Cochlear Implants: The Young People’s Perspective

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Cochlear implantation is a relatively new procedure, which has already had significant impact on the lives of many profoundly deaf children and adults, in providing useful hearing to those unable to benefit significantly from hearing aids. After 16 years of cochlear implantation in the United Kingdom, there is now a body of evidence covering a range of outcomes, much of which covers perceptual and linguistic outcomes. This study looks at the impact of cochlear implantation on a group of 29 young people aged 13–16 years, using a semistructured questionnaire. It examines issues from the perspective of the young people themselves, including their understanding of and degree of satisfaction with the way their implant works for them, their social and communication abilities and choices, their educational challenges, and their identity. It concludes that the young people in this group feel positive toward their cochlear implants and the decisions made on their behalf by parents. Many have a flexible attitude to communication modes and an identity which is not fixed in terms of conventional descriptors.

Pediatric implantation was first carried out in the United Kingdom in 1989, and since then, over 2,700 children have received implants in the United Kingdom, with over half the profoundly deaf children starting school now having a cochlear implant (http://www.ihr.mrc.ac.uk/) Initial studies of the impact of cochlear implantation have focused on improvements in the ability to hear and on speech perception and production. Where spoken language has been studied, research has often been carried out in controlled environments rather than in real-life settings. An evaluation of recent research by Thou-tenhoofd et al. (2005) demonstrated that more information is needed about the impact of implantation on children’s everyday lives, at home with their family and at school, and there is a growing interest in the study of these areas.

One group of particular interest is teenagers who use cochlear implants. Adolescence is a time when individuals are developing independence, establishing their own worldview, and the sense of themselves as persons, with evolving identities. Tooher (unpublished), in her review of the literature on psychosocial issues faced by hearing-impaired adolescents, comments that during adolescence hearing-impaired young people have the additional challenge of developing their identity which may be dependent on the communication mode they use. She observes that for the first time they can make choices about their choice of communication type for themselves, independently of their parents. How these young people with implants see themselves and their deafness, where they belong in terms of deaf and hearing communities, and how their implant affects their views is important. It is of particular interest to those making the decision about implantation on their behalf, usually their parents, and to those supporting them educationally.

Although previous studies, for example, Gregory, Bishop, and Sheldon (1995) and Cambra (2005), have looked at family, social, and psychosocial issues with reference to severely or profoundly hearing-impaired young people, a review of the literature failed to find many studies which looked in detail at the lives of
those who have received cochlear implants. However, in one very recent study, Huber, Hitzl, and Albegger (2006) have reported on the educational and consequent employment status of young people with cochlear implants in Austria, suggesting that cochlear implantation facilitates integration into the hearing world. Additionally, Pans et al. (2006) reported on the development of a psychosocial support program for teenagers with cochlear implants, having found evidence of “problems related to their social–emotional development.”

Implantation is more often carried out with younger rather than older children, and until recently, it has not been possible to study teenagers in any detail as there were insufficient numbers to do so. However, with growing numbers implanted, increasingly there are teenagers with their own perspectives and experiences and able to discuss these. These young people are the focus of this study. The study includes those implanted very young as well as those implanted over the age of 11 years. Clearly, those who have received a cochlear implant in adolescence will have a different perspective to those who were implanted so young as to have little memory of life as a hearing aid user, and it is important to include their views.

Hallberg, Ringdah, Homes, and Carver (2005), quoting their earlier study in 2004, describe the need to move away from purely quantitative studies in looking at the outcomes of cochlear implantation in terms of standardized questionnaires or tests of speech perception and communication and toward qualitative studies which pick up on perceptions of quality of life and other psychological issues. Using a qualitative approach also has the advantage of tapping into the issues considered important by the young people themselves. Therefore, the primary method adopted in this study was a semistructured questionnaire. This study, in reporting the views of this group of young people with implants obtained through interviews, provides some of the first information to enable us to consider their opinions.

Methodology

This research project was designed to elicit the opinions of deaf young people with cochlear implants who were aged 13–17 years at the time of interview. Their views were sought using a semistructured interview procedure.

The sample was drawn from two major pediatric cochlear implant programs in the United Kingdom, Nottingham Cochlear Implant Programme (NPCIP) and the South of England Cochlear Implant Programme. Two mailings were undertaken. Of 128 invitations, 33 positive responses were received (26%), and 29 of the 33 were interviewed. No young person was excluded from the study. Where necessary, adaptations were made (e.g., simplification of language or ideas during the interview) and this was noted. A semistructured questionnaire (see Appendix) was designed to elicit information during the interviews across key themes.

Pilot interviews with three young people from a different cochlear implant program were undertaken to test the effectiveness of the questionnaire. In the light of these interviews, minor amendments were made to the questionnaire to make the language and the issues clearer to the interviewee.

