reimbursement criteria were defined as: 1) pure tone average thresholds of 85 dB HL or greater at 500, 1000 and 2000 Hz, 2) latency of peak V in brainstem auditory evoked potentials at 90 dB HL or higher, 3) little or no benefit from hearing aids. In people with post-lingual deafness, a phoneme score, using monosyllabic words at 70dB, of less than 30% has to be recorded using hearing aids which indicate that these do not give sufficient benefit. But these criteria do not take into account the current possibilities of cochlear implantation. The US Food and Drug Administration (FDA) criteria permit implantation in cases in which the PTA (at 500, 1000 and 2000 Hz) exceed 70 dB for both ears and if open-set sentence recognition (e.g., HINT) is 60% or less in the best-aided condition; the Belgian criteria are much stricter than this.

Many health care practitioners would argue that these criteria, and in particular these frequencies, do not reflect the ‘real’ world, and that as a minimum other frequencies (including 4000 Hz) and tests should be used. In England, Raine has proposed that tests with noise and softer speech would be more appropriate.²² In fact, these are the criteria already used in some countries, for example Germany.²³ It is interesting that the German approach does not specify audiological criteria, with the possibility that this gives the

clinician a greater clinical freedom.²⁴ In the study by Athalye et al²⁵, that interviewed people who had been refused implantation, the majority believed the decision had been made on the basis of the audiological criteria: respondents spontaneously commented that the audiological assessments did not reflect the real life challenges of their hearing loss.

Bilateral implantation in children

A pilot project concerning bilateral implantation was initiated in Belgium in 2003 by the National Institute for Health and Disability Insurance (NIHDI) with 42 children under 12 years who have received a contra lateral CI. The children had to comply with several criteria in order to be considered for this project: presence of a full insertion of the electrode array, having shown good cooperation with the rehabilitation and good audiometric results with their first CI and a normal anatomy of the second ear (cochlea and cochlear nerve). The results of this project^{26,27} justified a standard reimbursement of the second implant in children younger than 12 years, which has officially been effective since February 2010²⁸. The indication for a second cochlear implant has also been broadened to include children between 12 months and 18 years with an auditory neuropathy or meningitis.

New evidence

There has been a substantial change in the overall level of knowledge about the effectiveness of cochlear implantation as a result of a number of additional studies and meta-analyses in recent years. There has also been a reduction in the relative cost of implants while the operation and the technology have dramatically improved. These changes are reviewed below and strongly indicate the urgent need to review the guidelines on cochlear implantation.

If we look at the key issues concerning the new evidence on cochlear implantation in adults, these fall under the following areas.

The evidence concerning the impact on older people of Cochlear Implantation

More recently positive outcomes are being reported in a number of studies concerning the impact of cochlear implantation on older people. These show that for patients between 60²⁹, 65³⁰ and 79³¹ years positive outcomes are being achieved.

Vermeire et al.³² of the University Hospital Antwerp did a study on 89 adult CI-users of whom 25 were older than 70 years. They came to the conclusion that although the audiological performances of the elderly group were significantly lower than that of the younger age groups, the quality-of-life outcomes of the elderly group were similar to younger adult cochlear implant recipients.

Further the results for older patients compare well with younger patients, with some studies showing equivalent gains as for those with younger adults.³³

Thus Noble³⁴ found that similar outcomes for older and younger adults though younger bilateral subjects were better on localisation. Olze³⁵ also noted positive results, including QoL and tinnitus measures, and Poissant found gains in speech understanding and QoL measures.³⁶ Even where performance has not been as good, the outcomes have still been very positive³⁷. A decline in gains was found by Williamson but with only a slightly poorer performance in subjects over 80 years of age.³⁸ Lenarz³⁹ also found that patients over 70 showed a similar learning curve to that of younger

adults and found no difference between average performance of the older patients and younger adults in a range of standard speech tests. Park also found that speech recognition improved in all age groups (<50, 50-65, >65) and the quality of life improved markedly and in all age groups to a similar extent. The effect was not dependant on the prior use of a hearing aid.⁴⁰ While Budenz found that subjects who were older benefited less this was primarily due to a correlation with the duration of the hearing loss not the age of the subject as such.⁴¹ Berrettini also found a decline in benefit in a systematic review for fitting post 70, but he too concluded that there was "improvement of the quality of life and perceptive abilities after CI," and that "advanced age is not a contraindication for the CI procedure."⁴²

