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KRISTINA M. HILTON BSc Hons

EXPLORING THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH SEQUENTIAL COCHLEAR IMPLANTS

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CANTERBURY CHRIST CHURCH UNIVERSITY

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Firstly, I would like to thank the young people who took the time to tell me about their experiences of being deaf and living with cochlear implants. I learnt so much from hearing their stories and very much value the trust they placed in me to convey their experiences.

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Summary of the MRP portfolio

Section A is a review of the literature on the psychological and social implications of cochlear implants in deaf children and adolescents. The literature is critically evaluated in relation to health-related quality of life, quality of life, psychological and emotional well-being, social well-being and identity. Relevant theories are outlined and discussed. Methodological limitations and gaps in the literature are discussed, and the review concludes with recommendations for further research.

Section B describes a study using Interpretative Phenomenological Analysis to explore adolescent experiences of receiving and living with sequential cochlear implants. Semi-structured interviews were conducted with eleven adolescents. The master and sub-themes are presented and the results are discussed with consideration of previous research findings and theoretical, clinical and research implications.

Section C is a critical appraisal of the qualitative study, including critical reflections on the research process relating to the following topic areas; research skills learned and further areas for development, what would be done differently if the project were to be repeated, consequences of the research in terms of clinical practice, and future research projects.

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Section A:
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Abstract

The parents of children born with severe-profound deafness commonly opt for them to receive a cochlear implant (CI), a technological device that provides the sensation of hearing and facilitates a child’s access to sound and speech. The National Institute for Health and Clinical Excellence (2009) recently reviewed their guidance, and now recommend that children receive two CIs, rather than one. Children who received one implant before the revision of the guidelines are being offered a second implant. Rates of emotional and behavioural disorders are reportedly higher in deaf young people than their hearing peers, however the psychological and social implications of CIs for young people are unclear. This review sought to provide a comprehensive summary and critique of all available literature. Electronic databases were searched using key terms, and 49 relevant articles were identified. The findings indicate that young people with CIs tend to have levels of health related quality of life, psychological well-being, self-esteem, and social well-being that are comparable to hearing peers. CIs have also been associated with improvements in these areas, when compared to pre-implant. However, young people also experience some difficulties in social interaction, and it is apparent that psychosocial outcomes are complex. There were a number of methodological limitations in the literature, and this review concludes with recommendations for further research.

Introduction

Paediatric Severe-Profound Deafness and Cochlear Implants

Levels of deafness (mild, moderate, severe or profound) are defined according to the quietest sound you can hear. Each year in the United Kingdom (UK), around 350 severely-profoundly deaf children are born (90% of whom to hearing parents) and around 100 more children become deaf in early life due to illness (Ear Foundation, 2011). These children may receive little benefit from hearing aids and would need to rely on lip-reading or British Sign Language (BSL; Action on Hearing Loss, 2012). However, most UK parents opt for their child to receive cochlear implants (CIs; Ear Foundation, 2011), which are technological devices that provide a sensation of hearing, facilitating access to speech perception and production. A microphone and sound processer (worn behind the ear) transmit sounds via a transmitter coil (worn on the side of the head) to an implanted receiver-stimulator package that delivers electrical pulses to an array of electrodes surgically placed in the cochlear, stimulating nerve fibres and providing the sensation of hearing (National Institute for Health and Clinical Excellence [NICE], 2009). Prior to 2009 children with severe-profound deafness who did not receive adequate benefit from hearing aids were eligible to receive a unilateral (one-sided) CI (UCI; NICE, 2009). However, following a revision of NICE (2009) guidance children are now eligible to receive simultaneous bilateral (two-sided) CIs (BCIs), due to their additional benefits in auditory and speech perception when compared to UCIs (NICE, 2009). Children and adolescents (hereon referred to as young people) who had a UCI prior to this change are being offered a second sequential CI (SCI).

The context of paediatric CIs will now be briefly explored.

Speech and Audiological Outcomes

UCIs facilitate gains in hearing and speech perception and production, and are most cost-effective, when compared to non-technological support (e.g. lip reading or sign language) or hearing aids (Bond et al., 2009). Earlier implantation correlates with improved verbal communication, with the best outcomes seen in children aged two years and under (Yoon, 2011). Reviews suggested that BCIs and SCIs further improve speech perception, and possibly sound localisation, compared to UCIs (Johnston, Durieux-Smith, Angus, O’Connor & Fitzpatrick, 2009; Sparreboom et al., 2010), and initial findings suggest BCIs may be cost effective (Lammers, Grolman, Smulders & Rovers, 2011). Although these reviews asserted that SCIs were most beneficial within a certain time window, adolescents and young adults reported additional hearing benefits up to 19 years of age, even with >16 years between implants (Galvin, Hughes & Mok, 2010).