The interviews were carried out by an experienced teacher of the deaf who had no connections with either implant program and was unknown to the young people. They took place at the young person’s home or school, as requested by them. It was emphasized that their comments would be confidential to the research group. Respondents were asked to indicate their preferred language and communication mode (sign or speech), and the interview procedure took account of this. All the young people requested either spoken language or spoken language supported by sign. British Sign Language interpretation was available but not requested.

Interviews were video recorded and transcribed by the researcher. The words of the young people were transcribed verbatim with any gloss clearly indicated. Where prompting was necessary, this was noted on the transcript.

Background data for all the young people interviewed was collected from the BCS System for Cochlear Implant Centres¹ used by both implant centers. This covered etiology, age of deafness, age of implantation, implant system used and number of electrodes in use, home language, and gender. These data were organized in the form of an attribute table.
QSR Nvivo software\textsuperscript{2} was chosen as the tool for analyzing the data obtained from the interviews scripts. All scripts were imported into Nvivo together with the attribute table. This table enabled exploration of potential variables, for example, age at implantation across the group. Preliminary themes that had been identified in the construction of the interview questionnaire (see Appendix), for example, deafness and the cochlear implant, family interaction, and experiences in school, were used to sort the data. Responses to particular questions or groups of questions within these themes were collected together and read by members of the project team. The researcher also coded the data using tree nodes to ensure that information contained in all the questionnaire responses was identified and classified—for example, collating references to bullying which appeared outside the particular question designed to elicit information on this subject. This type of coding also enables exploration of new, emergent themes and tighter classification of data.

Nvivo was interrogated to examine responses within the identified themes and to explore relationships. Where appropriate, these responses were cross-referenced with the variables contained within the attribute table to look for patterns in the data.

### The Young People

Although the sample came from only two cochlear implant centers and consisted of mainly young people from the Nottingham Cochlear Implant Programme, it nevertheless included participants from a wide area across England and Wales\textsuperscript{3} The young people were divided into three groups: those implanted early, under 5 years of age; those implanted between 5 and 11 years of age; and those implanted between 11 and 14 years of age. Table 1 shows the demographics of the groups.

All the young people in the research cohort were using a Nucleus Cochlear Implant; five had only partial implantation. Three young people reported that the number of electrodes in use had been reduced over time and were contemplating possible reimplantation.

Of the sample, one third (8, 33\%) attended mainstream school and a further smaller group (5, 11\%) a resourced mainstream school. A special school for deaf pupils was attended by half (15, 52\%) the group, with one attending another type of special school.

The study group was compared against the complete group of young people aged 13–16.11 years from the Nottingham implant program. This was felt to be a fair comparison as 27 of 29 young people were registered on the NPCIP. The age profile at implant,

### Table 1 Study Group attributes

<table>
<thead>
<tr>
<th>Group</th>
<th>Gender</th>
<th>Etiology</th>
<th>Onset of deafness</th>
<th>Average age at implant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early implanted (&lt;5 years), N = 13</td>
<td>Male 6</td>
<td>Meningitis 5</td>
<td>Congenital 8</td>
<td>3 years 10 months Range: 2 years 4 months–4 years 10 months</td>
</tr>
<tr>
<td></td>
<td>Female 7</td>
<td>Viral 1</td>
<td>Acquired 5</td>
<td>Unknown 7</td>
</tr>
<tr>
<td>Midimplanted (5–11 years), N = 12</td>
<td>Male 6</td>
<td>Meningitis 1</td>
<td>Congenital 11</td>
<td>7 years 4 months Range: 5 years 1 month–11 years</td>
</tr>
<tr>
<td></td>
<td>Female 6</td>
<td>Mondini 1</td>
<td>Acquired 1</td>
<td>Unknown 1</td>
</tr>
<tr>
<td>Late implanted (11–14 years), N = 4</td>
<td>Male 3</td>
<td>Meningitis 1</td>
<td>Congenital 3</td>
<td>12 years 5 months Range: 11 years 5 months–13 years 6 months</td>
</tr>
<tr>
<td></td>
<td>Female 1</td>
<td>Genetic 1</td>
<td>Acquired 1</td>
<td>Unknown 1</td>
</tr>
<tr>
<td>Total group</td>
<td>Male 15 (52%)</td>
<td>Meningitis 7 (24%)</td>
<td>Congenital 22 (76%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female 14 (48%)</td>
<td>Other 3 (10%)</td>
<td>Acquired 7 (24%)</td>
<td>Unknown 19 (66%)</td>
</tr>
</tbody>
</table>
onset of deafness, and the range of etiologies of the study group mirrored those of the complete group and were therefore a representative sample. However, in terms of schooling, there was a bias in the study group toward education in special schools; 52% of the study group attended a special school for deaf pupils as compared with 28% in the complete group of those who were invited to participate.

