Adolescents’ Experiences of Receiving and Living With Sequential Cochlear Implants: An Interpretative Phenomenological Analysis

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There is currently a unique opportunity to examine the experiences of young people who receive a second sequential cochlear implant (SCI), after only having had 1 cochlear implant (CI) for most of their lives. Eleven young people who had opted to receive an SCI were interviewed. Interpretative phenomenological analysis resulted in the identification of 6 master themes. Most participants enjoyed improved confidence and social well-being following their SCI and felt that 2 CIs were superior to 1. The majority identified themselves as hearing and deaf, but not culturally Deaf, as they strived to live in the hearing world. However, this was not without challenges and many young people experienced feelings of difference in the hearing world. These findings have clinical implications in terms of the role of clinical psychologists and other mental health professionals in CI clinics and in providing information to families making decisions about CIs. These findings add to the emergent deaf identity development literature in young people with CIs.

Children and adolescents (hereafter referred to as young people) who are severely or profoundly deaf are eligible to receive cochlear implants (CIs). The National Institute for Health and Clinical Excellence (NICE) develops clinical guidelines to ensure high-quality and evidence-based care for patients using the National Health Service (NHS) in the United Kingdom. Prior to a revision of NICE (2009) guidelines, young people received a unilateral cochlear implant (UCI). However, pediatric CI candidates now receive simultaneous bilateral cochlear implants (BCIs) if they meet the audiological criteria bilaterally, due to the possibility of further audiological benefits from bilateral implantation. Young people with an existing UCI are eligible to receive a second, sequential cochlear implant (SCI) until the end of their 18th year.

CIs and Psychosocial Well-Being

Given that rates of emotional and behavioral disorders (Hindley, Hill, McGuigan, & Kitson, 1994; Van Gent, Goedhart, Hindley, & Treffers, 2007) and social exclusion (e.g., Stinson & Lang, 1994) are reportedly higher in deaf young people than in their hearing peers, it is important to consider the psychosocial well-being of young people who receive CIs. Studies have typically been conducted with parents, although there is an emerging evidence base with young people.

Questionnaire and interview studies of satisfaction with UCIs and quality of life (QoL) for young people with UCIs indicate that, in addition to a positive experience of hearing and improved speech perception or production, young people also feel more confident...
and less frustrated due to their abilities to communicate orally, with improved or extended social or family relationships (Anmyr, Olsson, Larson, & Freijd, 2011; Chmiel, Sutton, & Jenkins, 2000; Preisler, Tvingstedt, & Ahlstrom, 2005; Schorr, Roth, & Fox, 2009; Wheeler, Archbold, Gregory, & Skipp, 2007). A younger age at implant and a higher duration of UCI use have been associated with higher self-reported QoL (Hyde, Punch, & Grimbeek, 2011; Schorr et al., 2009). Levels of health-related QoL (HRQoL) reported by young people with UCIs or BCIs are mostly comparable with those of hearing controls (Huber, 2005; Loy, Warner-Czyz, Tong, Tobey, & Roland, 2010; Warner-Czyz, Loy, Roland, Tong, & Tobey, 2009). However, concerns regarding disadvantages of UCIs have also been reported, including continued difficulties in hearing in noisy environments and groups and the restrictiveness of CIs (e.g., exclusion from some sports). With the exception of the interview study by Wheeler et al. (2007), the use of forced-choice questionnaires in the majority of studies somewhat limited the depth of exploration of psychosocial issues.

Fewer studies have examined these issues more rigorously. Huber and Kipman (2011) found that the emotional, behavioral, and social well-being reported by adolescents with UCIs or BCIs was comparable with that of hearing peers, as measured by the Strengths and Difficulties Questionnaire, used routinely in child and adolescent mental health services. Adolescents who had used a UCI since preschool period and who used spoken language to communicate were also found to have positive self-esteem and good social integration in mainstream education (Moog, Geers, Gustus, & Brenner, 2011). Levels of self-esteem reported by children (Martin, Bat-Chava, Lalwani, & Waltzman, 2010; Nicholas & Geers, 2003) and adolescents (Percy-Smith, Caye-Thomasen, Gudman, Jensen, & Thomsen, 2008; Sahli & Belgin, 2006) with UCIs were comparable with those of hearing peers. Levels of loneliness comparable with those of hearing peers (Schorr, 2006) and a normative sample (Leigh, Maxwell-McCaw, Bat-Chava, & Christiansen, 2009) have also been reported. A more detailed picture was presented in a recent interview study with young people with UCIs (Punch & Hyde, 2011). Although these young people spoke about a positive psychosocial development, they described difficulties in group communication due to listening challenges. They also described feeling self-conscious about deafness and CIs in adolescence and they worried about their friendships, fitting in, dating, and the future.

In summary, studies of young people with UCIs have found that they have comparable levels of psychosocial well-being as their hearing peers and that both groups of young people may be subject to similar psychosocial issues, such as loneliness. It is apparent, however, that young people with UCIs may experience psychosocial difficulties related to their deafness.

CIs and Deaf Identity

It is proposed that adolescence is a crucial period for identity development (Erikson, 1968), which suggests it is important to explore identity in young people with CIs. Neil Glickman presented a theoretical model of the development of identification with the Deaf culture and community in deaf people, and the Deaf Identity Development Scale (DIDS) was developed in line with this model (Glickman & Carey, 1993). This model consists of four cultural orientations: (a) Culturally hearing, where spoken language is valued and deafness is perceived as a disability; (b) Culturally marginal, where neither culture is identified with; (c) Immersion in Deaf culture or sign language, with negative views of the hearing culture; and (d) Bicultural, where one identifies with both cultures. It predicts that bicultural identification, the culmination of a developmental process, is associated with the most positive outcomes. However, factors such as age of onset of deafness, being in a hearing or deaf family, and educational and social experiences are said to have an effect on Deaf cultural orientation, and whether one moves “forward” or “backward” in the model will be dependent on these factors (Glickman & Carey, 1993).

In response to the perceived limitations of the DIDS, the Deaf Acculturation Scale (DAS; Maxwell-McCaw & Zea, 2011) was developed. It is based upon an acculturation model, which suggests that psychological and behavioral changes occur in line with ongoing contact with a new culture. The DAS addresses a perceived need to assess acculturation to each culture independently, given the context of technological
advances and an increasingly bicultural Deaf community (Maxwell-McCaw & Zea, 2011).