The importance of hearing preservation

Since the early days of multichannel cochlear implant research there has been a strong requirement placed on electrode design to minimise trauma in the cochlea⁴³. More recently, the goal of minimising trauma to preserve residual hearing has become an imperative with the development of the concept of combined electrical and acoustic stimulation in one ear for candidates who have good low frequency hearing. It provides electrical stimulation in the basal section of the cochlea, avoiding the apical region to maximise the potential for acoustic stimulation. Minimal trauma and hearing preservation is also associated with better outcomes when using either electric only stimulation⁴⁴ or combined electrical and acoustical stimulation^{45,46,47}.

Surgical experience

Concerns about the surgical risks of implantation in older patients have been addressed. Several recent papers^{48,49,50} have reported generally low rates of surgical complications in elderly CI recipients. Carlson compared surgical complications between younger and older CI recipients and found that while anaesthetic-related problems are slightly more common in older patients post-op, medical complications were not a problem. It was also shown that the operation has only a minimum anaesthetic risk.⁵¹

Reduction of costs

In Belgium, as in many other countries, the costs for cochlear implantation have fallen greatly in the past 10 years. Today the current price is nearly the same as in 2006, which is a real cost saving of € 3000/device (in today's terms at 1.9% inflation). The warranty has increased from 3 to 5 years since 2011 and, since 2012, more accessories have been included in the kit. In addition, there was a 3% budget cut in 2013. All this has reduced the cost per implant dramatically.

The cost benefit analysis concerning unilateral cochlear implantation shows that the cost effectiveness of implants in adults has continued to be positive. This is, further supported by a meta-analysis by Turchetti et al.⁵² who found that:

“monotateral implantation is generally a cost-effective intervention... Overall Cost/QALY estimates indicate that monolateral cochlear implantation is also a cost-effective intervention for elderly patients”

Bilateral cochlear implantation in adults

The NICE review found evidence to support the effectiveness of bilateral cochlear implants but - due to the limited evidence of additional patient benefit and the assessment of cost effectiveness of the second implant - they concluded that they could not recommend bilateral implants at that time.⁵³ Since then, there have been a number of studies and technology assessments which

have been positive. A technology assessment by Raman et al,⁵⁴ found that unilateral cochlear implantation had been effective in improving speech perception and the health-related quality of life in adults with profound hearing loss. Furthermore, they found that bilateral cochlear implantation provides added improvements in speech perception in noisy environments compared to unilateral implantation and better sound localisation.

Van Schoonhoven⁵⁵ in a meta-analysis found that while there continued to be difficulties in comparing studies, all studies showed “a significant bilateral benefit in localization over unilateral implantation.” Bilateral implants were also beneficial for speech perception in noise and for some self-reported measures. They concluded that “The current review provides additional evidence in favour of bilateral cochlear implantation, even in complex listening situations.” Similar findings were found in a separate meta-analysis by Gaylor⁵⁶ which concluded that “Results from studies assessing bilateral implantation showed improvement in communication-related outcomes compared with unilateral implantation and additional improvements in sound localization compared with unilateral device use or implantation only”. In another systematic review Crathorne⁵⁷ found the same problems in a study comparison and heterogeneity of studies but again noted that all studies reported improvements in bilateral cochlear implantation for improved hearing and speech perception and that quality of life is improved in the absence of worsening tinnitus. The systematic review authors⁵⁸ conducted global sensitivity analyses at the study level concluded:

“The incremental cost-effectiveness ratios for bilateral cochlear implantation vary widely and appear to depend on the gain in QALY due to the second implant”. The results of this review confirm that more empirical data are required to estimate the cost-effectiveness of bilateral implantation.

Moreover, ratios are developed on the basis of the gain between the first and second fitting without any analysis of differences resulting from whether the first or second implant was in the best ear and without any reference to more real world benefits. The costing ratios also do not take into account our growing understanding of the links between hearing loss and dementia which might affect the overall assessment of the cost benefit threshold even with the current measures of benefit.

