Perspectives of adults with cochlear implants on current CI services and daily life

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Perspectives of adults with cochlear implants on current CI services and daily life

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This paper reports on a survey and interviews carried out with adults who have gone through the cochlear implantation pathway. It explores their experiences of current services, the assessment process for implantation, and the impact on their daily lives, including views and experiences on communication, independence and confidence. It also explores, in today's financially challenging climate, their awareness of current funding issues and the value of their implant to them.

Keywords: Cochlear implants, Assessment, Services, Health economics, Quality of life, Policy and practice

Introduction

Cochlear implantation can have a significant impact on an adult's quality of life, socially, emotionally, and in terms of employment (e.g. Athalye *et al.*, 2014; Du Feu and Fergusson, 2003; Tye-Murray *et al.*, 2009). Functionally, expected outcomes include improved ability to hear, communicate, to hold conversations in social situations and increased confidence in talking to others (Athalye *et al.*, 2014).

However, in today's financially challenging climate, it has come under increasing scrutiny. Despite the high costs, research suggests that cochlear implantation of adults appears cost-effective (e.g. Lamb and Archbold, 2013) and adult cochlear implant (CI) users attribute considerable value to the implant (Buhagiar, 2012).

To gain further insights into the perspectives of those who underwent cochlear implantation in adulthood, this study explored their views on the current pathway and beyond: focusing on CI services, funding issues, functional outcomes, and their perceived value of their CI(s).

Methods

The current study consisted of an online questionnaire containing both open and closed questions and semi-structured qualitative interviews. The study was carried out in accordance with The Ear Foundation's ethics procedures which follow the ethical guidelines for educational research (British Educational Research Association, 2011), by a team of professionals experienced in working with adults with CIs, health economics, research and policy & public affairs. The questionnaire was developed and refined to explore the experiences of those who underwent cochlear implantation as an adult. The sample consisted of a self-selected group. Dissemination took place via The Ear Foundation Research Database and other Users' forum databases. Questionnaire responses were received from 149 adults with CIs, and eight interviews were carried out to explore issues further. Table 1 illustrates the general background demographics of the respondents.

Responses to the closed questions were quantitatively analysed, and open responses were independently and qualitatively analysed using a Grounded Theory approach (Glaser and Strauss, 1967). Themes emerging from the data were discussed and agreed by the research team.

Results

In general, out of 149 open responses, 123 respondents (83%) reported positive effects of cochlear implantation on daily life, while three respondents (2%) said the CI or outcomes were limited, four respondents (3%) mentioned their lives remained the same, one respondent (1%) said daily life after their CI had worsened, and 18 adults (12%) did not respond. Each of the following sections represents a theme.

Communication and information access is vital

Respondents commented on the different stages of the CI pathway. They considered assessments to be high in quantity and complexity, and would have wanted more efficient uptake and advice:

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Table 1 General background demographics of the respondents ($N = 149$)

Demographics	Categories	%	*n*
Age	18–30	4	6
	31–50	14	21
	51–70	44	66
	70+	38	56
Gender	Male	35	52
	Female	65	97
Onset of hearing loss	From birth	15	23
	Not from birth but under 5 years of age	13	19
	5–18 years of age	23	35
	19–40 years of age	26	39
	Over 40 years of age	21	31
	Do not know	1	2
Number of CIs	One	93	139
	Two	7	10
Duration since first CI implantation	Below 1 year	11	17
	1–2 years	16	24
	3–5 years	18	27
	6–10 years	24	36
	10+ years	30	45
Age of first CI implantation	18–30	10	15
	31–50	19	29
	51–70	54	81
	70+	16	24
Use of assistive listening devices	Loop/Telecoil	42	62
	None	31	46
	Remote microphone	11	16
	TV/Phone streamer	7	11
	FM/radio aid system	6	9
	Phone app	5	7
	Other	10	15

Table 2 Responses on dependency on others

	Before implantation		After implantation	
	%	*n*	%	*n*
Dependency on others for communication				
A lot	67	97	8	11
A little	25	36	58	78
Not at all	8	11	34	45
Type of communication support				
Does not apply	35	50	51	68
Lipspeaker	15	21	2	3
Notetaker	15	21	4	5
Speech-to-text reporter/Palantypist	10	14	9	12
Interpreter and sign language support	8	11	6	8
Sign-supported English	3	5	3	4
Other	35	50	33	44
Amount of communication support needed				
Every day	40	57	16	21
Weekly	8	11	7	10
Monthly	8	12	11	15
Not at all	44	64	66	88
Telephone use				
A lot	7	9	28	36
A little	38	52	49	62
Not at all	56	77	23	29

