# Exploring the experiences of teenagers with cochlear implants

Victoria Watson1, Carl Verschuur 2, Judith Lathlean3

*1 Hearing and Balance Centre, ISVR, University of Southampton, Highfield, Southampton SO17 1BJ, UK.*

*2 University of Southampton Auditory Implant Service, University of Southampton, Highfield, Southampton SO17 1BJ, UK.*

*3 Faculty of Health Sciences, University of Southampton, Highfield, Southampton SO17 1BJ, UK.*

*E-mail:v.watson@soton.ac.uk*

Key words: cochlear implant, teenager, experience, surgery, rehabilitation , deaf, identity.

# Exploring the experiences of teenagers with cochlear implants

# Abstract

*Objectives:* Teenage cochlear implant users’ perceptions of deafness, surgery, fitting of the device and life as a cochlear implant wearer were explored in order to gain a more comprehensive understanding of teenagers’ experiences of living with the device.

*Methods:* Semi-structured in-depth interviews were undertaken and analysed using thematic analysis.Ten teenagers aged 14-16 years with at least one cochlear implant were interviewed.

*Results:* Seven teenagers experienced great pre-operative anxiety and two reported significant post-operative pain. Four of the teenagers described a mismatch between their expectations and the disappointing reality of adjusting to the device. However, all the teenagers reported an enhanced sense of well-being as a result of being able to interact more easily with their world around them. The teenagers differed in the extent to which they identified with the hearing and deaf world.

*Discussion:* Despite the early challenges, over time the teenagers experienced many functional and psychosocial benefits. Most felt their lives were now easier as a result of the cochlear implant(s). They described complex, flexible identities.

*Conclusions:* By giving prominence to the teenagers’ voices this study has added new knowledge concerning their experience of surgery. The findings also more fully revealed the challenges of adjusting to the device and the impact of having a cochlear implant on the teenagers’ identities. Clinical recommendations are made to address the gaps in service highlighted by these findings.

Cochlear implants have dramatically changed the hearing and communication possibilities for severe and profoundly deafened individuals who gain little or no benefit from hearing aids. There are around 11,000 cochlear implant users in the UK; of those more than 500 are teenagers (13-19 year olds) and their numbers are growing (Ear Foundation, 2016; personal communication with UK cochlear implant centres). Teenage cochlear implant users have distinct needs, including dealing with the challenges of adolescence and living with deafness and a cochlear implant. Ensuring that they are well supported is important. With rising numbers there is growing interest in the experiences of cochlear implantation in this age group.

Previous research involving teenagers with cochlear implants is limited. It is only recently that those implanted as small children have reached adolescence (Mance and Edwards, 2012). Research has focused on audiological outcomes such as speech perception (Kiefer et al, 1996), including in those teenagers who were pre-lingually deafened (Schramm et al, 2002; Shpak et al, 2009). However, pre-lingual deafness (being deafened before language is acquired) can be associated with poorer outcomes compared with post-lingual deafness, if there is a delay in implanting the child. This has been attributed to auditory deprivation, where peripheral neural degeneration and the brain’s ability to process auditory information is limited resulting in reduced cochlear implant benefit (Shpak et al, 2009).

The aim of the present study was to explore wider outcomes to extend the knowledge base and understanding about the impact on teenagers’ everyday lives of having a cochlear implant. The literature describing the non-audiological outcomes of cochlear implantation in teenagers is sparse and dominated by quantitative approaches, often using measures not designed for teenagers. While this allows comparison with normal-hearing teenagers, using an instrument designed for the wider teenage population may not capture the important issues specific to teenagers with cochlear implants.

Studies utilising a variety of quantitative and qualitative tools have highlighted some of the social, psychological and educational benefits experienced by teenagers with cochlear implants. For example, the educational achievement, mental health and self-esteem of teenagers with cochlear implants have been found to be comparable to their hearing peers (Huber et al, 2008; Huber and Kipman, 2011; Sahli and Belgin, 2006). The literature also indicates that teenagers with cochlear implants have good social skills and a positive self-image (Moog et al, 2011). Teenagers with cochlear implants have reported a sense of belonging in both the hearing and deaf world, which is flexible depending on the situation (Rich et al, 2013). Research suggests that teenagers who feel part of their peer group have good psychological well-being, particularly if the peer group is hearing (Mance and Edwards, 2012).