Studies which also look at self-reported benefits from patients show that patient perception is that

bilateral implants make a significant difference. For example, Noble et al.⁵⁹ found in a review of self-reported benefits that “it remains evident that bilateral implantation offers substantial benefits across the age spectrum.” This has been further borne out in a pioneering study on adults who have been implanted sequentially and were then asked about their personal perception of the advantages of having a second implant. The results showed an impact which is not always measured by more traditional approaches. Participants noted a further improvement once they got the second CI, which they described as follows:

Psychological

- Reduced sense of isolation
- Increased happiness
- Increased energy
- More relaxed
- Reduced depression
- More confident

Lifestyle

- Improvement at work
- Improved social life
- Increased independence
- Increased drive
- Better family relationships
- Have a 2nd CI in case the 1st one fails

Asked if they were given a second £15,000 to spend on either a second cochlear implant or to keep, all but one answered that they would have the implant. All but one would recommend others to have the implant. This was expressed by one of the interviewees who said that:

“I still feel it’s worth trying, like I said, if I had £30,000 I would put on the table right now.”(P1)

Given both the strong clinical evidence and patient experience, which to date has not been so sensitively captured, it is important that future assessments of suitability for implantation take this fully into account in the development of any future guidance.

Certainly in psychological terms, and therefore real life effects and benefits, we know that people generally invest more value in the loss of something they already have than in risking something for further potential gains.⁶⁰ Therefore, measurement should start from the assumption of full hearing rather than from the marginal utility of difference between the first and second implant. This would measure the level of loss and the extent to which this has been addressed by the device. This has been referred to as measuring the revealed disability that someone is facing.⁶¹

For deaf adults, there is no reimbursement of a second cochlear implant in Belgium although it has widely proven to be cost-effective and an increasing number of countries (Germany, Austria, Sweden,...) reimburse patients in such cases. Based on the fact that 79% of the hearing aid users in Belgium have received reimbursement for the binaural hearing aid⁶², it seems contradictory that there is no reimbursement for a second CI.



Changes in technology lead to better outcomes

Technological advances in the quality and performance of implants have led to further improvements and the evidence of NICE on UK adult studies, including bilateral data, was collected on patients who were mainly wearing technology from the late 90s. This was due to the time lag inevitably involved in studies with substantial data sets. Certainly for many studies these devices are likely to have been analogue processors with no input processing.

In addition, costs have fallen during this period, with industry estimates of a reduction of around 10-15% in the devices. This would substantially alter the QALY ratios according to the current ways of measuring benefit and would also alter some of the presumptions of other studies which have looked at these issues.

There have been a significant number of changes in the technology recently:

- Up until 2004/2005 the sound processors were analogue: after that digital processing was introduced. Essentially this change was the same as the process of 'hearing aid modernisation' that took place with the analogue to digital hearing aid upgrade;
- At the same time dual microphones have been introduced for improved directional hearing particularly in background noise;
- Input (pre-) processing of the sound signal for improved hearing in background noise and in quiet conditions has been introduced.

Comparing studies on the benefits of cochlear implantation merely relying on these studies would be equivalent to judging the performance of digital hearing aids on the basis of old analogue aids. They are essentially different devices in terms of how the technology works and the benefits experienced by patients.



Recommendation

1. RIZIV/INAMI should review its current guidance on cochlear implantation, and in particular on their audiological criteria for both unilateral and bilateral cochlear implantation, especially for adults.

SECTION 3:

The views of the Patients

Qualitative research methods are now increasingly recognised as capturing issues which quantitative or laboratory based methods may miss. In the study by Athalye et al (2014)⁶³, which interviewed adults who had been refused cochlear implantation, the majority had been refused implantation on the grounds of the current audiological criteria. Athalye showed that patients were clear about the impact of deafness on their work situation.