Findings

A number of common themes emerged from the data:

- Using the technology
  - Advantages
  - Disadvantages
  - Understanding of the technology
- Making the decision to implant
- Communication
- Identity
- Education
- Advice to others

Using the Technology

At the time of the study, all except two of the young people reported that they wore their processors all day every day. This was established by asking the young people how much the implant had been worn the previous day and checking this was their usual practice. The more general question: “How much do you wear your implant?” can be more susceptible to over positive responses. The two who did not wear them constantly were still showing high levels of use, but did not wear it when they wanted “to relax and watch TV” or “until later in the morning at weekends.” This in itself is interesting, indicating that for these two young people, using an implant involves some effort or choice and is not the same as natural hearing for them.

Overall, there was the feeling that the implant was essential to them, with many of the group reporting that they felt bereft if there was a problem and they could not use it (12, 41%). The following comments illustrate their thoughts on what happened if there was a problem and they could not use their implant:

- “I miss hearing. I like hearing. I am always fed up when it gets broken.” (male; 13 years; spoken language)
- “I don’t like it if it’s not working because I don’t know what is happening.” (female; 13 years; sign and speech)
- “I feel very sad, a bit worried, a bit upset.” (female; 14 years; sign and speech)
- “Can’t hear anything or understand.” (female; 13 years; sign and speech)
- “I hate it so much. Very frustrating because I can’t hear.” (female; 16 years; spoken language)

This very high level of use may or may not be characteristic of the population as a whole, as not all those invited to take part in the study did so and ethical constraints meant the others could not be followed up. It may have been that those volunteering to take part were those who found their implant valuable. However, at the very least it does suggest that a study such as this could easily identify 29 young people who were committed users of implants and felt very positive about them.

Advantages of implantation. The advantages of the implants to the young people were many and various. Every young person had something positive to say about his or her cochlear implant, and overall, positive statements outnumbered negative ones by 9:1.

A couple of young people were particularly excited by the benefits of their cochlear implant:

- “The average that a hearing person can hear is 20dB. I can hear 25dB—without implant I wouldn’t manage. I can hear a lot better … you feel much more confident talking to the teacher because you can hear really well with it.” (male; 15 years; spoken language)
- “When I had hearing aids when I was little (they) didn’t help at all … but cochlear implant—wow! It’s amazing to hear everything.” (female; 16 years; spoken language)

When asked “on a scale of 1–5 how much can you hear with your cochlear implant?” (5 indicating a high level of benefit), the range was from 3 to 5 with the average 4.4.
The greatest benefits of implantation cited were the following:

- Improved interaction with family and friends (15, 33%)
- General awareness of sound, music (10, 22%)
- “Better than hearing aids” (7, 16%)
- Improved speech production (4, 9%)

However, there are other advantages:

- “It helps me relax, really good, and I miss talking.” (male; 15 years; spoken language)
- “If I have my hearing aid on it embarrass me. If two people talking if I have my implant I can hear what both saying. I can see what is going on behind me.” (female; 13 years; spoken language)

Only one person gave using the phone as a main advantage of having a cochlear implant. A question directly related to telephone use revealed a range of ability to use the telephone by speaking while almost all used text communication.

When asked directly whether there were any changes that could be made to improve their implant, 24% (7) of the group were unable to think of anything, and 52% (15) of the group cited suggestions that were aimed at extending the use of the implant, for example, 34% (10) suggested that the speech processor should be waterproofed. One person wanted the implant to be made permanent and another a better design such that the electrodes would last a lifetime.

Disadvantages of implantation. A number of questions were asked to ascertain the possible disadvantages of cochlear implants. When asked directly to list disadvantages, 11 (38%) of the group failed to come up with anything negative about their implant. Of those who gave disadvantages, these included:

- Headaches which they associated with their implant (4, 14%)
- A number complained that the postaural speech processor falls off during energetic activity, particularly sports (3, 10%)
- Some commented on the restrictions of cochlear implantation, for example, not playing rugby or deep scuba diving (2, 7%)
- Having the cochlear implant operation/going to hospital (2, 7%)

However, in response to other questions, the teenagers also suggested that there were situations where it could be difficult to use the implant. Problems were experienced most often when noises were at the extremes, either very loud or very quiet, and 11 (39%) mentioned difficulties where there was a lot of background noise:

- “In noisy situations it is hard to hear people talking.” (male; 15 years; spoken language)
- “In noisy environment, a crowded place like the town also in the train station.” (female; 16 years; spoken language)
- “In a noisy environment. At parties, sometimes ladies talk to me and ‘sorry I didn’t get that’.” (female; 14 years; spoken language)

- “It is hard outside because the traffic very loud.” (female; 13 years; sign and speech)
- “Really quiet sounds. Mum would call me and I wouldn’t hear it. Wouldn’t hear it in a crowd as well.” (male; 14 years; spoken language)