- ‘Appointments before my implant were terribly traumatic, hundreds of tests that were constantly repeated, and no indication that I was going to get an implant. I felt as if I had to jump through hundreds of hoops to prove how deaf I was, how bad my life was’ (Questionnaire, P36)

However, the adults appreciated that the professionals listened:

- ‘They led me through the process without any sort of bias at all. No saying yes you must have this, no sort of discouragement.’ (Interview, P1)

Surgery was considered frightening; three interviewees spontaneously commented that surgery was their (and their partners’) main obstacle, resulting in actively postponing implantation. However, access to information and a good support system from family and friends seemed to help lessen that fear of surgery:

- ‘For me it was the fear factor, leaping into the unknown. What if it doesn’t work for me I am going to lose anything I have got left.’ (Interview, P8)

Participants felt that emphasis was rightfully placed on the risks involved in surgery (e.g. according to protocol), but more attention could also be paid to the benefits:

- ‘sometimes you’ve got to take the risk. There’s risk for everything. […] You have to weigh up the benefits.’ (Interview, P2)

The switch-on procedure and immediate results afterwards were considered effective:

- ‘“switch on” brought immediate amazing results […] I was able to hear a random sentence from my daughter in the car on the way home without looking at her!’ (Questionnaire, P8)

Increase of independence and confidence

Respondents were asked about their dependence on others before and after implantation with regard to communication, support, and telephone use (Table 2). They were also asked about their confidence at home, work, socially, and during sports activities (Fig. 1).

Other open responses for type of communication support included family and friends, colleagues, and lip-reading.

Respondents reported that before implantation they were almost entirely dependent on family, and this shifted after implantation as confidence returned and they gained increasing independence. This was important for not only themselves, but also for the safety, well-being, and informal caring for partners, therefore reducing additional needs and costs for services, for instance:

- ‘I can hear emergency sirens and alert my husband! […] an excellent facility to support my being able to move around safely.’ (Questionnaire, P103)
- ‘At the time of switch on my husband who had Parkinson’s became unable to cope so I was able to take over the day to day things in life and became his carer.’ (Questionnaire, P134)

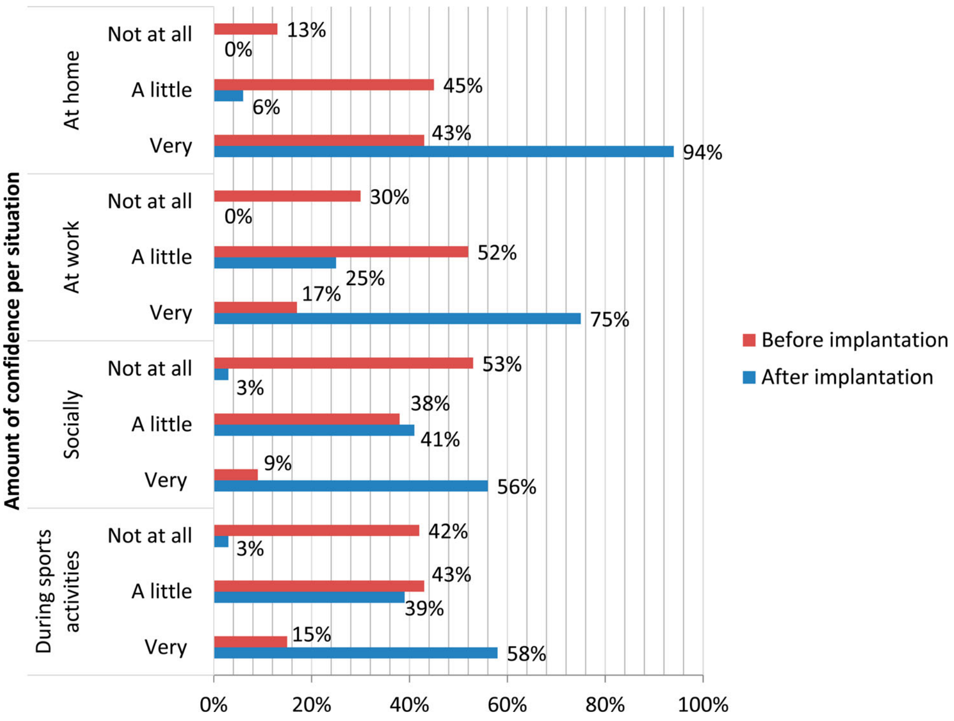

Figure 1 **Confidence before and after implantation in different situations**

- 'Now because I've got my independence and confidence back I don't have the depression, I want to grab life and have a life for me.' (Interview, P3)

Impact on family and social life

Out of 123 responses, 111 respondents (90%) reported that having a CI affected their family members. The most frequent responses were: easier access and involvement in communication with family (43%), less dependency on the family (21%), and less stress for the family (13%). Cochlear implantation allowed families to reconnect and address their social isolation, including increase of their family's confidence in their abilities, for instance:

- 'People feel more confident to include me' (Questionnaire, 101)
- 'they are now confident of my ability to cope' (Questionnaire, P2)

Positive effects on education and employment

The spontaneous open responses on education and employment ($N = 58$) illustrated that before implantation, the hearing loss led to a loss of confidence and problems in communication, particularly in the older age groups. Forty-three respondents (74%) reported (including 10 respondents who said they were not being able to study or work without support) that this resulted in negative consequences for education or work, as opposed to 15 respondents (26%) who were able to cope (albeit, including: not much contact with others, study, or jobs). They struggled and lost confidence in themselves to do their job or progress, were dismissed for being considered unfit for the job or were forced into early retirement. Cochlear implantation, and as a result the ability to hear, provided access to communication in education and employment. Out of 35 open responses, 30 respondents (86%) reported this led to positive effects, whereas five respondents (14%) reported no or negative effects (one negative response due to the background noise still perceived). This meant progression in education, greater chances of getting a job, more effective execution of the job and opportunities to develop one's career. For example:

- 'First job application after implant that I did not have to declare deafness I interviewed for and got the job and recently doubled my initially part time hours; So from meagre benefits to full time employment – PRICELESS!' (Questionnaire, P2)
- 'There's no way I could've worked with them [those with special educational needs] before, being able to hear what sounds they can say and can't say' (Interview, P3)

Economic and personal value of the CI

Respondents were asked the economic value they hypothetically placed on their implant. The majority (60%) valued their CI(s) above £150 a month. However, many also reported that they were unable to place a financial value on their CI:

- 'It has given me my life back. How to value that?' (Questionnaire, P121)

Respondents raised a variety of cost issues; addressing the high cost for second implants and the need for increased post-implant support. However, they suggested that increased awareness and subsequent demand may help reduce costs and improve understanding:

- 'Decent hearing (as is decent vision and health) is a benefit that should be universally available to all for nothing.' (Questionnaire, P122)
- 'Stop looking at the medical side of it and look at the holistic approach. […] Deafness is an invisible thing so they don't understand the emotional and psychological impacts.' (Interview, P3)

Discussion

The CI pathway in the UK is currently well defined with NICE guidelines (NICE, 2009). However, the major issues which emerged in this study showed that adults' experiences of the pathway could be improved. Assessments were found to be numerous and complex, and the respondents showed a great fear of surgery. Although professionals showed empathy, many adults asked for more communication and information throughout the CI pathway, and access to other CI users/advocates may be valuable, like one adult already did: 'I support my elderly Mother and have counselled several people who are considering an implant' (Questionnaire, P144).

In line with previous literature (e.g. Dalton *et al.*, 2003, Du Feu and Fergusson, 2003; Tye-Murray *et al.*, 2009), this study supports the impact of hearing loss on emotional, social, employment and quality of life aspects; demonstrating dependency on others, particularly family, need for communication support, loss of confidence, isolation, and difficulties in seeking and maintaining employment. In line with expectations found in Athalye *et al.* (2014), a shift was found after implantation with improvements in communication, confidence, managing social situations, and additionally positive effects on education and employment, independence and family life. The particularly marked change in confidence at work may well lead to improved employment prospects. Potential candidates, especially older adults, should continue to be considered for implantation, given the evidence of benefit and societal costs of not managing hearing loss (Archbold *et al.*, 2014).

Although CIs are seen as highly effective (NICE, 2009) and are valued by these users, similar to findings of Buhagiar (2012) CI users often have difficulty expressing their benefit in financial terms. Respondents showed awareness of current financial restrictions (Athalye *et al.*, 2015) and the impact on their own funding. They valued NHS availability as most candidates would be unable to afford them privately, particularly given the much greater price of implants over hearing aids.

Conclusion

Despite this small sample of (older) adult CI users, several new and important issues were raised. First, there seems to be a further need for better communication and access to information from professionals throughout the CI pathway; a support system of existing users or those at similar stages of the pathway may help. Second, the improved ability to communicate and increased confidence following cochlear implantation also brings greater independence, advancements in employment and strengthened relationships with family. The resulting reduction in stress and isolation may lead to less dependency on health and social care services. Finally, CIs are highly valued economically, but even more so personally. Discussions on funding in public health need to include non-health care costs and measures of real-life outcomes in order to increase accessibility and funding, and reflect the value CIs can have for adults.

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Disclaimer statements

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Conflicts Interest There were no conflicts of interest to declare among the authors at date of submission of this paper.

Ethical approval Ethical considerations: this study asked the views of adults with hearing loss, not patients, and did not ask for clinical data. Data was kept in compliance with the Data Protection Act. The study was carried out in accordance with The Ear Foundation's ethics procedures (more information in-text).

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