Although these findings are encouraging, the methods used to explore these dimensions do not fully reveal the teenagers’ own perspectives. Capturing the perspectives of adults and children has been achieved using qualitative methods. Adult perspectives were explored using semi-structured interviews, which highlighted their experience as a ‘journey’ which ended with them ‘coming back to life’ following the switching on of the device (Hallberg and Ringdahl, 2004 p 118). Children’s views have been more difficult to examine and the lack of literature reflects this. The most successful approach was the use of ‘proxy’ reporting, where an adult (typically the parent/guardian) reported on behalf of the child. Using this method Archbold et al (2002) reported increased confidence and improved communication abilities in children following implantation.

Nevertheless, there remains a gap in the literature regarding an understanding of teenager’s experiences of having a cochlear implant and the issues that are important to them, relative to what is known about adults and children with this device. Health-related quality of life has been examined in teenagers with cochlear implants in a small number of studies. The questionnaires have typically been generic, though, and not specific to teenagers with a cochlear implant (Huber, 2005; Duarte et al, 2014). This is problematic since the dimensions may be too broad to fully capture the effects of having a cochlear implant, particularly in this age group who are dealing with the additional challenges of increasing autonomy, peer relationships and identity formation (Huber, 2005). Including a cochlear implant specific module in the quality of life measure (that is, questions that address aspects that are specific to teenagers with cochlear implants) in addition to the generic measures, indicated that adolescents report less positive outcomes (Warner-Cyz et al, 2011). This further highlights the need to consider teenagers as a separate group as their perspectives are likely to differ from children.

Only three studies have been found that have directly explored the experiences of teenagers with cochlear implants. Wheeler et al (2007), Mather et al (2011) and Hilton et al (2013) conducted individual interviews with small numbers of teenagers. The research highlighted that the teenagers generally felt positive towards their cochlear implant as a result of improvements in their listening and communication abilities, although adapting to a cochlear implant, particularly if it is the second device, can be a challenging process. The teenagers struggled with some of the practical limitations of the implants but also found it difficult when others were not aware of their listening needs. Whilst illuminating studies, the scope for exploring the user perspective was limited since there was no involvement from the teenagers in the design of the study. This is important since when the perspectives of the teenagers are not central to the research process, the teenagers’ perspectives may be ‘filtered through the interpretations of adult researchers’ (Shaw et al, 2011 p4).

The purpose of this research was to explore the experiences of teenagers with cochlear implants in order to gain a deeper and broader understanding of the issues that are important to them. This new knowledge may enable services to better meet the needs of this age group.

# Method

*Recruitment and sampling*

This study was approved by the National Research Ethics Committee (reference 10/HO501/28). Additional approval was granted from the University of Southampton Institute of Sound and Vibration Research. A research committee at the school for deaf children granted permission for the interviews to be carried out at school under the supervision of a member of school staff.

Participants were recruited from two sites: a cochlear implant centre and a school for deaf children. The parents of every teenager between the age of 13 and 19 years of age who attended the cochlear implant centre in this study were emailed by a member of staff to introduce the study and to ask them to discuss it with their child. Six parents agreed to bring their child for interview. The researcher emailed a consent form, study information sheet and the interview questions to the parents, to share with the teenagers. Three of the teenagers who agreed to participate were under 16 years of age so parental consent was sought for them (Alderson and Morrow, 2011).

All of the teenagers who wore one or more cochlear implants and who attended the school for deaf children were invited by letter to be interviewed about their experiences of having the device. Four teenagers agreed to take part (S7-10). Parental consent was sought for two of these participants. The teenagers were also asked to complete a short questionnaire when they attended the interview, which asked about their demographic and hearing history.

*Data collection*

Semi-structured interviews were used as they allowed the teenagers to tell their own stories, using open questions which allowed participants to explore ideas on their own terms and introduce other topics which may be new to the researcher. The interview schedule comprised 15 questions relating to the teenagers’ experience of living with a cochlear implant, from making the decision to have the operation to how their life is now (Appendix). The interview questions were informed by key research papers (Wheeler, 2007; Mather et al, 2011) and earlier development work with teenagers with cochlear implants not detailed in this article.

The teenagers from the cochlear implant centre were interviewed in a clinic room at the centre with a member of staff present. This was a requirement of the cochlear implant centre. The researcher asked the member of staff to leave the room when questions 9 and 10 were asked as these asked about the teenager’s experience of coming to the cochlear implant centre. Four interviews were conducted face to face (S1, S2, S5, S6). Two of the interviews were conducted via Skype because the teenager lived too far away to attend in person (S3,S4). The cochlear implant centre requested that parents stayed during the interviews, to support the teenagers. They were seated behind the teenager in order to minimise their presence and were carefully briefed to avoid them becoming involved in the interview in any way. The same member of cochlear implant centre staff was present throughout all of the interviews. The teenagers from the school were interviewed in the Audiology clinic room with the Audiology clinician present in an adjoining room. This was a requirement of the school, to ensure the safety of the pupils. All of the interviews were recorded on a digital voice recorder, with the parents and teenagers permission.