Comments included:

“They used to run a bet on how long it would take me before I would be crashed out. It’s insulting really isn’t it? I was the real butt of jokes. Deaf and dumb, you know.” P7

“I find it very frustrating when my hearing goes down and I can’t communicate with students, I cannot participate properly in management decisions.” P1

“The HR manager who would simply say ‘I don’t know if you are up to this job any more. You can’t hear what people are saying to you, how can you do your job? I am going to have you assessed if you are fit to do the job’ basically. That was actually quite frightening. I was possibly going so deaf that I wouldn’t be able to work properly.” P4

“I was less functioning. I was taking on more and more work and gradually at the end of the day I was falling asleep in the car. I thought one of these days I am going to wipe out a family because I am going to crash on the other side. It is a mental exhaustion.” P7

They also spontaneously raised the lack of real world criteria in the testing situation:

“I think the assessment should incorporate background noise, if it incorporated the fact that most people don’t speak the Queen’s English, it doesn’t take into account the dialect - like with your dialect I would find that very difficult to understand with no lip patterns, I feel that it was a very easy exercise and it really peed me off to be perfectly honest, and I didn’t feel it was any reflection on real life, unless you count sitting in a lounge having a conversation with someone real life, it’s not at all.” P2

“I didn’t feel that it was a real life procedure and I thought if all the sound had come from this direction and realised that there was sound coming from here - it sounded like a massive wall paintbrush for a very profound thing.” P2

“The conditions they did the testing in were ideal. It was perfect but they made no allowance for the difficulties you get if somebody is talking from the side, or if there is any background noise. They were absolutely perfect conditions and of course under those circumstances you do very well and it makes no allowances for problems you run into in real life from ideal conditions.” P3

The interviews of the adults reflected their understanding that they may have to wait until they have very little hearing left before being provided with an implant. For example:

“At times I have acute problems that render me most incapable of undertaking any teaching or administrative duties because I cannot understand people. Given that I am in a very highly productive part of my life I think it would be a risk worth while taking and I would try to get it to work if the auditory nerve was functional, there should be no reason why I could not eventually train myself to use the implant and though it might be significantly different to my right ear,... I think it would add a lot of functionality. At present the situation I face is that I have to wait until I become completely bloody deaf on my right ear before they are going to do anything.” P1

It was also noted for these candidates hearing aids were not able to address the issues they were experiencing; after the refusal for an implant, they were left with the same major challenges, particularly at work. As the survey noted, the participants’ unaddressed hearing loss:

“had a massive negative impact on their study/work/life/work(whether current or in the past). The participants were a mix of different professions including university lecturers, students, teachers, defence personnel, managers and hence had a range of communication needs at work. All the participants reported to have severely struggled at some point in their work lives while facing moderate difficulties on a day to day basis. One participant had to medically retire because of his hearing loss while another felt that his performance was extremely compromised owing to his hearing difficulty. Another also reported having taken early retirement.”

If not addressed, these experiences of people using hearing aids were likely to lead to them becoming less productive, and in extreme cases, giving up work.

Quality of Life Measurement

Accurate Quality of Life (QoL) measurement depends on ensuring that the instruments which we are using are sufficiently attuned to weigh correctly all the issues that the adult is experiencing. As Loeffler⁶⁴ concluded after reviewing some of the established QoL instruments “QoL instruments are an essential addition to speech perception tests to quantify the outcome of cochlear implants. Compared to speech perception tests QoL scores allow a more comprehensive insight into patients’ daily life and activities.” However, it is important to ensure that these instruments are sensitive to the life experiences of users. For example, the authors of the 2011 AHRQ report demonstrated a significant effect on disease-specific functional and QOL scales for unilateral cochlear implantation in adults, but no effect according to generic scales⁶⁵. This effect has also been apparent in a number of other studies. Essentially, when more disease specific measures are used a significant impact of quality of life is shown for CI users in most studies. The Nijmegen Cochlear Implantation Questionnaire (NCIQ) is more reliable and sensitive to clinical changes than generic tests such as SF36 and Health Utilities Index. Even so, it is not clear that all the potential benefits are currently considered by such tests and we need to look at how these can be refined further.⁶⁶

Recommendation

2. Greater weight needs to be given to the real world impacts of hearing loss and the use of more relevant Quality of Life measures, including better models for assessing patient perception of benefit.

SECTION 4:

Wider impact

Economic benefits of cochlear implantation

“I feel that so much of my previous life and true self has been restored, regaining my pride and ability to contribute actively in society on an equal basis.”