It was also clear that situations involving many people could be difficult as well as situations where people did not understand or pay attention to the needs of the implant user. Situations in which people were talking all at once was cited by 4 (14%) young people:

- “Sometimes hard. My friends, family talking. Bit hard for me listen like all talking all the time.” (male; 14 years; spoken language)
- “Sometimes my form, the children in the classroom, all chat chat chat, can’t hear.” (female; 14 years; sign and speech)

The young person may not realize what they have not understood at the time, and neither may those around them: “They just carry on, don’t realise and just carry on and then a couple of weeks later I go I didn’t really understand. I have a really confused face and I say I think I understand and they go ok.” (female; 14 years; spoken language)

Concerns about the technology (10, 35%) gave rise to a further problem for some young people because the implant was so useful to them that they felt
dependent on it and thus there were fears and worries about it going wrong. This relates to the earlier discussion where many felt bereft if something went wrong. Ten of the young people demonstrated anxiety about this, four expressed concern regarding long-term failure of the implant, and others (9, 31%) described how much they hated to have it not working, even for a brief period.

- “The fact it can break down and the fact that some time in your life have to have another operation to replace it.” (female; 14 years; spoken language)
- “I just worry and get a bit upset because I don’t like it when cochlear is gone. I like it to work all the time and I was a bit worried if no sound. Nothing.” (female; 14 years; sign and speech)

This was a reality for three of the young people who reported that the number of electrodes in use had been reduced over time and they were having to contemplate possible reimplantation. Archbold, Lutman, Gregory, O’Neill, and Nikolopoulos (2002) reported that for parents this was also a major issue, the fear that the technology could fail and another operation would be necessary.

There were also some more general concerns about the workings of the implant and the effect that having something like that inside one’s head could create:

- “Sometimes you start to panic, wonder whether it’s going wrong on the inside. I’m fine with being deaf it’s just the actual breaking down. It’s like having some of your organs failing.” (female; 14 years; spoken language)
- “I get hit. It kill me. There’s the cochlear in the head, it is drilled into the skull. Take some bone out of the skull. Fit cochlear in place but that bit of skull is thin so when hit, crack it. Give me brain damage. If you smack hard it kill you.” (male; 15 years; sign and speech)

These comments illustrate the difficulties for some of these young people in coming to terms with an implant, although they may recognize the benefits and, in some cases, a lack of understanding of the technology they have implanted within them.

Understanding of the technology. We were interested to find out how much the young people did in fact know about the implant itself and the way it worked. For the most part their understanding of the way the implant worked was often basic with two thirds (19, 66%) giving only very limited description of the technology and one quarter (7, 24%) not being able to give any information at all. Only one tenth (3) gave a full explanation. Examples of limited descriptions are given below:

- “There’s a little thing inside my ear and the magnet on top. It transfers the sound into your brain. It’s how I think it works.” (female; 14 years; spoken language)
- “Inside in cochlear attached to some nerves and make me hear.” (male; 13 years; spoken language)
- “Picks up electrical signal, put a little magnet in your head that makes it stick better but I don’t know exactly how it works.” (male; 15 years; spoken language)

There were some more comprehensive accounts. For example:

- “The outside sounds I hear go through the microphone then the computer imports the sound through the microphone into the cochlea. Turn them into signals that are sent to the brain” (male; 14 years; spoken language)
- “They have to put a special coil into your cochlea which then helps send impulses to your brain so that your brain can understand the noises that are being made. The speech processor you get is the main power source, taking sounds from outside.” (male; 16 years; spoken language)

Although most could not give a full description of the technology, the majority had few problems in knowing what to do if it should go wrong, an issue which is, of course, more important to them. They all discussed changing the batteries, checking anything that might not be working and alerting their parents or teacher of the deaf. Most of them reported that if there was a serious problem they would contact their cochlear implant team and they seemed confident it would be remedied.
However, although this means that on a daily basis most were competent at managing the technology, it also means that a significant number did not have an understanding of the technology they were to be using for the rest of their lives, and maybe did not have sufficient information on which to make major decisions which may be required such as that of reimplantation.

The Decision About Implantation

Although those interviewed clearly indicated that they benefited from their implants and chose to wear them, the decision to have the implant and the operation involved is not necessarily an easy one. Colletti, Carner, and Colletti (2006), Economides et al. (2006), Ligny et al. (2006), and Nikolopoulos, O’Donoghue, and Archbold (1999) all demonstrate that implantation is more effective at younger ages, and thus, more often than not, is a decision that has to be made by parents on behalf of their child. Some authors opposing implantation as a procedure to use with deaf children have argued that because it is an elective measure involving surgery, it should only be carried out when the child is of an age when they can decide for themselves (Lane & Bahan, 1998). However, with the evidence of the effectiveness of early implantation, this is not realistic, and parents are faced with this decision earlier and earlier.