Participant S2’s interview was discarded due to the involvement of a British Sign Language (BSL) interpreter who diverted the course of the interview by changing the focus of questions and involving the teenager’s father, despite careful briefing beforehand. This teenager’s responses were not considered to be an accurate reflection of his views. None of the other teenagers required a BSL interpreter.

Nine interviews were used in the analysis. This number of interviews was considered large enough to demonstrate patterns across the data but was also small enough to allow deep analysis of the data in the time available and to retain the focus on the individual experiences (Braun and Clarke, 2013).

The average age of the participants was 14 years (range = 14-16 years). Four participants were female and five were male. All were congenitally or pre-lingually deafened. The age at implantation of the first cochlear implant ranged between 14 months and 10 years. Five teenagers had undergone sequential cochlear implantation, the most recent being one year prior to interview (S9). The age range at which the second implant was received was between 7 and 14 years. The average duration between the first and second implant was 8.5 years (range = 6-12 years). The range of duration of implant use (since the first cochlear implant was received) was 2 years - 14 years, 6 months. Seven of the teenagers interviewed had used a cochlear implant for more than 11 years. A summary of the teenagers’ demographics is presented in table 1.

All of the teenagers communicated with spoken English. One teenager also used BSL at school (S3) and another used it when talking with her deaf friends (S7). Four teenagers attended the same school for deaf children in the south of England (S7-10), the remainder were in different mainstream schools. All except two teenagers had received their implant(s) at the same cochlear implant centre in the south of England. Participant S8 had a visual impairment although they did not report that this had a significant impact on their life. The other participants did not report any additional needs.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Participant number** | **Age at time of interview** | **Gender** | **Aetiology/age at onset of hearing loss** | **Age at first CI** | **Age at second CI** | **Duration of implant use (since 1st CI)** |
| S1 | 16 years | Female | Unknown/ 12 months | 14 years | - | 2 years |
| S3 | 15 years | Male | Cytomegalovirus (CMV)/2 yrs | 10 years | - | 5 years |
| S4 | 16 years | Male | Congenital | 4 years,6 months | - | 11 years, 6 months |
| S5 | 14 years | Female | Meningitis/12 months | 14 months | 7 years | 12 years, 10 months |
| S6 | 15 years | Male | Unknown | 3 years | - | 12 years |
| S7 | 16 years | Female | Congenital | 3 years,6 months | 12 years | 12 years, 6 months |
| S8 | 16 years | Male | Meningitis/12 months | 18 months | 12 years | 14 years, 6 months |
| S9 | 15 years | Male | Congenital | 2 years | 14 years | 13 years |
| S10 | 14 years | Female | Congenital | 2 years | 8 years | 12 years |

*Table 1. Demographics of the interviewees.*

*Data collection*

The semi-structured interviews were carried out between December 2013 and November 2014. The interviews lasted between 18 and 32 minutes (mean = 26 minutes). The interview questions were based on aspects of having a cochlear implant that had previously been identified in the literature. Additional questions were included as a result of developmental work carried out during the early stages of this study where a small group of teenagers from the school for deaf children referred to earlier were recruited to design a website for teenagers with cochlear implants to share their experiences. Two teenagers added insights which informed

questions such as how the teenagers made the decision to have the device and the way in which they conceptualised their identity (‘hearing, deaf or both’). During the development of the website there were requests for information about how the surgical procedure was carried out, prompting the inclusion of a question about the operation. None of the teenagers involved in the website development were subsequently interviewed.

*Analysis of the data*

The interviews were transcribed by hand. Thematic analysis was used to analyse the transcripts. This is a qualitative data analysis method which involves coding all of the data by hand (identifying relevant words or phrases) then identifying patterns across the data (themes) which are of relevance to the research question.

Codes were developed more extensively where the data was richer, for example the teenagers experiences of surgery. Themes were developed from the major topics of the interview schedule since these were considered to reflect the main aspects of the teenagers’ experiences. Broader, main themes contained narrower, sub-themes within. Over-arching themes were used to organise themes into meaningful groups, such as those relating to the operation and post-operative time (Figure 1).

The findings of the analysis were checked with three of the participants who were interviewed at the school, in order to minimise the likelihood of misinterpreting their accounts. The teenagers considered a visual map of the over-arching themes,

themes and sub-themes, similar to figure 1 but with some wording adjusted to reflect the age range of the group. No differences in interpretation were noted.

# Results

During the interviews the teenagers recounted their experiences related to all aspects of having a cochlear implant, from making the decision to have the device through to their lives at home and at school. The key elements of the process are represented by seven themes and sub-themes where appropriate, as shown in Figure 1.