Children with CIs are more likely to be placed in mainstream schools and use spoken language than other profoundly deaf children, although it is unclear whether oral communication is an outcome of, or deciding factor in, mainstream schooling (Thoutenhoofd et al., 2005).

Societal Context

Two opposing models of deafness are associated with an ongoing debate about paediatric CIs. A medical model suggests that deafness is a deficit and disability, amenable to improvement with CIs that allow hearing parents to opt for their deaf child to share the family’s ‘hearing’ culture and language (Davis, 1997; Levy, 2002). It is argued that it is unethical to restrict CIs, since deafness has been associated with poor educational level and income (Nunes, 2001).

In contrast, the Deaf community (a capitalised ‘D’ is convention when referring to the cultural aspects of being deaf) is viewed by its members as a minority culture, which has its own history, visual language and value system (Crouch, 1997; Lane & Grodin, 1997). Some consider paediatric CIs to be a threat to Deaf culture, akin to genocide/ethnocide (Lane, 1992; Lane & Bahan, 1998; Lane & Grodin, 1997).

There are however signs of changing perceptions. The National Association of the Deaf now acknowledge CIs are a tool for some forms of communication and recognise technology’s role in improving quality of life (QoL), and parents rights to informed choices (Christiansen & Leigh, 2004). Although CIs may reduce sign language as a ‘first language’, a large study indicated that around half of parents supported sign language before and after implantation (Christiansen & Leigh, 2004). These data suggest CIs may represent a change in Deaf culture, rather than the end of it.

Severe-Profound Deafness and Mental Health

Severe-profound deafness has wide ranging implications. Rates of emotional and behavioural disorders reported by deaf young people are higher than in hearing peers (Hindley, Hill, McGuigan, & Kitson, 1994 [UK]; Van Gent, Goedhart, Hindley & Treffers, 2007 [The Netherlands]). Higher rates of mental health problems in deaf adults suggest these difficulties may continue into adulthood (Fellinger, Holzinger & Pollard, 2012). Suggested risk factors for emotional difficulties include social isolation, difficulties being understood in the family (Fellinger, Holzinger, Sattel, Laucht & Goldberg, 2009), characteristics of deafness (cause, age of onset) and environmental factors (e.g. school) (Van Gent, Goedhart & Treffers, 2011). In terms of social factors, emotional mental health problems have been positively associated with peer rejection (Van Gent et al., 2011) and psychosocial difficulties are reportedly

3.7 times higher in deaf young people compared to their hearing peers (Danmayer, 2009).

Aims of this Review

Given this context, it is important to consider the mental health of deaf young people who have received CIs. CIs have the potential to change the trajectory of a child’s development, yet an earlier review of paediatric CI outcomes highlighted that, while medical outcomes are well documented, research into psychological and social outcomes is lacking (Thoutenfood et al., 2005). Understandably, it is not possible to conduct randomised controlled trials with these young people, and Thoutenfood et al. (2005) highlighted the limitations of proxy/questionnaire measures commonly administered by CI clinics in existing studies. This has since prompted greater attention and research into psychological and social implications. This paper aims to comprehensively review this literature, seeking to establish the implications of CIs for the mental health and social well-being of young people.

Review

Systematic searches were completed using a range of databases (see methodology in Appendix A). Forty-nine papers were identified and categorised according to how receiving CIs relates to mental health, including health-related QoL (HRQoL), QoL, psychological well-being, social well-being and identity.

HRQoL

HRQoL has been defined as “a construct [which] refers to the impact of the health aspects of an individual’s life on that person’s QoL or overall well-being” (Sach & Barton, 2007, p. 436), for which a range of quantitative measures have been developed. Childhood deafness has been associated with suboptimal HRQoL in comparison to hearing children (Petrou et al., 2009). The findings of eight studies of

HRQoL in young people with CIs will be outlined below (for further detail and tabular presentation see Appendix B).

Two studies presented retrospective pre-post UCI parent ratings, indicative of significant improvement in HRQoL following UCI (Cheng et al., 2000; Sach & Barton, 2007). Although the level of change varied, this was perhaps attributable to the larger sample and longer follow-up period in the latter study.