We do have a much better evaluation of the impact of hearing aids on employment prospects and therefore, by extension, it would be reasonable for working age adults to assume at least a similar level of impact of implantation. Hearing aids have been found to mitigate the effect for those with moderate to severe hearing loss by 65-77% and that those with severe hearing loss who did not use hearing aids had unemployment rates nearly double those who did use amplification (15.6% versus 8.3%).⁶⁷ This suggests, along with what we know about the problems that deaf people have in maintaining successful employment when they suffer profound deafness, that the use of cochlear implantation could have a profound impact on the ability of deaf people to maintain their employment status or gain employment and therefore stay more productive.

If the impact on employment was addressed there would be large economic benefits. A Canadian study⁶⁸ concluded that “Cochlear implantation not only improves quality of life but also translates into significant economic benefits for patients and the Canadian economy. These benefits appear to exceed the overall costs of cochlear implantation.”

Those who have implants saw a significant increase in median yearly income compared to pre implantation of \$42,672 vs. \$30,432. A similar, though considerably smaller, effect was also found by Harris et al.⁶⁹ who identified a mean increase of \$1249 in yearly income 3 years after cochlear implantation.

Recent research in the UK also found that the direct costs of not addressing hearing loss to the health system amounted to £450 million in 2010/11. While lost earnings through hearing

loss was calculated at over £4 billion per annum on the most conservative estimate. Further that the net burden of illness in terms of reduced quality of life associated with hearing loss could be conservatively estimated at £26 billion in the UK for 2013.⁷⁰

Though, as Sorkin has noted, there is scope for further studies aimed at assessing the social and economic aspects of cochlear implantation and she concluded that “For adults, there have been no comprehensive studies on the impact of CI on the employment and advancement of working age adults. There are also no studies documenting the general benefits to society of providing hearing to those who have lost it or who were born deaf. Having such data would provide additional impetus for timely referrals for people of all ages.”⁷¹

There is an urgent need to conduct more studies on the long term economic impact of implants in adults but there can be little doubt from what we already know about the impact of hearing loss on employment prospects that the overall benefit of greater availability of implants for those who are experiencing significant hearing loss would be significant.



Impact on Social Care Issues

As Lin⁷² has shown “The magnitude of the reduction in cognitive performance associated with hearing loss is clinically significant with the reduction associated with a 25 dB hearing loss being equivalent to an age difference of 7 years.” This is consistent with other studies that have looked at the relationship between declining social networks, which is a common consequence for older people with progressive hearing loss, and the onset of dementia or cognitive decline.⁷³ It is also the case that when those in the older age group use hearing aids there has been a measured improvement in cognitive ability.⁷⁴ Further, we know that the risk of death within a year for a socially isolated older person is typically 26 % greater than the risk for a person of the same age who does not report being socially isolated.⁷⁵ While it is clear that much more work still needs to be done in this area to establish the causative mechanisms for the association between hearing loss and cognitive decline, the fact that cognitive decline can, to some extent, be mitigated by the use of hearing devices means that we should

take far more seriously both the potential health impacts and the consequential costs of not doing so in any costing models for making governmental decisions.

While the Government is rightly concerned about the cost of adult social care the impact of hearing loss on this, including the growing association between hearing loss and dementia, is underplayed. Debates about social care costs and social care legislation would suggest both more focus and a bolder approach. The government’s healthy aging strategy could provide more specific recommendations about communication support and end of life care including the effectiveness of cochlear implantation in preventing earlier admission and greater dependence in elderly patients. Arguments about particular social benefits (and associated cost savings) in elderly recipients of cochlear implants or other interventions will go a long way to addressing any concerns about the (self-evidently) fewer remaining expected life years to which QoL measures can be applied.

Recommendations

3. As part of the development of cost benefit analysis for cochlear implants, when assessing the cost benefit ratios for cochlear implantation more account needs to be taken of the growing evidence on the links between hearing loss and the co-existence of other conditions in older people, particularly dementia.

4. The funding models used for decision making on adult implantation (particularly for older adults) need to look at the wider health and social care costs implicit in not proceeding to intervention alongside the (obvious) potential costs of the intervention itself. The possibility that not addressing hearing loss in a timely fashion could transfer substantial additional costs onto the health and social care system later should be explicitly acknowledged.

SECTION 5:

Conclusion

Despite the historic advancement of Belgium in the use of cochlear implantation and its reimbursement, it is now lagging behind other countries with regards to criteria, reimbursement and utilisation

Why are adult cochlear implantation rates so low?