As highlighted by table 1, the group was heterogeneous in terms of duration of deafness, age at fitting of implant(s) and number of implants. Consequently, not all of the themes that are presented relate to every participant, and this is indicated where relevant.

The themes that capture the key aspects of the teenagers’ experience with the cochlear implant are presented and discussed.

A big jump

* Hoping for some improvement
* Wanting to get it over with
* A lot to take in

**It had a big impact on my life**

I never liked it

* A burden to wear
* Normal life is on hold

A horrible experience

* Feeling scared about the operation
* Unclear expectations of recovery
* Feeling a complete wreck

Sometimes you just want to switch off

* Using up all your hearing
* Positive regard for clinical service
* A long wait

**It was worth it in the end**

Belonging to both worlds

* I forget I’m deaf
* deaf not Deaf
* Connecting with both worlds so I can hear

Not a magical thing

Makes life all round easier

* Feeling better about myself
* A better understanding of the world
* Listening without effort

**‘A horrible experience’**

Figure 1. Overarching themes (in bold), themes and sub-themes.

**It had a big impact on my life: a horrible experience/I never liked it**

Feelings of fear and anxiety characterised seven of the teenager’s accounts of the time leading up to the operation. Two teenagers were too young at the time of the operation to recall the experience (S4, S6). Five of the teenagers were referring to their second cochlear implant, while two spoke about the time before their first device. Their accounts were similar irrespective of which device they were referring to.

When asked to recall the pre-operative time before her first cochlear implant one teenager reported that she ‘hated’ it (S1). One teenager (S8) reported that he was so afraid of having another operation that he had initially discounted the idea of a second cochlear implant, while another (S9) struggled to cope with his feelings before the operation for his second implant and explained that he *‘almost had a nervous breakdown’* waiting to go to theatre. Feelings of anxiety were associated with uncertainty about three areas: what the operation involved, the possibility of something going wrong and concerns about the after effects of surgery. As S8 commented:

*‘Well…it’s just cutting open my head and…it doesn’t sound good!’*

Four teenagers recalled having unclear expectations of recovery or no consideration of what it may be like, perhaps because they perceived it to be a straightforward process:

*S8: Um, well, I thought I’d just have an operation and go…that’s what I thought…I didn’t think about after.*

One teenager had discussed *‘all what it was about’ (S1)* with the audiologist but despite this he still struggled to overcome his fears. All of the teenagers in this study who could recall the pre-operative time reported that they had received a great deal of information and had been given opportunities to meet other teenagers or children with cochlear implants. Although two reported that they accessed information from professionals, peers and online, this did not reassure them. Two of the teenagers reported that they had managed to persuade themselves that the ‘cost’ of the operation for the second implant was worth the expected gain.

A range of other physical and psychological effects were reported after surgery by three of the teenagers. One teenager recalled that after her first implant she was ‘feeling a complete wreck’ after the operation (S1). Three teenagers reported dizziness and tiredness (all following their second implant). Two of the teenagers in this study reported substantial post-operative pain. One teenager was speaking about her first implant, the other about her second.

**Sometimes you just want to switch off**

The post-operative period was an unpleasant experience for four of the teenagers, who felt dissatisfied with the device and the slow pace of their recovery which limited their usual activities. This was the case irrespective of whether they were speaking about the first or second device. For eight of the teenagers, the implant was a burden to wear during the early days. Four teenagers described feeling underwhelmed when the device was switched on for the first time, with three experiencing an unpleasantly loud sound which they found difficult to get used to. Participant S5 likened it to ‘a massive drum being beaten in your ear’. Headaches and tiredness were also reported by three teenagers. Two of the teenagers struggled with the responsibility for managing the device, such as needing to wear it consistently. This was a challenging time for the teenagers who were trying to meet the demands of recovering from surgery and wearing the device which could often be painful.

Temporarily adjusting their lifestyle to the new implant was also difficult for four of the teenagers, who felt like normal life was ‘on hold’. Three teenagers reported feeling bored and frustrated at home, described by participant S9 as ‘cabin fever’. Another felt as though she could not properly relax until the processor had been removed. Attendance at school was interrupted for two of the teenagers as they tried to manage their tiredness. One teenager recalled that she had to adapt her behaviour to the new sound to avoid encountering loud sounds and that as a result ‘it was difficult to act normal’ (S5).