In the context of a wider interest in deaf identity development, only a few studies have examined these issues in young people with UCIs using quantitative measures (Leigh et al., 2009; Moog et al., 2011; Wald & Knutson, 2000).

Using the DIDS, Wald and Knutson (2000) found that adolescents with and without implants tended to score highly on the bicultural scale, but hearing identity was rated significantly more favorably by those with UCIs. In line with this, a study that used the DAS found that adolescents with and without UCIs tended to be biculturally acculturated, but adolescents with CIs tended to be more hearing acculturated and those without CIs tended to be more Deaf acculturated (Leigh et al., 2009). A later study by Moog et al. (2011) examined identity in a group of adolescents with UCIs using the Group Identification Scale (Jambor & Elliot, 2005). The results indicated a fairly even division among young people who reported identifying with the hearing community (32%), Deaf community (30%), or mixed identification with both the Deaf and hearing communities (38%). These findings indicate that the majority of these young people, most of whom were reported to interact with hearing peers inside and outside of school, identified with the hearing community to some extent. It is also important to note that in contrast with the studies above, a subset of these young people with UCIs identified mainly with the Deaf community.

A recent study by Mance and Edwards (2012) used a repertory grid technique to examine the self-perceptions of 22 adolescent with UCIs. They examined participants’ perceived closeness to different groups of peers. The majority of participants perceived themselves as closest to hearing peers (38%) and deaf peers who used spoken language (38%), rather than to deaf peers who used sign language (24%). Information on psychological well-being was gathered using the Beck Youth Inventory (Beck, Beck, & Jolly, 2001), which examines anxiety, depression, anger, disruptive behavior, and self-concept. The key findings from this study were a significant positive association between perceived degree of closeness to hearing peers and better psychological well-being. Conversely, those who perceived themselves to be less similar to hearing peers and more similar to deaf-signing peers had poorer psychological well-being. There was no evidence to suggest that perceived similarity to other deaf peers who used spoken language was related to higher or lower levels of psychological well-being. It is important to note that causality of these associations cannot be determined. The authors discussed these findings with reference to the social comparison theory (Tajfel & Turner, 1986).

It was suggested that many CI recipients seek to interact with hearing peers using spoken language, and it may be that hearing peers are perceived as a higher-status group. It is also important to note that many of the participants attended specialist deaf schools that emphasized spoken language. This provides a context for understanding the above findings, because the participants’ school setting may have been associated with their development of identity and communication preference.

Earlier studies with nonimplanted deaf adults (Bat-Chava, 2000; Hintermair, 2007; Jambor & Elliott, 2005) and adolescents (Cornell & Lyness, 2004; Weinberg & Sterritt, 1986) reported associations between bicultural or culturally Deaf identities and more positive psychosocial well-being. The recent findings with young people with and without UCIs that are outlined above present a more balanced view. Three of the studies indicate that identification or acculturation with a particular group was not associated with psychosocial well-being (Leigh et al., 2009; Moog et al., 2011; Wald & Knutson, 2000). However, one study did find that perceiving oneself as closer to hearing peers was associated with better reported psychosocial well-being, although the context of this study needs to be considered in interpreting these findings. Importantly, none of these studies found that hearing identification or acculturation was associated with increased psychosocial difficulties. It could be hypothesized that, through facilitating hearing and speech, UCIs increase young people’s success in integrating into the hearing world.

In summary, adolescents with UCIs tend to report bicultural or hearing identity or acculturation, although the variation in measures across studies limits comparisons. It is also important to consider findings from an interview study with adolescents with UCIs (Wheeler et al., 2007). These young people identified themselves
as deaf (in terms of their hearing), but not culturally Deaf. For many participants who used spoken language and British Sign Language (BSL), “identity [was] not a fixed concept . . . but reflects the complexity of their experience” (Wheeler et al., 2007, p. 311).

SCIs and Psychosocial Well-Being and Identity

Although there is a certain window within which SCIs are most beneficial, adolescents and young adults have reported additional hearing benefits up to 19 years of age, even with more than 16 years between implants (Galvin, Hughes, & Mok, 2010). A study gathering the parental perspective of SCIs in younger children has found significant gains in HRQoL using CI-specific measures (but not on generic measures) following SCI use (Sparreboom, Snik, Emmanuel, & Mylanus, 2012). To date, only two studies have been published with young people who received an SCI (Mather, Gregory, & Archbold, 2011; Redfern & McKinley, 2011), both of which focused mainly on audiological benefits (sound localization and general ease of listening), with only a brief evaluation of psychosocial implications. Of note, in a questionnaire study, 68% of users felt that the SCI enhanced their QoL, and 84% felt more confident in group conversations (Redfern & McKinley, 2011). An interview study outlined the complex individualistic, and sometimes challenging, process of adjusting to the SCI (Mather et al., 2011). No studies have examined issues of identity in these young people. It is important to explore this issue because findings to date suggest that SCIs affect the experience of these young people in hearing environments and in communicating and socializing with their hearing peers. The Deaf acculturation model (Maxwell-McCaw & Zea, 2011) suggests that psychological and behavioral changes occur in line with contact with a particular culture. It can, therefore, be hypothesized that these changes in ease of communication with hearing peers may affect how these young people view themselves in terms of their relationship to a Deaf, hearing, or bicultural identity.

Summary and Aims

The revision of the NICE (2009) guidelines provides a unique opportunity to explore the experience of SCIs. These young people are the only individuals who can compare having one versus having two CIs and so are well placed to contribute to discussions surrounding simultaneous bilateral implants. Although two implants are considered audiologically superior, no studies have rigorously examined issues of decision making, psychosocial well-being, and identity development in young people who opt to receive SCIs, and it is important not simply to assume improved well-being. Therefore, this study aimed to address the following research questions:

1. What factors are involved in young peoples’ decision to proceed with an SCI?
2. How do young people with SCIs identify themselves in relation to the Deaf and hearing worlds?
3. What are young peoples’ experiences of the impact of the SCI on their identity?
4. What are young peoples’ experiences of the impact of the SCI on their psychological and social well-being?