With the acknowledged benefits of cochlear implantation in adults, why are the implantation rates so low? A review into health technology assessment in general concluded:

“... innovations can significantly improve clinical practice, but the rapid growth of medical technology, and the increasing volume of new knowledge from basic and applied clinical research, have made it virtually impossible for care providers to keep pace with treatment advancements.”⁷⁶

While this may be true as an explanation of why practice does not keep up with the technology it is vital that we address the lag between the promise of cochlear implantation for a wide variety (and large number) of adults and what is actually being achieved on the ground. We have demonstrated that the impact of hearing loss is under recognised, that adults affected by hearing loss do not seek help early, and that when adults do seek help they are not routinely referred for

assessment. Access to cochlear implantation is part of this issue, and as we have shown, current audiological criteria in Belgium are considered by many to be too restrictive. In addition, the criteria do not recognise the real life challenges of hearing loss, which require other assessments to be taken into consideration.

Public and Personal awareness

There continue to be major barriers in public awareness concerning first taking action on hearing loss and then taking further action if interventions have ceased to provide a hearing benefit. As noted above, earlier studies have shown that this is directly related to perceptions of stigmatisation of those with hearing loss and the concerns of wearing hearing devices.⁷⁷ A Mori poll in 2005 showed that almost a quarter of respondents in the UK are worried that people would think they are getting old if they wore a hearing aid and would also be seen as being less capable. While these attitudes are common in most countries, we need to challenge them to ensure that Audiology services are offering state of the art technology and the health policy is looking to integrate support and services for older people through better reimbursement.

There is a major issue about doctors awareness of the impact of deafness in general and their lack of knowledge of the benefits of cochlear implantation in particular. Patients also complain about their



doctors' general lack of audiological awareness.⁷⁸ There is however growing recognition of both the benefits of cochlear implantation for adults and the need for doctors to take a more proactive role in the referral and management of patients who would benefit from cochlear implants.⁷⁹ We know the number of adults currently implanted is low compared to the number who could benefit⁸⁰ and we also know that the cost of not addressing deafness in the community is great in terms

of other costs to society in terms of increased depression, links to dementia and morbidity.⁸¹

In this context it is also crucial that the public is fully informed about their hearing options and can make informed choices. Audiologists in turn need to be aware of the benefits of cochlear implantation to the wider group of adults now having them successfully fitted so that timely referral for implant assessment in a cochlear implant centre is made.

Recommendations

5. A better training of doctors and audiologists concerning the potential benefits of cochlear implantation for adults and older patients is required as a matter of urgency.

6. More work should be done by the Public Health Authorities in Belgium concerning the benefits of people addressing their hearing loss and steps should be taken to reduce the potential stigma associated with hearing loss so people are encouraged to take action.

Conclusion

The health system in Belgium is still massively underutilising the potential of implant technology to transform the lives of adults and especially of older people due to a combination of outdated selection criteria, failure to invest in capacity and a lack of awareness among both health professionals and the general public.

We need an updated review of cochlear implant criteria and a number of substantial changes in both the understanding of the benefits of cochlear implantation and how this knowledge is then communicated to health professionals across the system. We will then need improvements in how cochlear implantation is reimbursed and provided. The consequence of failing to do this will be increased costs in other parts of the health and social care system, greater dependence in a working population which is being required to work for longer, and a loss of wellbeing and increased ill health in old age.

We need a dialogue on a national level with health communities and across governments that will support a concerted action to address the low value put on addressing hearing loss. The Government of Health Care should produce an action plan to focus health providers on the awareness and the impact of hearing loss, the changing technology and on the importance to

refer people on time. The debate must become one about the quality of life issues and how good communication is fundamental to a good life. Understanding that health and wellbeing are fundamentally affected by hearing loss and deafness must become central to the thinking of health providers.

Hearing technology has made huge strides in the last decade and we now need to see a revolution in the provision of cochlear implantation for adults which matches the introduction of digital hearing aids.

The late Lord Ashley was known to call his cochlear implant a “miracle” for the way it allowed him to function as a successful MP and then as a Peer. It is time that everyone who needs a cochlear implant had access to their own “miracle”.

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