**It was worth it in the end: makes life all round easier/not a magical thing**

Despite these difficulties, many of the teenagers described benefits far beyond an improvement in hearing. Three reported an increased sense of well-being as a result of being able to interact more easily with the world around them. The cochlear implant enabled them to feel more independent, confident and relaxed around people. Five teenagers reported feeling happier and more sociable as they no longer worried about not hearing. One teenager also noticed that their deafness was much less prominent, even in challenging listening situations:

*‘when it’s like playing football and they’re shouting things and when I drop my cochlear [implant] they [say] ‘oh yeah you’re deaf, I forgot’ (S8)*

Through being able to interact more easily with friends and family, without drawing attention to their deafness, three teenagers felt they had regained their place in the hearing world as equal communication partners:

*‘I’m actually making conversation with them instead of blushing and saying ‘I’m sorry I don’t know’ (S1)*

The ability to interact more easily with others was also attributed by one teenager to an increased awareness of others emotional state, due to a better ability to detect subtle changes in their tone of voice.

All of the teenagers reported hearing a range of new sounds such as birdsong, music and train announcements. Hearing in noisy environments was also easier. Overall, participating in everyday life required less effort as S1 explained:

*‘ I don’t have to worry about listening really hard again…recently I went to the cinema and I can actually pick up, not everything, but most of the things they were saying cos when I went to the cinema [before] I had to watch it and basically guess what was going on and research what the film’s about beforehand’*

These findings suggest that the teenagers’ cochlear implants allowed them to find their place in their social worlds. However two of the teenagers also reported that they felt self-conscious, choosing to hide the device under their hair or wishing it could be ‘put on the inside’. These feelings were expressed by both a female and male participant. There were also some frustrations expressed by one teenager about the hardware and the fragility of the device.

**Belonging to both worlds**

The teenagers’ identities were complex and varied. Two teenagers saw themselves as deaf (S1, S9) (with a small ‘d’, indicating deaf in an audiological sense), two felt more comfortable in both the hearing and deaf worlds (S6,S8) and one felt that she was mostly hearing (S5). Teenagers with two cochlear implants reported a mostly hearing identity, with those with one device reported being either in the middle of the two worlds or mostly deaf. None of the teenagers reported a culturally Deaf identity (with a capital ‘D’, indicating an association with Deaf culture), indeed one teenager clarified that while she considered herself to be deaf she was not involved in Deaf culture.

The teenagers who aligned themselves mostly with the hearing world explained how their cochlear implants allowed them to forget about their deafness. Being able to function more like a hearing person allowed them to feel less different, which was reinforced when friends perceived them as hearing:

*‘I think all my friends see me as hearing…because I’m not actually, you know, I don’t appear any different to them’ (S5)*

Fitting in with hearing friends was important to two of the teenagers, who were keen to project a normal image by hiding the device under their hair or wishing it could be smaller and less noticeable.

The teenagers differed in terms of what degree of deafness was acceptable. For one teenager, being deaf was comfortable, while being Deaf was not. For her, being a member of the Deaf community with its particular cultural, social and linguistic characteristics represented an identity too different from the mainstream.

However, being part of the hearing world presented some challenges. For two of the teenagers there was a conflict between wanting to fully integrate with the hearing world but wanting others to accommodate their deafness. When others failed to do this it could be difficult to cope with:

*‘sometimes it’s quite frustrating because... everyone’s like ‘she hears fine’ and everything but ... actually it’s quite frustrating sometimes because I have to put in extra effort ‘ (S5)*

*‘it’s sometimes quite hard because they don’t look at you when they’re talking and they forget that I’m deaf too’ (S1)*

However, one teenager recognised the advantages of being part of the deaf world as a way of overcoming these frustrations. They embraced the benefits of bimodal communication and wanted to ‘*bring everything together*’ (S6). Maintaining a bicultural identity enabled him to communicate more easily:

*‘Most of the deaf people sign so much that they don’t speak that much so it’s kind of hard for me to communicate with them cos I want to speak but if I go to hearing only some things can be quite difficult listening to them, it’s very hard* *but in between, both together, much easier’ (S6).*

# Discussion

A key finding from our study was that teenagers reported major challenges before and after cochlear implant surgery. Almost all reported significant pre-operative anxiety and two recalled that they experienced substantial post-operative pain. Although most of the accounts related to experiences of getting a second cochlear implant, two teenagers’ experiences of the pre-operative time with their first implant were similar. The extent of the pain and discomfort post-operatively has not previously been highlighted by similar studies (Wheeler et al, 2007; Mather et al, 2011; Hilton et al, 2013). This is perhaps because previously teenagers have not been directly asked about their experience of the operation. However, this study indicated that it is a significant event for them which warrants further exploration.