The group was asked what involvement they had had in the decision to implant and whether they felt they should have had more of an input. The majority of the group, nearly two thirds (18, 62%) were quite clear that their parents had made the decision and only 3 (10%) felt that they had made the decision themselves. The others felt they were involved but had not made the decision themselves. All those who felt that they had been involved in the decision were over 8 years of age at the time. In general, they gave the impression that the notion they should have had more of a say in the decision-making process is untenable. In this context it is interesting that all the young people seemed aware that having a cochlear implant fitted does actually involve someone (usually your parents) making that decision for you.

- “I can’t make the decision myself. I was really young at the time. I didn’t know much about. I am really pleased they made that decision.” (male; 15 years; spoken language)
- “I respect them for making the decision.” (female; 15 years; spoken language)
- “I was too young to understand but I’m ok with that. I know it was for my good to have the best outcome in life.” (female; 14 years; spoken language)
- “When I was young I didn’t have responsibility. I don’t know anything and my mum and dad they did the whole thing.” (male; 14 years; spoken language)

None of those in the group seemed to be resentful of their parents for taking this decision, or not involving them, but rather the reverse—that they were grateful for the choice they had made. Those implanted after the age of 12 years were likely to have had more of a say in the decision. For two of them, the decision was not made easily but after some consideration:

- “I did not want it for a while but when my teacher told me about it in more detail, I heard more and it seemed good, I thought I will have one.” (male; 15 years; spoken language)
- “I said no for a while but then I decided to have one because I realised that I can’t hear anything for the rest of my life. I thought I would have a cochlear implant and see what difference it made.”
- Interviewer: “Why didn’t you want it to start with?”
- “I think I was a bit scared of the operation.” (male; 15 years; spoken language)

For another boy, although he described his mother as making the decision, he had clearly been involved and consulted:

Interviewer: “Do you remember who made the decision for you to have your implant?”

“It just had to happen, it was my choice and my Mum’s choice.”

Interviewer: “Were you involved in the decision at all?”

“When it come down to it … it was my Mum’s choice because I did not fully understand what
was going on because I was young and she had to make the right decision for me.”

Interviewer: “Did you talk about it at the time?”
“We did and she explained everything.” (male; 16 years; spoken language)

Overall, the group accepted that for some children parents would make the decision, they expressed no surprise about this and felt that their parents had acted on this in their best interest. Perhaps the greatest testament to this is the assertion of three young people who were facing possible reimplantation due to failed electrodes that they would not hesitate to have the procedure repeated when the time was right.

Communication

The young people did not seem to be surprised to be asked a question about their preferred mode of communication. Many of the young people could sign, either using sign-supported English as their preferred form of communication or as a second mode/language. Twenty of the cohort (69%) used spoken language as their preferred mode of communication, the others using sign-supported English. It is interesting that although implants are associated with spoken language, many of the young people could sign and were flexible in their use of language and mode, varying it depending on the situation:

- “With my deaf friends I sign, with the others I talk.” (female; 14 years; sign and speech)
- “I sign with deaf but I communicate with hearing people.” (female; 16 years; sign and speech)

For this group, communication rather than language choice seemed to be the most important issue. They will use sign, speech, or text as seems most appropriate to them in any given situation. As already mentioned, one third state as a main advantage of the implant, improved interaction with family and friends and over two thirds (20, 70%) felt they were understood by their family all or most of the time.

“Yes cochlear implants work because you can hear more, talking to friends, understand everything, go out have a good time. If have a cochlear implant easier to have a good time …” (female; 14 years; sign and speech)

This is consistent with research looking at parental perspectives on implantation, Archbold et al. (2002) and also Sach and Whynes (2005) where 57% reported that family life had benefited from cochlear implantation due to improved communication.

Identity

A key issue in the debate about the appropriateness of implantation for deaf children has been around the notion of identity. The aim of an implant is to improve the ability to hear and access sound. Nikolopoulos, Archbold, and O’Donoghue (1999) and Peng, Spencer, and Tomblin (2004), among others, have reported consequent improvement in speech and spoken language skills, which may carry the implication that to hear is better. To change or not to change? Would those with implants feel themselves to be deaf or hearing? Moreover, what would be their views on whether it was better to be deaf or hearing? Wald and Knutson (2000) questioned a group of 45 adolescents with and without cochlear implants regarding issues of Deaf identity and concluded that the groups were similar in many respects but that the cochlear-implanted group rated hearing identity as a desirable goal more favorably than the nonimplanted group. The authors attribute this to the audiological benefit that the implanted group received.