A qualitative approach was adopted in order to address these questions, as qualitative methods aim to understand and represent the experiences and actions of people as they encounter, engage, and live through situations (Elliott, Fischer, & Rennie, 1999).

It was hoped that the findings would inform clinical provision and provide useful information both for parents considering UCI or BCI and for young people contemplating an SCI.

Method

Interpretative phenomenological analysis (IPA) was selected as it is concerned with how people make sense of their major life experiences (Smith, Flowers, & Larkin, 2009), in contrast with, for example, grounded-theory methods (Glaser & Strauss, 1967) that are concerned with theory generation.

Participants

IPA requires a reasonably small homogeneous sample to allow for detailed examination of convergence and divergence of themes (Smith et al., 2009). Eleven participants who met the following inclusion criteria were recruited:

1. Had received an SCI since the revision of the NICE (2009) guidelines
2. Were between 12 and 18 years of age at the time of the interview (because it was hypothesized that identity formation occurs in adolescence [Erikson, 1968], the minimum age of 12 was aimed to facilitate discussion of these issues)
3. Had received the SCI a minimum of 6 months prior to the interview to allow for initial adjustment and experience in using the SCI
4. Had no other disability (e.g., severe physical or learning disability) that would affect homogeneity.

Individual and demographic characteristics of participants are displayed in Table 1 below.

Recruitment

Participants were recruited from three NHS CI clinics. Verbal consent to be contacted by the researcher was sought by the clinical psychologist or another clinician known to the family. A cover letter and young-person-and-parent information sheets were provided or posted if verbal consent was sought over the telephone. Interested participants and their parent(s) were contacted 2 weeks later to discuss any questions and arrange a time for the interview. Accordingly, 11 of the 12 young people approached agreed to take part.

Interview Schedule

IPA studies should allow participants to offer a rich, detailed, first-person account of their experiences (Smith et al., 2009); hence, a semistructured interview schedule (see Appendix) was developed in accordance with the research questions. Issues explored in UCI interview studies were considered (Preisler et al., 2005; Wheeler et al., 2007), and discussions were held with two research supervisors, one of whom worked in

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<tr>
<th>Characteristics</th>
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<tr>
<td>Gender</td>
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<td>17–18 years</td>
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<td>Deafness</td>
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<td>Communication</td>
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<td>Speech</td>
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<td>Atheist/no religious group</td>
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Note. BSL = British Sign Language.
a CI clinic. The interview questions aimed to explore the SCI decision and subsequent experience of living with an SCI, focusing on identity, impact, and challenges. Questions pertaining to identity aimed to explore identification with the Deaf and hearing worlds, encompassing issues such as socialization, communication, and the impact of the SCI. The need to ensure the suitability of research tools for a deaf population was considered (Levinger & Ronen, 2008), and advice regarding wording and content was sought from a Speech and Language Therapist (in deafness) and two Teachers of the Deaf. Finally, a young person with a UCI and his parents were consulted, and they felt the interview schedule was relevant and acceptable.

Ethical Considerations

Approval for the study was sought from the relevant NHS Research Ethics Committee and locally for each site. The code of human research ethics of the British Psychological Society (2010) was adhered to throughout the study.

Interview Procedure

Nine of the 11 participants chose to be interviewed at home, and two were interviewed at their CI clinic. None of the three BSL users accepted the offer of an interpreter. Confidentiality and its limits were discussed and consent forms were completed. Most interviews lasted around 1 hr. No participants felt the need to accept the offer of contact from their CI clinic to discuss arising issues. Three participants opted to receive a copy of their transcripts and all participants wanted to receive a summary of the findings.

Data Analysis

In line with IPA, the first three transcripts were read and reread to enable the researcher to familiarize herself with the data. Initial comments regarding descriptive, linguistic, and conceptual issues were noted. Descriptive comments focused on the content of the transcripts and understanding the relevant issues for each participant, while linguistic comments focused on participants’ use of language, for example, repetition, pauses, and laughter. Conceptual comments focused on developing an overarching understanding of the participants’ experience, moving the analysis to an interpretative level. After this initial detailed reading of the transcripts, emergent themes that encompassed the detailed analysis were recorded, aiming to reduce the volume of detail while maintaining the complexity of the analysis (Smith et al., 2009). This process was repeated for subsequent transcripts. Patterns and connections in the themes were examined for all the cases together, as is suggested for larger samples (Smith et al., 2009). Recurrence of themes across transcripts—and similarities and differences between themes—were considered, resulting in master themes and subthemes.

Quality Assurance

Yardley’s (2000) guidelines for qualitative research were applied throughout the study. IPA emphasizes the “double hermeneutic” of the researcher’s interpretation of participant’s “sense making,” and the researcher considered her differing experience as a hearing individual carefully (“sensitivity to context”). As part of the process of developing subthemes, transcripts were coded according to support for each possible emerging theme. This allowed the data to be traced from initial comments to initial clustering of themes, resulting in the final structure of themes (Smith et al., 2009). An independent supervisory audit of a transcript was conducted, and details of the analysis were discussed with another supervisor. These processes are in accordance with principles of “commitment and rigor” and “transparency and coherence” (Yardley, 2000) and the need to ground qualitative research in examples and conduct credibility checks (Elliott et al., 1999). The researcher considered the importance of reflexivity (Yardley, 2000) and bracketing one’s assumptions (Smith et al., 2009) by being interviewed about her assumptions prior to conducting interviews and using a reflective diary throughout the research process.

Results

The analysis resulted in six master themes and 22 subthemes, outlined in Table 2, which will be explained with illustrative quotations.
Consideration and Commitment to the Second Implant

This master theme encapsulates the importance of the decision and the subsequent adjustment period.

An important decision. Participants considered their decision carefully, “A million years it took me” (P9, 10, 280), seemingly due to the important prospect of better hearing, which needed weighing up against the risks. Four participants described making a joint decision with their parent(s) and four participants reported that their parent(s) made the decision for them, with their agreement. Three participants reported making the decision alone. There did not appear to be a relationship between the age of the participants and their reports of who made the decision to proceed with the SCI, and within each subset, there was a mixture of participants in their early and late teens.