Pre-operative anxiety among teenagers has been well documented in the literature for a range of elective surgical procedures (Chieng et al, 2014b; Jlala et al, 2010, Fortier et al, 2011). Studies have reported that teenagers have expressed strong emotions related to major surgery, including fear of the procedure and feelings of helplessness, which can last some time beyond the recovery from surgery itself (Rullander et al, 2013). After surgery there can be difficulties associated with a lack of social contact with friends in the early stages of recovery. The result of this increased anxiety can be an increased perception of pain post-operatively, and an unpleasant recovery period as a result (Chieng et al, 2014a, b). Anxiety invokes a similar physiological response to pain in the sympathetic nervous system and so increases in anxiety may exacerbate pain (Walding, 1991). It is possible that if teenagers are better supported to manage their feelings leading up to the operation, for example by receiving pre-operative counselling, some of the discomfort following surgery may be reduced.

The ways in which teenagers who wear cochlear implant conceptualise their identity has also been highlighted in this study. Of the five teenagers in this study who spoke about their identity, three explained the ways in which their cochlear implant allowed them to fit more easily into the hearing world whilst maintaining a connection with their deafness. Two teenagers reported identifying more with the deaf (oral) world. This tendency to align more with hearing deaf oral peers is well supported by the literature (Mance and Edwards 2012; Leigh et al, 2009. Punch and Hyde (2011) reported that parents noticed their child behaved more like a hearing person with a cochlear implant yet felt comfortable with both a deaf and hearing identity. In addition, teachers perceived that it was during adolescence that there was a move towards this bicultural state.

The literature suggests that contact with hearing peers, either inside or outside of school may be associated with identifying with the hearing community, along with expectations for developing spoken language and being in a mainstream school (Moog et al, 2011; Mance and Edwards. 2012). Children in mainstream schools are more likely to report bicultural and hearing identities, and this is an important determiner of self-esteem, regardless of how well they are doing with their cochlear implant (Moog et al, 2011; Bat-Chava, 2000; Leigh et al, 2009).

Social comparison theory supports the notion that having a cochlear implant means better identification with hearing peers who may be perceived to be better off. Having a cochlear implant makes accessing the mainstream easier, and as a result they are achieving a positive social identity by using their hearing to assimilate into the hearing world (Tajfel, 1981; Bat-Chava, 2000). However, the use of spoken language did not predict a mostly hearing identity for all of the teenagers interviewed in this study, suggesting other factors may be important.

The deaf identities described by two of the teenagers in this study indicate that they felt deaf in an audiological rather than cultural sense, (the latter usually denoted with a capital ‘D’). Hardy’s (2010) conceptualisation of identity among adolescents with cochlear implants most closely reflects the views of the teenagers in this study. In this model, identity is broadly classified into three types: aligning oneself with deaf peers, hearing peers or ‘the bridge between two worlds’ (p65). Group alignment is influenced by how easily the teenager communicates with deaf or hearing people and their friendship preference and experience. The teenagers in this study spoke about how they felt more hearing or deaf depending to some extent on who they were communicating with. Wheeler et al (2007), Rich et al (2012) and Ahmad et al (2002) also reported that teenagers’ identity is flexible, with benefits to be gained from aligning oneself with the hearing world but also from being able to communicate using sign language. It is not yet clear how identity in teenagers with cochlear implants develops throughout adolescence since the current theoretical models are inadequate. Further research is needed to explore this complex process, including the influence of ethnicity, religion and cultural backgrounds (Ahmad et al, 2002).

This study is limited by the narrow age range of the participants and small geographical area from which the participants were recruited. Seven teenagers had used a cochlear implant for 11 years or more and so recalling the early experiences with the device in some detail may have been difficult for them. In order to more comprehensively capture the experiences of this population a more diverse group should be consulted from a wider geographical area. There were also challenges associated with interviewing the teenagers. The presence of a parent or staff member may have curtailed or influenced their responses. More anonymous data collection methods such as email interviews may be preferable for this group (Mason and Ide, 2014).

A number of clinical recommendations are made based on the findings of this study. The most recent Quality Standards document from the British Cochlear Implant Group does not refer to teenagers as a separate group or include recommendations for tailored information provision or pre-operative psychological support, or in the early stages of adjusting to the cochlear implant (BCIG; 2016). The following changes in service provision are suggested:

* More support should be provided and over a longer period of time following surgery. There should be better management of expectations. This seems to be particularly important for those adjusting to a second implant.
* Whilst there is adequate information available regarding the operation and some aspects of the recovery process, little attention is currently given to the emotional impact of the procedure and how to manage these feelings. Teenagers may benefit from learning coping skills to help manage their anxiety before surgery as well as having the opportunity to express their feelings before and after surgery.