When asked if they saw themselves as deaf or hearing, the replies varied:

- “I can’t hide the fact that I’m deaf.” (male; 15 years; spoken language)
- “Some days deaf, some days hearing.” (female; 13 years; spoken language)
- “Sometimes I feel like I’m hearing, sometimes I feel like I’m deaf. I can’t feel it (gestures to implant).” (male; 15 years; sign and speech)

Only 6 (21%) of those interviewed described their identity as hearing; all the rest saw themselves as either deaf or deaf and hearing. The majority therefore perceived themselves as deaf to some degree. Six present as having a strong deaf identity because they answered
"deaf" to all three questions, asking whether they or others thought of them as deaf or hearing. There was no clear link between perceived identity and schooling, although two young people attending sign-dominant special schools gave their identity as deaf. Beyond this there was no relationship between the use of speech and/or sign and their own identity as deaf.

For some of the group implanted at an older age, implantation followed the sudden loss of hearing. Polat (2003) argues that those who acquire a hearing loss at a later stage in life may find it more difficult to accept their deafness and may demonstrate poorer adjustment than those who were congenitally or prelingually deaf; one young man, implanted following sudden acquired deafness at the age of 12 years was clearly struggling with this:

- “I know I’m deaf … without your cochlear implant you are always going to be deaf … it is hard to cope with … I always want to be normal.”

- “Just the fact that it is not very comfortable to have behind your ear for a long time … it can get to you sometimes how people have to ask you questions … people don’t understand it is just hard to get used to the whole thing about being deaf … makes things harder than they need to be.” (male; 16 years; spoken language)

Another girl commented:

“… it would be harder to adjust to having a cochlear implant later on you have to get used to having a cochlear implant, to the fact that you are deaf—I have had eleven years to get used to it but there is a girl at my school she has only had a cochlear implant for a couple of years and she is really not comfortable with it at all—she can’t bear being deaf … even though she is in a school for the deaf she is not comfortable, it takes time to adjust so you have to consider that.” (female; 14 years; spoken language)

Some commented on the fact that because of their good spoken language skills and, in particular speech intelligibility, the young people were sometimes perceived as hearing by people who did not know them well. This is consistent with the study in 2005 by Punch and Hyde, looking at “hard-of-hearing” adolescents.

- “For the first time they might think that I’m hearing but then they realise, then they ask me if I’m hearing or deaf and I tell them.” (female; 13 years; sign and speech)

- “Don’t really know because everyone thinks I am hearing. To be honest inside me I’d say I’m hearing because I can hear what everyone is saying.” (male; 14 years; spoken language)

Such comments seem to suggest some ambiguity as to whether they think of themselves as deaf or hearing. Peng et al. (2004) have reported that the speech of the majority of those profoundly deaf implanted early is easily intelligible. This may lead to a deaf young person with an implant to being perceived as hearing. To be thus perceived, yet see oneself as deaf is likely to create some tension particularly for those who felt themselves to be deaf yet also felt hearing to be desirable. It may be that they are in the position of feeling that they do not belong to either the deaf or the hearing world. In addition, it may be that, if perceived as hearing because of quality of speech intelligibility, these young people do not have the accommodations that they need in school—particularly in mainstream school and in noisy conditions, as they have already commented. This issue was also reported by Punch and Hyde (2005) who found that people who treated students “normally” forgot to make these adjustments.

Another interpretation would be that they are not only realistic but also positive about their identity with respect to the deaf and hearing worlds. They are deaf, have a hearing loss, and they may sign but in many ways, and because of their ability to hear and their use of spoken language, they also see themselves as part of a hearing world. This may be reflected in the flexible use of language and mode, which is characteristic of many of them. As for many other people, identity for these young people is not a fixed concept, setting identity in a one-dimensional way but reflects the complexity of their experience, a complexity which for many of them is positive.

As Hyde and Power comment:

“The question would seem to be not the “either/or” one (will the implant make the child a hearing
person or the nonfitting make them a Deaf person) but a question which results in the best ethical appreciation of the risks and the benefits that eventuate. The best outcome for the individual may be competence and affiliations with both hearing and Deaf communities …” (Hyde & Power, 2006, p. 7)

Education

Within the group, the young people were educated in a range of different settings. Just over half the group were in special schools, including one young person in a school for children with learning difficulties. However, it should be noted that this was higher than the percentage across the cohort as a whole, from whom the majority of this study group was drawn. Of the 20 who were in mainstream, 5 (17%) were in schools with a resource base for hearing-impaired children. The general trend in this study was that following on from a primary mainstream placement, the young people moved on to a more specialized provision for their secondary school education. Although this group may not be representative in terms of secondary provision, this trend was also found in the Scottish study, reported by Thoutenhoofd (2006) when faced with the more challenging acoustics and language and curriculum of secondary schooling, the young people had moved toward specialized provision.

Two thirds of the young people (22) felt that their cochlear implant helped them to understand the lessons. Six (21%) stated that their implant helped them most or some of the time with two in this group stating that the use of sign support was equally important. Some of those being educated in mainstream schools reported that they depended on their teaching assistant (TA) for support:

“Both—cochlear implant is important to listen to teacher but TA is important to work with me to understand—for example, write it down, explain, what to do, how to do it, make me understand.”