Although two participants had no doubts about their SCIs, most described a period of uncertainty. They sought information, including attending information sessions at CI clinics, which they experienced as “interesting” (P3, 10, 295), and they seemed to benefit from hearing about others’ experiences.

Fear and discomfort. Many participants felt fearful about the pain and risks associated with surgery and the possibility that the SCI may not work:

I’m scared it kill me I’m scared (P5, 8, 227).

Participants also described postsurgery pain and discomfort, but there was a sense that in hindsight, this felt worth it, given their subsequent experience of their SCIs.

Excitement. Despite their fear, around half of the participants were excited about the SCI, and the impression was that participants were looking forward to new “hearing” possibilities:

That day I wasn’t even scared I was like yep ( . . )² I’m ready I’m excited (P3, 11, 315).

Adjustment and effort. Participants described the audiological adjustment to the SCI, including the time taken to practice and adapt, which required their commitment:

Well it felt really weird ( . . ) I’d kind of hear like beeps like I couldn’t hear any noises ( . . ) I could just hear like beeping sounds every time someone would talk (P6, 10, 288).
One participant was conflicted about the SCI’s hearing benefits as she was struggling with the emotional impact:

After I had my second one I thought oh I think it'll be completely fine but actually it's actually quite difficult cos I thought it was gonna be completely easy but actually it's quite difficult (P7, 26, 747).

Some participants commented on the extra responsibility of the SCI, including extra changing of batteries, additional appointments, and the effort of wearing two CIs.

Contentment With Two CIs

This master theme encapsulates participants’ experiences of happiness and contentment with their SCIs.

The benefits of hearing with two ears. Better hearing was experienced by all participants, and there was the impression that this improved their overall well-being:

My hearing has in general improved magnificently so I am utterly pleased with the fact I have two cochlears (P2, 9, 245).

More specifically, participants felt more able to decipher the direction of sounds, which gave rise to improved communication in group conversations and team sports, which seemed to make daily life somewhat easier.

Only one participant felt that her speech had improved following the SCI, which seemed to reduce her anxiety about others’ perceptions of her speech. Some participants commented that their first implant would always be superior to their second.

An even brighter future with two. Most participants felt that their future prospects improved following their SCI, “It’s made my future more stable and guaranteed” (P8, 17, 497), with some participants feeling that without their SCI, they would not have been able to access their chosen career. Most of the participants discussed their improved prospects in relation to the educational benefits of their improved hearing, such as the ease of hearing in a “noisy classroom,” which, with one CI, was “really hard” (P8, 4, 107).

Social gains. All participants experienced improved social well-being with their SCI. They felt able to engage in conversations with more ease, mishearing less, making socializing more enjoyable. There was a sense that this allowed participants to fit in with their peers and feel less different:

I got my second one I had more friends at college and that I only ask like repeating it once not more than one and I do have a laugh when I have second one cos it helped me to hear what the people were saying (P10, 12, 338).

Improved confidence. The majority of participants described improved confidence and self-belief following the SCI. As well as understandably being related to an increased ability to hear, it seemed that participants felt more resilient:

It’s made me more confident in myself to like sometimes if I didn’t have my second implant I used to think that I can’t say pardon to someone cos they’ll think it’s because she’s deaf that she can’t hear but I’ve learnt that even hearing people still can’t hear what people say so I’ve kind of been more confident in showing myself ever since having the second implant (P6, 19, 544).

In contrast, one participant, despite feeling more confident about her hearing ability, felt insecure about having two CIs and therefore disguised them. It seemed she felt she appeared more different and more obviously deaf and consequently worried about others’ perceptions:

I don’t know why I feel like I have to cover it up because I’m just worried (. . .) always worrying about what people think and I know it’s quite a bad thing but (. . .) I just never got over it (P7, 12, 336).

This participant reported that her parents made the decision for her to proceed with the SCI and, although she had agreed to proceed, she had been somewhat uncertain about it. This participant reported difficulties in adjusting to the SCI. This raises the issue of the importance of young people’s involvement in the decisions regarding implantation, if they have the capacity for this involvement.
The Importance of Being in the Hearing World

This master theme captures participants’ experiences of living in a hearing environment.

**Speech: value and commitment.** Most participants were very happy using only speech to communicate. Three participants who also used BSL described speaking as a challenge, “talking talking talking it’s hard” (P5, 13, 369) but were nonetheless motivated to further improve their skills. BSL was, however, experienced as an easier way of communicating and was a useful tool when they had difficulty expressing themselves using speech:

Sometime I do signing if I can’t if I can’t say the word it be easier me to sign it (P10, 1, 15).

However, most participants had never used BSL and felt that it limited communication and ultimately excluded people from the hearing community:

I just don’t like the idea of sign language it’s a language which specifically excludes you from other people as language should be something which you could use with well anyone preferably (P2, 21, 620).

**Inclusion and integration.** This theme captures the experience of having hearing friends and “fitting in,” made possible by CIs. All participants were content with having always been in, or having been able to progress to, mainstream schools (some with hearing impairment units):

It’s allowed me to be this person its allowed me to umm get out into a hearing school and talk with all my friends and make friends there and do things there and perform in a musical there all that sort of thing (P2, 12, 338).

**A better future.** Most participants felt they had a better, easier, and more “successful life” (P4, 21, 590) than they would have had without CIs. There was a sense that participants felt that their future prospects were altered and improved even when they had only one CI. It seemed that the ability to hear and talk facilitated access to what would have otherwise been inaccessible opportunities:

I wouldn’t be able to go on the phone ( . . . ) it’d be quite hard to finding a job ( . . . ) it’d just be a really really hard life if I didn’t have them cos I wouldn’t be able to live like trying to find a job because like you wouldn’t necessarily give a job to someone who can’t talk or hear um the majority of the jobs now days you need talking and listening to communicate (P6, 18, 532).

**Normality versus disability.** The majority of participants referred to hearing as the “normality,” which CIs and SCIs had allowed them to aspire toward:

Everyone treats me as I’m a normal hearing child ( . . . ) everyone’s so used to me talking and they don’t really think of me as a deaf child ( . . . ) I just think of myself as a normal hearing child (P6, 3, 63).