Three studies compared post UCI/BCI HRQoL to hearing controls using the KINDL/ KINDL-R (physical and emotional well-being, self-esteem, family, friends, and school), which has good psychometric properties (Bullinger et al., 2008). Young people reported mostly comparable HRQoL to hearing controls (Warner-Czyz, Loy, Roland, Tong & Tobey, 2009; Loy, Warner-Czyz, Tong, Tobey & Roland, 2010; Huber, 2005), with the exception of the younger age group (8-12 years old) in Huber's (2005) study. Two studies also found that HRQoL in specific domains was significantly lower than that reported by hearing children, namely adolescent self-esteem (Huber, 2005) and family and school factors (Loy et al., 2010). Certain domains of HRQoL therefore warrant further exploration.

Three studies compared young people's HRQoL ratings across age groups, with the aim of establishing any variations (Loy et al., 2010; Huber, 2005; Warner-Czyz, Loy, Nakonezny & Roland, 2011). Younger children reported the most positive HRQoL and adolescents reported the least positive HRQoL (Loy et al., 2010; Warner-Czyz et al., 2011), perhaps reflective of developmental factors. However, Huber's (2005) findings display the opposite pattern, although this study is limited by its small sample. It is therefore difficult to draw firm conclusions with regard to age variations. Interestingly, although younger children were more positive on a six item CI-specific HRQoL module, internal consistency was poor in the youngest two age groups (4-7 and 8-11 years old), leading the authors to doubt the suitability of such a brief measure for younger children (Warner-Czyz et al., 2011).

Although some parental and self-report HRQoL ratings were comparable (Loy et al., 2010; Huber, 2005 [13-16 year olds]), the importance of gathering both self-report and parental ratings is highlighted by studies that found 8-12 year olds were significantly less positive (Huber, 2005) and 4-7 year olds were significantly more positive than their parents (Warner-Czyz et al., 2009).

Findings regarding the impact of age of onset of deafness, age at implantation and duration of implant use on HRQoL were mixed. Younger age at implant and a later onset of deafness were associated with more positive HRQoL in adolescents, but not in younger children (Loy et al., 2010), and other studies found no differences (Huber, 2005; Warner-Czyz et al., 2009, 2011). Both shorter (Warner-Czyz et al., 2009, 2011) and longer (Loy et al., 2010) durations of UCI/BCI use were associated with more positive HRQOL.

Unexpectedly, no significant differences were found between parent rated HRQoL in children who received UCI and BCI (Beijen, Snik & Mylanus, 2007) and UCI and BCI/SCI (Lovett, Kitterick, Hewitt, & Summerfield, 2010). It may be that there are no differences, although these findings may have been affected by the methodological limitations including; UCI scores being close to ceiling, small samples, the need for longer follow-ups, and designs lacking the ability to detect small health utility differences (Lovett et al., 2010). These findings also need to be considered in the context that not all parents considered deafness to be a health issue (Sach & Barton, 2007). No studies to date have compared self-report HRQoL data in young people with UCI and BCI/SCI.

In summary, although conclusions regarding causality cannot be drawn, findings are consistent with the hypothesis that UCI/BCI positively impact HRQoL, resulting in comparable scores to hearing peers. Variability in the findings may be due to the methodological limitations outlined, or variation in the audiological backgrounds of participants (e.g. combining UCI and BCI, varying age of onset of deafness/implantation; Lin & Niparko, 2006). Furthermore, although the majority of participants attended mainstream education and used spoken communication, these factors require examination in relation to HRQoL. Future studies should conduct further comparisons, including pre- and post- implant, across UCI, BCI and SCI and between audiological backgrounds, whilst continuing to develop CI-specific measures of HRQoL. Comparisons with non-implanted deaf children are also required to further inform parental decision-making.

QoL

QOL can be broadly defined as an "individual's contentment or satisfaction with life" (Lin & Niparko, 2006, p. 1696). Maslow's (1962) theory of QoL, still considered a reliable theory (Ventegodt, Merrick & Anderson, 2003), would predict that increasing the hearing of a deaf child in a hearing environment would improve their QoL through fulfilling their physiological need to hear, facilitating access to higher level need fulfilment (e.g. belongingness, esteem needs). Numerous studies have examined the perceived benefits of CIs, and many aimed to assess 'QoL'. Detailed exploration of psychosocial issues is however limited by the wide use of forced choice, often ad-hoc, 'satisfaction' measures. Fifteen studies used questionnaires to gather parental perceptions of outcomes (e.g. hearing, well-being, social relations) of UCIs (Archbold, Lutman, Gregory, O'Neill & Nikolopoulos, 2002; Archbold, Sach, O'Neill, Lutman & Gregory, 2008; Chmiel, Sutton & Jenkins, 2000;