(female; 14 years; sign and speech)

Some subjects are more difficult than others:

“Yes but in Spanish and science they have videos. I don’t understand a word, I’m just sitting there watching the screen. In Spanish I have a CD and they speak and I’ve got to understand what they are saying … I hear something but it doesn’t make sense … the implant helps me hear more but the TA helps me understand.”

(female; 14 years; spoken language)

A number of the young people expressed the same view that although the implant helped them to hear, they still relied on a support worker or note-taker to help them understand. As stated before, the young people appear to rely heavily on their systems, and one young person is so dependent on his cochlear implant that he refuses to go to school if it is not working.

Overall, 33 statements from 22 young people were coded as negative experiences in relation to school (including contact with teachers). These reflected their experiences as a whole and not just in their current school. Some compared their old and new schools with mixed feelings when asked about the move to secondary education:

“Because primary school is not a deaf school, my new school got whole deaf children and we use headphones so that we can hear everybody but at my old school we just had the teacher and me.”

(male; 15 years; sign and speech)

For the deaf pupil, as for hearing pupils, transfer to secondary school is a potentially stressful event. When asked if anyone had done anything to make the transfer easier, 10 (34%) said no, 8 (28%) yes, and 3 (10%) felt they got support but had to ask for it.

A couple of young people talked about the difficulty of transferring to a school where the prevailing communication mode was different from theirs.

One young lady was feeling very isolated in her rural mainstream secondary school: “Sometimes I don’t understand … it is too hard for me, the teacher—I don’t understand what she is saying I’m quite frightened and upset”

(female; 14 years; spoken language). This of course describes the situation for many of the young people at school or in social situations. It can be a dilemma to not only want to be treated in the same way as others but also needing some help or modification in such situations.
This young person was one of five (17%) who experienced bullying at school, and this together with other accounts of spiteful behavior accounted for the rest of the negative experiences cited. Dixon (2006) cites research with deaf/hearing-impaired adults where 67% reported bullying at school with transfer to secondary school being a particularly difficult time. No association was found with type of school attended. This is consistent with the results from this study. However, there was no observed association with an oral approach as suggested in Dixon’s study.

One young man revealed that he had been bullied on his transfer to a special school because his speech was perceived as poor by his more oral peers and he relied on signed support. Another girl reported experienced bullying over a period of years. She was fully integrated into a mainstream school. The girl who was ostracized by her hearing peers was also fully integrated into a mainstream school and was hoping to transfer to a special school even though this meant boarding away from home. The rejection appeared to be based on her difficulties with interaction with her peers. Another teenager attended a resourced mainstream school and reported name-calling and general verbal abuse. Consideration had been given as to whether she should transfer to a special school for the deaf (using sign language) but she was reluctant to do so as she had established oral language skills.

Advice to Others

As a way of assessing their attitude as to the value of implantation, the teenagers were asked two questions about advice they would give to someone considering having an implant.

Their replies were characterized by sensitivity to the proposed situation and also the complexity and thoughtfulness of the responses.

The first scenario was a teenager who had become deaf as the result of a road accident, and the second scenario described the parents of a young deaf child who had been told that their child was a suitable candidate for a cochlear implant.

In answering the first question one young person took into account the impact that the accident itself might have on the individual involved and indicated that for those not used to the idea of implantation, the concept of an implant might seem daunting.

“If you suddenly have a car accident I’m sure you will be still shocked by it and hearing aids would be a good thing at first because if it was an implant it would be a bit too stressful.” (male; 14 years; spoken language)

Others showed an awareness that implants are not the only route to take and suggest considering hearing aids:

- “Try hearing aids first” (male; 13 years; spoken language)

- “I would tell him to have hearing aids first, because there are a lot of people with hearing aids who have brilliant hearing, good speech as well. And if he takes the cochlear implant straight away maybe he might be unhappy about it. If he’s got hearing aids and he is still unhappy you know you can still have cochlear implant later, but if you have a cochlear implant you can’t really change back.” (male; 14 years; spoken language)

- “It depends on how good (the) hearing test is. If it is bad should have cochlear implant. If it is good then have hearing aids.” (male; 15 years; sign and speech).

Some did see a cochlear implant as providing the best solution.

- “If you want to hear a lot better have it done. I think the implant is as close to normal as you can get.” (male; 15 years; spoken language)

Such concerns as to what was best for the child also featured in their response to questions about the deaf child and the family.