Some participants spoke about not feeling disabled, and one participant felt that CIs could “fix” the disability of deafness:

The idea of a deaf community separate the idea of valuing deafness is a bit odd umm to take pride in it umm its good to take pride in yourself but to take pride in a disability is not something I think you should do to the extent to not getting it fixed (P2, 10, 280).

In contrast, the participant who was struggling with the emotional impact of the SCI seemed to feel more deaf and dependent following the SCI:

It changed it affected how I saw myself as a deaf person ( . . . ) it made me think oh I need more help still so it’s like my first cochlear implant wasn’t there just forever it’s just it’s still needs some changes (P7, 21, 593).

**Being a hearing person.** Most participants had not sought contact with the Deaf community and did not seem fully aware of this concept in terms of its existence as a cultural orientation. Many felt more connected to feeling hearing:

I feel more connected to being a hearing person because they’re just my they’re who’s around me and I seem to fit in with them and I have fun with them and they’re mainly the only people I know...
I know a few deaf people but yeh I mainly feel like a hearing person (P8, 14, 396).

Not hearing, and being deaf all the time, was not desirable for these young people, who described this prospect as “weird” and “strange” (P6, 19, 541). Some participants felt more of a “complete” hearing person following their SCI, perhaps explaining why they opted for an SCI:

The second implant made me able to hear more I mean to be to more sure of myself and think of myself as a total hearing person cos when I’d be deaf I’d only hear out of one ear so I wouldn’t think so I wouldn’t think of myself as a proper hearing person (P6, 24, 685).

Connections to Deafness

This master theme encapsulates some participants’ identifications as deaf.

Deafness as a valued part of the self. Around half of the participants spoke about deafness as a defining part of themselves, “I am a deaf person like I said in that it defines who I am” (P2, 13, 370) and valued elements of being deaf, such as the ability to lipread. There was a sense that it was important for participants to positively incorporate their deafness into their sense of self and embrace ways of valuing their deafness, rather than perceiving it as a negative and limiting aspect of the self. Some participants spoke playfully about how they occasionally used deafness to their advantage, for example, one participant would say “I didn’t hear you” (P6, 2, 49) as an excuse if she had not tidied her room or done her homework, even when she had in fact heard. It seemed that participants acknowledged that they were different from their hearing peers in some ways, although there was a sense that this could be useful at times.

BSL means understanding. Although only a minority of participants used BSL, they clearly valued their ability to communicate using BSL. Three were fluent BSL users, and they described the ease of communication and understanding it provides, in comparison with speech, which requires more effort. They experienced BSL as unique to relationships with deaf friends, and it seemed participants enjoyed feeling competent and at ease in communicating:

It’s a bit more fun doing the signing ( . . ) when I’m with like deaf people who’s not hearing people we can signing each other and we can have a laugh and that (P10, 6, 177).

The importance of a shared experience of deafness and cochlear implants. Although the majority of participants considered themselves integrated in a hearing world with hearing friends, most participants had at least one deaf friend, often with a UCI or SCI. It seemed these relationships were so valued because they helped participants feel they were not alone, a feeling that was experienced by many young people who were often the only deaf young person at their school:

I’m not the only one whose deaf and its like really nice ( . . ) it always felt like that because I don’t I never see one ( . . ) when I have a deaf friend it makes me feel really happy cos I’m not the only one (P3, 23, 674).

Two of the fluent BSL users spent more time with their deaf friends. One participant was often immersed in Deaf culture using BSL with deaf peers, “Deaf school, Deaf club, umm Deaf activities week” (P1, 10, 288). The impression given was that they felt more relaxed and contented with deaf friends and that being with hearing peers was more effortful.

Bicultural Identity

This master theme encapsulates participants’ experiences of feeling both deaf and hearing, with a sense of, at times, being positioned between the two.

Being deaf, being hearing and being in the middle. Most of the participants identified themselves as being both deaf and hearing. They seemed to acknowledge their deafness but identified with their ability to hear with CIs:

I’m a hearing person in the sense that I hear pretty well I’m a deaf person in that I’m part machine and that’s what helps me hear ( . . ) even so logically
they are I don’t think there are actually mutually contradictory (P2, 11, 301).

The impression was that participants felt positioned between being deaf and hearing, “So I’m like stuck in the middle which is quite nice” (P3, 24, 706). It seemed that the ability to hear was privileged as an important aspect of identity, in that their deafness felt acceptable as long as they were able to hear:

I don’t mind being deaf as long as I can hear with these (P3, 17, 493).

Participant accounts gave the impression that they identified as being deaf, but not culturally Deaf:

I may see myself as a deaf person sometimes but I’m not part of the Deaf community (P2, 11, 297).

Most of the participants were not in fact aware of the Deaf culture or community, implying that they had not felt the need to seek contact with groups of other deaf young people and that perhaps their hearing parents had not promoted Deaf culture.

There was a sense from participant narratives that feelings of identifying as hearing or deaf varied dependent on when they experienced difficulties understanding others. It seemed that difficulties in communication emphasized feelings of deafness and difference, which were experienced as negative by some participants:

When I feel like I’m hearing when I understand everyone I feel completely comfortable but when I feel like deaf person is when I notice my cochlear implant or when I can’t understand what everyone’s saying and also when um I have to change I have to sort out a problem with these so that’s when I feel like oh I’m a deaf person (P7, 16, 461).

Furthermore, BSL users also described changing feelings of identity dependent on the peer group they are with and their mode of communication, although it seemed that feeling deaf was not described with negative connotations by these young people:

I will say a bit of both but if its like hearing people that I’m with I’m really more connecting hearing people or if its just like deaf people I’m hang around with I’m a bit more feel like connecting more deaf people if its like both together both really (P10, 17, 497).

Feeling Different in a Hearing World

This master theme encapsulates participants’ feelings of difference within their hearing world.

Sameness and difference. From feeling positioned in the middle of deaf and hearing, this theme captures the comparisons participants made and the resulting feelings of similarity with and difference from deaf and hearing people. Although a few participants felt the same as other deaf people without CIs, “I know they’ve been like a lot like the same as me” (P9, 21, 622), most felt different from them given they had superior abilities in hearing and talking:

I think like deaf people won’t be able to be as good as me like sometimes I think they can’t speak as well as me and stuff (. . .) it’s kind of made me not really want to have a deaf friend because I don’t really see any point in it to be honest (P6, 21, 597).