Specific recommendations include:

* Information about the surgical procedure for cochlear implantation should be given earlier than it is currently
* Information is presented in a variety of formats, including online
* Peer support/mentoring is used to help the teenagers manage their feelings in the pre and post -operative periods

This study highlighted several key issues for teenagers with cochlear implants that had not previously been fully discussed in the literature. They include the challenges of having surgery and adapting to the new device, whilst also developing one’s identity in the hearing world. There is emerging evidence that non-use or under-use of the second cochlear implant is becoming more prevalent (Emond et al, 2013). Possible reasons for this have been alluded to in this research, such as unmet expectations, but there are likely to be other factors that need to be explored. It now seems more important than ever to listen to the voices of teenagers.

# Acknowledgements

The authors would like to thank all of the teenagers who gave up their time to participate in this study.

# Disclaimer statements

**Contributors**

The first author was the lead researcher, with input from the second and third authors. The first author wrote the manuscript, with contributions from the second and third authors.

**Funding**

None.

**Ethical approval**

Ethical approval was obtained from the National Research Ethics Committee (10/HO501/28), with additional approval from the University of Southampton. Permission to carry out interviews at the school for deaf children was granted by the school’s research committee.

# Declaration of interest

The authors report no declaration of interest.

# References

Ahmad W., Atkin K., & Jones L. (2002.) Being deaf and being other things: young Asian people negotiating identities. *Social Science and Medicine,* 55: 1757-1769.

Alderson P., & Morrow V. (2011). Ethics of Research with Children and Young People. London: SAGE.

Archbold, S., Lutman, M., Gregory, S., O’Neill, C., & Nikolopoulos, T. (2002). Parents and their deaf child: their perceptions three years after cochlear implantation. *Deaf Education International*, 4(1),12-40.

Bat-Chava, Y. (2000). Diversity of deaf identities. *American Annals of the Deaf*, 145 (5):420-428.

BCIG (2016). Quality Standards: Cochlear implants services for children and adults.

Available from: http://www.bcig.org.uk/wp-content/uploads/2016/05/BCIG-Quality-Standard-2016.pdf

Braun V., & Clarke V. (2013). *Successful Qualitative Research.* London: SAGE.

Duarte, I., Costa Santos, C., Rego, G., & Nunes, R. (2014). Health-related quality of life in children and adolescents with cochlear implants: self and proxy reports. *Acta Oto-Laryngology*, 134, 881-889.

Ear Foundation (2016). Cochlear implants. Available from:<http://www.earfoundation.org.uk/hearing-technologies/cochlear-implants>.

Chieng Y., Chan S., Liam J., Klainin-Yobas P., Wnag W., & He H. (2014a.) Exploring influencing factors of post-operative pain in school-age children undergoing elective surgery. *Journal for Specialists in Pediatric Nursing*, 18(3): 243-252.

Chieng Y., Chan S., Liam J., Klainin-Yobas P., Wnag W., & He H. (2014b) Pre-operative anxiety and post-operative pain in children and adolescents undergoing elective surgical procedures: a quantitative systematic review. *Journal of Advanced Nursing*, 70 (2): 243-255.

Emond, A., Moore, M., Tjornby, C., & Kentish, R. (2013). Factors associated with poor use of sequential bilateral cochlear implants in young people: a preliminary audit of poor users. *Cochlear Implants International,* 14 (S4), S40-S43.

Hallberg, L. M., & Ringdahl, A. (2004). Living with cochlear implants: experiences of 17 adult patients in Sweden. *International Journal of Audiology*, 43,115-121.

Hardy, J. (2010). The development of a sense of identity in deaf adolescents in mainstream schools. *Educational and Child Psychology,* 27 (2), 59-67.

Hilton, K., Jones, F., Harmon, S., & Cropper, J. (2013). Adolescents’ experiences of receiving and living with sequential cochlear implants: an interpretive phenomenological analysis. *Journal of Deaf Studies and Deaf Education*, 18 (4), 513-531.

Huber, M. (2005). Health-related quality of life of Austrian children and adolescents with cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, 69 (8),1089-1011.

Huber, M., Hitzl, W., & Klaus, A. (2008). Education and training of young people who grew up with cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, 72 (9), 1393-1403.

Huber, M., & Kipman, U. (2011). The mental health of deaf adolescents with cochlear implants compared to their hearing peers. *International Journal of Audiology*, 50 (3), 146-154.

Kiefer, J., Gall, V., Desloovere, C., Knecht, R., Mikowski, A., & von Ilberg, C. (1996). A follow-up study of long-term results after cochlear implantation in children and adolescents. *European Archives of Otorhinolaryngology*, 253,158-166.