“It depends what you think is best for the child. A cochlear implant would be quite good but there is the side of the operation. The doctors have to be involved, have to look inside you, which might bother some people. And the cochlear implant doesn’t always work. There’s years of hard work, years of speech therapy, years of going to the hospital and having to overcome the technical problems and having to have another operation sometimes later, whereas with hearing aids you don’t have to have an operation to cope with them.” (female; 14 years; spoken language)
Overall, the view seemed to be that an implant should be considered, but after careful assessment:

- “Have cochlear implant, hearing aids not much help. Technology changing, future generations have better things.” (male; 14 years; spoken language)
- “If profoundly deaf I would strongly recommend cochlear implant because your cochlear implant is very useful, they do lots of things that hearing aids don’t.” (male; 16 years; spoken language)
- “Nowadays lots of young children have cochlear implants. I think it’s a good idea.” (female; 16 years; spoken language)

Some of the young people also perceived the need to reassure potential parents that the operation is not as worrying as it might seem:

“I would say not to worry about the operation because it is nothing really. You will recover soon and then I would say it really helps a lot and I would say the things that I can hear now but not before” (male; 15 years; sign and spoken language)

Comments

The interviews from these young people with implants gave rise to much rich information about how they viewed themselves in relation to others, their families, and education and highlight some significant issues. These may have implications for our future work with this growing group.

The young people in this study used their speech processors consistently, and any dissatisfaction that was reported was when having to manage without it. Many were unable to think of ways in which it could be improved, and the most popular suggestion was aimed at increasing the time for which it could be used, rather than removing it. Other studies have reported less strong rates of use and less adolescent satisfaction. Todini, Cavicchiolo, Ceriani, Ugazio, and Zaghis (2006) report 38% of prelingually deafened, late-implanted adolescents would not wish to be reimplanted should their system fail. No young person in this study offered this view. The group interviewed here all chose to be interviewed, and whether this represents the views of a larger group deserves to be investigated.

Although positive about their implants and what they give them and happy to recommend that others should consider cochlear implantation, they are pragmatic in their attitude about the relative benefits of hearing aids and implants when giving this advice. They suggest that implantation should be considered, but that it needs careful consideration.

Hyde and Power (2006) discuss the issue of informed consent at length, particularly with reference to elective surgery and Deaf cultural issues. They quote international legislation on the rights of children supporting their right to be involved and informed in decision making, relative to their age and maturity. However, the young people in this study gave no evidence of having problems with the issue of consent. They felt that it was their parents’ responsibility to make the decision on their behalf and that it had been the right decision for them. Older young people were included in discussions but might still rely on their parent’s judgment. Some who were faced with the real prospect of reimplantation were clear that they would go ahead with it.

However, many of the young people in this study did not have a good understanding of how their internal cochlear implant worked and some were unable to give any explanation at all about its functioning. This has implications for future work with this age group, who, if they are to make rational decisions in the future about situations such as reimplantation, or increasingly, bilateral implantation, need to understand the technology they wear more fully, and its implications. This is information that their parents received when they were younger and during adolescence they should have the opportunity to acquire it on their own behalf.

Although most of the young people in this study use spoken English as their main means of communication, they do not appear to have a “fixed” communication mode and are flexible, choosing to speak or use sign-supported English as feels appropriate to them. Placement in a particular educational setting with a strong oral commitment, for example, did not mean that the young people do not use sign between themselves or with signing deaf adults. Those who
prefer to use speech and sign in school may have intelligible speech, which enables them to function well in nonsigning environments.

This relates to the question of identity about which they were asked and which often emerges in discussions about implantation. Flexibility in communication mode is reflected in a perception of identity which is in general neither strongly Deaf nor hearing in this group. The majority recognize themselves as intrinsically deaf in the sense that they cannot hear without their implant but do not demonstrate a culturally deaf identity. Cochlear implantation has provided a new choice for deaf children and young people and one that is now used by the majority of profoundly deaf children. With developments in technology, earlier implantation, and increasing use of bilateral implantation, the benefits described by the majority of these young people are likely to increase for the next groups implanted and growing to be adolescents.

This group of deaf young people is the first to experience growing up as deaf, but with implants. In listening to them it may be possible to provide them with real choices, not those imposed on them by worlds that see themselves as hearing or as deaf.

To conclude:

The recognition that we can choose, that we can make choices, is a central point. Another aspect is the fact that it is the individual who makes choices and that this is an existential fact from which the person can never be free. However the choices are anchored in one’s own situation, not in the norms of the hearing world or the deaf world. (Ohna, 2004, p. 32)

Appendix

Semistructured questionnaire under the following headings:

- Deafness and your implant
- Other people
- Your family
- School/changing schools
- Friends
- Deafness and other issues

Notes

1. BCS System for Cochlear Implant Centres, Release 5.2 (2005) (Info@bawtry.net).
3. The research proposal and its information and consent forms received ethical approval at both centers. Invitations were sent to the families of the young people who were asked to respond by signing consent forms. The young people were then approached themselves and signed consent forms on their own behalf.
4. The data are discussed under the emergent themes, with quotations taken verbatim to illustrate them. The quotes are felt to be representative of the point made by a number of respondents. The demographic details following the quote give gender, age, and communication mode chosen.

References


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