Some participants had not sought friendships with other deaf children, and when they had sought these friendships, it was often with other young people with CIs. It could be hypothesized that participants perhaps wanted to feel distant from deaf people who could not hear or talk and wanted to align themselves with the hearing majority, perhaps due to what they perceived were negative societal perceptions of deafness and disability. Furthermore, the narratives of the majority of participants suggested they felt most similar to hearing people:

I can talk like hearing people I can hear like um I can do the same things as them I can do everything they do really and um the only thing I can do that they can’t do it take off my hearing (P6, 17, 496).

Feeling Different in a Hearing World

This master theme encapsulates participants’ feelings of difference within their hearing world.

Frustration and confusion at not hearing and understanding. The frustration experienced in situations where participants found it difficult to hear and follow conversations was captured across the interviews. This seemed particularly prominent in groups, where they felt excluded:

I feel annoyed frustrated a little bit upset because I wish I was hearing so I can understand everyone more involved (P1, 11, 310).
One participant described feeling angry when her friends and family said “don’t worry” instead of repeating things for her (P3, 3, 61), whereas another participant did not ask for repetition because she did not want “to be like a nagging person” (P7, 5, 141).

Feelings of isolation and difference in a hearing world. This theme captures participants’ experiences of feeling left out and “different” when they struggled to hear and understand:

When I feel like I being left out sometime I do feel like is it cos I’m being deaf or is it cos I can’t understand you or is it cos I’m explain it to you stupid way or hard way or I can’t explain really properly English sentence (P10, 17, 476).

Some participants had been teased and bullied by hearing peers, and their descriptions suggested they had needed to develop their resiliency in coping with this. Although some participants appreciated educational support, others did not want teaching assistant support because it made them appear different, one participant described feeling “embarrassed” (P6, 27, 775). One participant due to go to university worried about the perceptions of others and whether they would want to be friends with her because she needed a BSL interpreter:

They think I’m really odd with signer person worried worried yeh (P1, 20, 547).

Participants had been excluded from some contact sports due to the risk of impact to their implants, and they commented on their feelings of deafness when they went swimming and had to remove their implants.

It seemed that these restrictions felt frustrating for participants, perhaps because they signified special considerations that did not apply to their hearing peers. It is important to note, however, that a few participants felt contented with hearing peers and did not feel deaf or different.

Unfairness of prejudice and deafness. Around half of participants talked about negative prejudice of others toward deafness. They felt that many people assumed deaf people could not hear and speak, or were “dumb” (P1, 21, 572), they did not want to be treated according to these assumptions and hence strived to be perceived as hearing:

Well like sometimes um they’ll talk really slowly and have to like pronounce their words and like when I first joined the school no-one knew I was deaf cos I’d always have my hair down and um they talked to me like normal and one day I had my hair up and they everyone found out I was deaf but I think if I told them I was deaf they’d probably like try and talk really slowly and use sign language and I just wanted them to think I was hearing (P6, 5, 130).

There was the impression from some participants that having CIs protected them from prejudice and possible bullying:

I didn’t had any implants on they will probably take the mickey out of me being deaf (P3, 8, 225).

Although many participants were confident about their future career, some were concerned about prejudice:

There’s some people out there in the world who like use like don’t take people with a disabilities (. . .) I don’t want people to say to me well you can’t have this job because you’re deaf like I’d hate that to happen (P6, 29, 840).

Looking different. Just less than half of the participants, all female, felt CIs were a visual sign of their difference from hearing people. They initially hid their CIs so they were not judged as “deaf” before making friends. It seemed that some did not like the aesthetic appearance of the implants and tried to cover them up. Five participants felt they looked more deaf following their SCI:

What it affects me about having two is making it more obvious cos when I have my hair up it makes me more obvious that I’m really really like feels like I’m really alone I don’t know why I feel like that is just makes me feel like that (P3, 27, 787).

However, feelings were mixed due to the hearing benefits of the SCI:

Well less like a deaf person because it makes me hear better and make me feel more like I’m one of them but then more of a deaf person because it just feels a lot more standing out (P8, 8, 232).
The experience of one participant was quite striking; since her SCI, she started covering or disguising her implants and was struggling with her feelings of self-consciousness:

Yeh I think it’s cos they’re kind of there cos it’s kind of like visual cos it’s not it’s not like having an operation done inside you it’s like something’s done with your ears and then you have to have things on your ears that everyone can see (P7, 9, 252).

Discussion

The purpose of this study was to investigate the factors involved in participants’ decision to proceed with their SCI, their identification with the Deaf and hearing worlds, and their experience of the impact of their SCI on their identity and psychological and social well-being. The results suggest that although participant experiences of their SCI are mainly positive, many participants continue to experience feelings of difference in the hearing world. The results will now be discussed in relation to the research questions, and consideration will be given to previous research findings and the theoretical, clinical, and research implications.

The findings encapsulated by the theme “consideration and commitment to the second implant” address the research question regarding the factors involved in young peoples’ decision to proceed with an SCI. In line with Mather et al. (2011), participants were motivated by the possibility of better hearing, which seemed to outweigh their fears about the surgery and possible complications. It is important to acknowledge that the experience of major surgery was anxiety provoking for the young people and their willingness to undergo the surgery demonstrated a huge commitment to the SCI. As outlined earlier, four participants reported making the decision with their parent(s), whereas four reported that their parents initially decided that they should proceed with the SCI and they then agreed with their parent(s). It may have been difficult for some parents, who had taken full responsibility for the decision for the first CI due to the child’s young age, to allow the young person a role in the decision regarding the SCI. One participant who reported significant difficulties in adjusting to the psychological impact of the SCI reported that her parents made the decision for her to have the SCI and she had felt uncertain about it. This highlights the importance, and the ethical issue, of young peoples’ involvement in the decision-making process. Had this young person made a joint decision with their parents, there may have been the opportunity for the exploration of their concerns, which may have influenced the final decision and ultimately resulted in them not proceeding with the SCI.