Leigh I. W., Maxwell-McCaw D., Bat-Chava, Y., & Christiansen J. B. (2009). Correlates of psychosocial adjustment in deaf adolescents with and without cochlear implants: a preliminary investigation. *Journal of Deaf Studies and Deaf Education*, 14(2): 244-259.

Mance, J., & Edwards, L. (2012). Deafness-related self-perceptions and psychological well-being in deaf adolescents with cochlear implants. *Cochlear Implants International,* 13 (2), 93-104.

Mason, D.M., & Ide, B. (2014). Adapting qualitative research strategies to technology savvy adolescents. *Nurse Researcher*, 21(5):40-45.

Mather, J., Gregory, S., & Archbold, S. (2011). The experiences of deaf young people with sequential bilateral cochlear implants. *Deaf Education International*, 13(4), 152-172.

Moog, J., Geers, A., Gustus, C., & Brenner, C. (2011). Psychosocial adjustment in adolescents who have used cochlear implants since preschool. *Ear and Hearing*, 32, 75-83.

Ohna, S. (2004). Deaf in my own way: identity, learning and narratives. *Deafness and Education International,* 6 (1): 20-38.

Punch, R., & Hyde, M. (2011). Communication, psychosocial and educational outcomes of children with cochlear implants and challenges remaining for professionals and parents. [doi: 10.1155/2011/573280](http://dx.doi.org/10.1155/2011/573280)

Rich, S., Levinger, M., Werner, S., & Adelman, C. (2013). Being an adolescent with a cochlear implant in the world of hearing people: coping in school, in society and with self-identity. *International Journal of Pediatric Otorhinolaryngology,* 77,1337-1344.

Sahli, S., Arslan, U., & Belgin, E. (2009). Depressive emotioning in adolescents with cochlear implant and normal hearing*. International Journal of Pediatric Otorhinolaryngology*, 73 (12), 1774-1779.

Sahli, S., & Belgin, E. (2006). Comparison of self-esteem level of adolescents with cochlear implant and normal hearing. *International Journal of Pediatric Otorhinolaryngology*, 70, 1601-1608.

Sarant, J. Z., Cowan, R. S. C., Blamey, P. J., Galvin, K. L., & Clark, G. M. (1994). Cochlear implants for congenitally deaf adolescents: is open-set speech perception a realistic expectation? *Ear and Hearing*, 15 (5), 400-403.

Schramm, D., Fitzpatrick, E., & Seguin, C. (2002). Cochlear implantation for adolescents and adults with prelinguistic deafness. *Otology and Neurotology,* 23 (5), 698-703.

Shaw, C., Brady, L, & Davey, C. (2011). Guidelines for research with children and young people. Retrieved from: <http://www.nfer.ac.uk/schools/developing-youngresearchers/NCBguidelines.pdf>

Shpak,T., Koren, L., Tzach, N., Most, T., & Luntz, M. (2009). Perception of speech by prelingual pre-adolescent and adolescent cochlear implant users. *International Journal of Audiology,* 48, 775-783.

Tajfel, H. (1981). Human Groups and Social Categories. Cambridge: Cambridge University Press.

Walding, M. (1991). Pain, anxiety and powerlessness. *Journal of Advanced Nursing*, 16: 388-397.

Warner-Czyz, A. D., Loy, B., Tobey, E. A., Nakonezny, P., & Roland, P. S. (2011). Health-related quality of life in children and adolescents who use cochlear implants. *International Journal of Pediatric Otorhinolaryngology,* 75, 95-105.

Wheeler, A., Archbold, S., Gregory, S., & Skipp, A. (2007). Cochlear implants: the young people’s perspective. *Journal of Deaf Studies and Deaf Education*, 12(3),303-16.

**Appendix**

Interview Schedule

There are no right or wrong answers. It is your views that I want to explore.

Are you happy for me to record the interview?

1. Did you decide to have a cochlear implant or did your parents? How did you/they decide?
2. If your parents decided for you, do you know anyone who decided to have a cochlear implant? How did they decide?
3. What was life like before your cochlear implant?
4. How did you feel about having the operation? What was it like?
5. Tell me about the recovery/early days with your implant.
6. What was the switch on like?
7. What do you like about having a cochlear implant?
8. What do you dislike about having a cochlear implant?
9. Tell me what it’s like coming to the cochlear implant centre for your appointments.
10. Is there anything you would change about them to make the experience better?
11. Do you think having a cochlear implant affects how you are with your friends and family?
12. Do you think having a cochlear implant affects work/school/college?
13. How do you see yourself? Deaf, hearing, both or something else?
14. Is there anything you would change about your cochlear implant?
15. Is there anything else you want to say that would help me understand what it’s like to have a cochlear implant?