In terms of the impact of the SCI on participants’ psychological and social well-being, the theme “contentment with two CIs” encapsulates a range of positive gains associated with better hearing. All except one participant did not describe improved speech (although their skills were already good), in line with findings that SCIs do not generally improve speech production (Cullington, Bele, Brinton, & Lutman, 2012). This study used a qualitative approach to examine in detail the psychosocial experiences of an SCI, building upon earlier briefer interview and questionnaire studies (Mather et al., 2011; Redfern & McKinley, 2011). The analysis suggests that the young people who received an SCI experienced hearing benefits that improved the quality of their social relationships because they are less hindered by not being able to hear, particularly in larger social situations. This was associated with improved confidence for the majority of the young people interviewed. Young people also reported feeling that their life prospects were improved since having the SCI, which seemed to have had a positive psychological impact. These findings occur in the context of existing literature of psychosocial well-being reported by young people with UCIs; hence, it could be hypothesized that, through further improving hearing abilities, SCIs provide additional psychosocial benefits.

The themes “bicultural identity,” “the importance of being in the hearing world,” and “connections to deafness” provide information pertaining to the research questions regarding how participants identify themselves in relation to the Deaf and hearing worlds and their experience of the impact of their SCI on their identity.

Specifically, participant descriptions of feeling hearing and hearing-and-deaf (“bicultural identity”) identities support earlier UCI identity studies (Moog et al., 2011; Wald & Knutson, 2000; Wheeler et al., 2007).
However, participants felt deaf in terms of not being able to hear without CIs, rather than culturally Deaf, which differs from Glickman’s model of bicultural identification (Glickman & Carey, 1993), where individuals are comfortable in both Deaf (e.g., sign language, Deaf community) and hearing cultures. Although participants identified with the hearing world, it seemed that their social comparisons (Festinger, 1954) left them feeling neither fully deaf nor fully hearing. This is in line with a grounded-theory study that theorized that deaf adolescents in mainstream education (some with CIs) were deaf aligned, hearing aligned, or “the bridge between two worlds” (Hardy, 2010). Current participant descriptions seem to reflect the latter concept, supporting the assertion of Wheeler et al. (2007) that identity is not a fixed concept for young people with UCIs. It could be that the findings reflect emerging and forming identities (Erikson, 1968) or that young people with CIs may grow into adulthood continuing to feel they are between two worlds, warranting further development of theoretical models of deaf identity.

The theme “importance of being in the hearing world” captures participants’ predominantly hearing worlds and a sense of their hearing identities, supporting the acculturation model (Maxwell-McCaw & Zea, 2011), which suggests identity becomes more salient dependent on the level of interactions with the cultural environments (Leigh, 2009). Because young people with UCIs whose speech perception and language are close to those of hearing peers have been found to identify most strongly with the hearing world (Moog et al., 2011), it could be hypothesized that the hearing benefits reported by participants following SCIs strengthened their identification and acculturation with the hearing world, perhaps due to facilitation of more positive social comparisons. Furthermore, mainstream schooling seemed integral to feeling included in the hearing world. This can be understood in the context of findings that mainstream schooling (with its focus on spoken communication) has been associated with bicultural and hearing identities (Bat-Chava, 2000) and has been reported to be an important mediating factor for self-esteem in deaf young people, regardless of UCI status (Leigh et al., 2009). It could be hypothesized that mainstream schooling provides young people with an opportunity to make upward social comparisons to confirm their similarity to “better-off” others (Brunk & Gibbons, 2007). Using the Social Identity Theory (Tajfel, 1981), Bat-Chava (2000) suggested that one way that members of the deaf minority achieve positive social identity is by attempting to access the mainstream. It could be hypothesized that having SCIs made it easier for these young people to access the hearing mainstream via an “individual mobility route,” contributing to the psychosocial benefits experienced following SCIs. Bat-Chava (2000) indeed asserted that “today’s deaf children educated in the mainstream will be less likely to turn to the Deaf culture as a result of frustration with oral communication” (p. 427).

Participants did not seem dependent on connections with Deaf culture to increase or protect their self-esteem, as has been suggested by findings of associations between hearing identities and lower psychosocial well-being in nonimplanted deaf adults and adolescents (Bat-Chava, 2000; Cornell & Lyness, 2004; Hintermair, 2007; Jambor & Elliott, 2005; Weinberg & Sterritt, 1986). However, the theme “connections to deafness” highlighted that being “deaf” (with a small “d”) was integral to the identity of some participants, perhaps in line with additional findings of associations between bicultural identities and psychosocial well-being in the above studies. Although participants did not ascribe to the cultural model of Deafness as in the earlier studies, it is possible that identifying as both deaf and hearing was important in maintaining the well-being for some of the participants.

Integration in the hearing world was still, however, associated with feelings of difference and isolation for many young people, despite superior hearing afforded by the SCI. These findings are in line with concerns raised by young people with UCIs (e.g., Punch & Hyde, 2011). Participants disliking their “different” appearance could be perceived as a barrier to aligning oneself with the hearing in the search for a positive social identity (Bat-Chava, 2000). Many participants valued their deaf friends, perhaps reflecting some similarity to findings from nonimplanted deaf teenagers and adults, who had more positive self-esteem when they associated more closely with other deaf people (Bat-Chava, 1993). This finding also supports the suggestion of Bat-Chava (2000) that in addition to attempts to access the mainstream, another way that deaf individuals achieve positive social
identity is through identifying with other members of this group, where, for example, deaf attributes and qualities are valued. These relationships may have provided a normalizing experience of being deaf with CIs, helping with feelings of loneliness that may have been experienced in hearing groups (Leigh et al., 2009).

There could be an assumption that young people with SCIs have improved hearing abilities and, therefore, do not experience emotional challenges; however, findings from this sample of young people indicate that identity development and achieving psychosocial well-being are complex processes.

Limitations of Study and Areas for Future Research
Although the use of a qualitative approach has had the advantages of producing detailed accounts that allow for exploration of the complexities of experiences, there are some limitations on the extent to which conclusions can be drawn regarding identity and psychosocial well-being. The use of quantitative measures of acculturation (e.g., DAS) and psychosocial outcomes (e.g., depression, self-esteem, peer acceptance) in future studies, which also consider factors such as schooling, will allow comparisons among young people with UCIs, BCIs, and SCIs and their nonimplanted deaf and hearing peers and will further inform parental and young people’s decision making. In particular, young people who receive SCIs present the opportunity for pre- and post-SCI comparisons. Adolescents are in a period of identity formation (Erikson, 1968) and it is important to acknowledge the complexity of identity development. There is a need for future studies to focus on the issue of identity in young deaf people in a wider sense, in terms of consideration of ethnicity and other cultural and religious identities. Ahmad, Atkin, and Jones (2002) highlight this issue in their study with young Asian deaf people with UCIs. They reported that the young peoples’ identities were complex and that they held multiple identifications that were used flexibly according to different situations.

This study is somewhat limited by the relative recency of the SCI for some young people, and longitudinal studies are needed. Research is also needed regarding why young people decline an SCI because it cannot be concluded that all deaf young people wish to become more hearing.

Clinical Implications
The findings suggest that it would be unreasonable to assume that young people with SCIs, who acquire more superior hearing abilities, experience no difficulties in being part of a hearing world. Many of the young people experienced feelings of difference, and the process of adjusting to an SCI presented challenges for some. Participants also grappled with their identity as a deaf person who is able to hear. These findings are perhaps transferable to the wider population of young people who receive SCIs and, therefore, support the role of clinical psychologists and other mental health professionals in CI clinics. This provision allows young people to have psychological input in relation to SCI decision making and provides access to further psychological input if required. Psychologists and other mental health professionals have a role in promoting psychological thinking in a medical setting, for example, in considering the emotional impact of anticipating and experiencing such major surgery. It will be important for this provision to focus on exploration of issues of identity with young people prior to, and following, receiving an SCI. Comprehensive assessment of the mental health and emotional well-being of SCI recipients is vital in developing an understanding of the experiences of young people who feel different and isolated. This is an important role for mental health professionals in CI clinics, who will be able to provide therapeutic support where necessary. These implications may also be pertinent to young people with UCIs and BCIs.

Conclusions
This study examines the experience of young people with SCIs, using IPA—a rigorous qualitative methodology that aims to examine how individuals make sense of their life experiences. Adjustment to the SCI required considerable effort, and on the whole, most participants were extremely pleased to have an SCI and strived to be as hearing as they could possibly be. However, this wish to be integrated into the hearing world led the young people to confront feelings of difference, which was experienced as emotionally difficult at times. It is evident that these young people experience a multitude of complex feelings. The findings add to the emergent deaf identity development.
literature in young people with CIs. They are also important in evaluating the implications of the introduction of SCIs and of living with two implants. Moreover, these findings have important clinical implications in terms of the role of clinical psychologists and other mental health professionals in CI clinics.

Notes
1. \((P_x, x, r) = \) Participant number, page number, line number.
2. \((. . .) \) Material omitted for clarity or confidentiality.
3. In the United Kingdom, young people attend “college” between the ages of 16 and 18 years.

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Conflicts of Interest
No conflicts of interest were reported.

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References
Appendix: Interview Schedule

Background information

Do you use speech or British Sign Language, or both, to communicate?
Do you have a preferred way of communicating?
(If yes) Tell me about why you prefer that way?
(or if they did not understand, how do you like to communicate? And why?)
Have you always been deaf?
(If no) What happened to make you deaf? How old were you?
Are your parents hearing or deaf?
Do you have any brothers or sisters? Are they hearing or deaf?
Is your school a mainstream school or specialist school for young people who are deaf?
(If mainstream), is there a deaf unit?
How do you feel about that? What do you like/dislike about your school?
How old were you when you had your first cochlear implant?
Did you use your first cochlear implant every day? Why?
How old were you when you had your second cochlear implant?
How long have you been using your second cochlear implant? (or, when was your second cochlear implant switched on?)
Do you use your second cochlear implant every day? Why?
Are there any times when you do not use your first or second cochlear implant? (If yes) Why?

What factors were involved in the young people’s decision to proceed with the second CI?

When did you find out that you could have a second cochlear implant?
What did you think about that?
How did you decide?

Prompt Q: What did you think would be good about a second cochlear implant?

Did anyone help you decide?
(If yes) Who helped you decide?
How did they help?
What was it like making the decision?

How do the young people identify themselves in relation to the Deaf and hearing worlds?

In what ways do you see yourself as a Deaf person?
(or if they did not understand:
Do you think of yourself as Deaf? Why? Why not?)

In what ways do you see yourself as part of the Deaf community?
In what ways do you see yourself as a hearing person?
(or if they do not understand:
Do you think of yourself as hearing? Why? Why not?)

Do you feel more connected to being a Deaf person, or a hearing person, or a bit of both? Tell me about that.

Prompt Q: In terms of being a Deaf person or a hearing person, how do you see yourself? Tell me about that.

Prompt Q: How do you feel about being deaf?

How do you communicate with your parents/siblings/wider family? How do you feel about that?
Do you have deaf friends, or hearing friends, or both?
How do you communicate your deaf/hearing friends?
In what ways is it different spending time with deaf and hearing friends?
Do you prefer spending time with one group or another? Tell me about that.
Have any of your friends/siblings got one or two cochlear implants?
What’s that like?
How does that affect what you think about cochlear implants?
Has the second CI changed or affected their identity?

- How do you see yourself? How would you describe yourself as a person?
- How did the first cochlear implant affect or change the way you see yourself?
- How has the second cochlear implant affected or changed the way you see yourself?
- How has the second cochlear implant changed the way you think?
- How has the second cochlear implant changed the way you feel?
- How has the second cochlear implant changed the way you act?

Has the second CI affected their quality of life?

- How has the second cochlear implant changed your life, in either a good or a bad way?

  Prompt Q: What have some of the positive changes been?
  Prompt Q: What have some of the difficult changes been?

Is there anything you can do now that you couldn’t do before the second cochlear implant? What’s that like?

Is there anything you need help with because of being deaf?

  Who helps?
  What do they do?
  What’s that like for you?

Have there been any difficult times with your second cochlear implant?

What are the advantages and disadvantages of your second cochlear implant?

What are your expectations (hopes and fears) about the future? Tell me about that.

Where would you hope to see yourself in 5 years’ time?

How will having a second cochlear implant help you get there?

What things do you worry might get in your way?