Huttunen et al., 2009; Huttenen & Valimaa, 2010; Hyde, Punch & Komesaroff, 2010; Incesulu, Vural & Erkam, 2003; Kelsay & Tyler, 1996; Nicholas & Geers, 2003; Beadle, Shores & Wood, 2000; Nikopoulous, Lloyd, Archbold & O'Donoghue, 2001; Stacey, Fortnum, Barton & Summerfield, 2006), BCIs (Hyde, Punch & Grimbeek, 2011), and SCIs (Scherf et al., 2009a, 2009b). Only three studies gathered views of young people with UCI/BCI using questionnaires (Anmyr, Olsson, Larson & Freijd, 2011; Chmiel et al., 2000; Schorr, Roth & Fox, 2009).

Unsurprisingly, positive outcomes in hearing and speech perception/production were reported. In terms of psychosocial benefits, parental and self-report studies indicate that young people experienced positive psychological well-being following UCI, BCI and SCI (feeling more confident and less frustrated due to improved oral communication), with improved and/or extended family and relationships. SCI were reported by parents to further improve hearing (particularly sound localisation) and provide more natural communication compared to a UCI (Scherf et al., 2008, 2009). Due to the methods used, conclusions about causality cannot be drawn.

Importantly, concerns and disadvantages were also reported, related to developing communication skills, social acceptability, restrictiveness of equipment (e.g. exclusion from some sports), and remaining frustration. Given that most studies evaluated UCIs, remaining frustration could be explained by remaining difficulties hearing (Archbold et al., 2008).

The findings of three parental (Hyde et al., 2010; Kluwin & Stewart, 2000; Sach & Whynes, 2005) and two self-report interview studies (Preisler, Tvingstedt & Ahlstrom, 2005, [8-11 year olds]; Wheeler, Archbold, Gregory & Skipp, 2007, [13-16 years old]) following UCI supported above findings, although naturally provided richer descriptions. In the first interview study regarding SCIs, young people reported experiencing improvements in sound localisation, listening in noise and general ease of listening compared to using one CI (Mather, Gregory & Archbold, 2011).

Comparison studies. Only four of the above questionnaire studies employed statistical comparisons. Oral communication (Hyde et al., 2011) and the ability to identify emotional sounds (Schorr, 2006) predicted positive QoL, although single word speech perception did not, possibly due to limitations in the measure (Schorr, 2006). One study compared parent-reported QoL of children with UCIs to non-implanted deaf children, QoL advantages were most common for children implanted under aged five, with more than four years of UCI use (Stacey et al., 2006). In line with this, a younger age at implant and longer CI use has been associated with higher self-reported QoL (UCI; Schorr et al., 2009) and social participation (UCI/BCI; Hyde et al., 2011). Users of hearing aids used their devices significantly less often than those with UCI/BCIs, and reported significantly more problems in team sports/outdoor activities, suggesting CIs may be associated with more positive QoL (Anmyr et al., 2011).

In summary, although the above findings are consistent with improved QoL following UCI/BCI, and QoL advantages in comparison to non-implanted deaf peers, a number of methodological limitations are evident, including a lack of robust comparative data (pre- and post- implant, to hearing peers, and across age groups) and studies with young people with SCI. Furthermore, the interview studies did not fully adhere to suggested criteria for good quality qualitative research (see Appendix C; Yardley, 2000), tending to describe the findings with limited exploration of theoretical issues and qualitative analysis. Detailed exploration of the psychosocial implications of CIs were lacking, therefore the subsequent sections of this review will focus upon studies where this was the main objective.

Psychological and Emotional Well-Being

Behavioural difficulties. Findings from four studies examining pre- and post-UCI parent-reported behavioural difficulties in younger children (aged two to 13 years) are mixed (Edwards, Khan, Broxholme & Langdon, 2006; Knutson, Wald, Ehlers & Tyler, 2000; Pulsifer, Salorio & Niparko, 2003; Purdy, Chard, Moran, Dipteach & Hodgson, 1995). Only two of the studies reported some clinically significant emotional/behavioural problems prior to implant, and although these improved somewhat following implantation, some still met clinical significance and some gains were not maintained at 12 month follow-up (Edwards et al., 2006; Purdy et al., 1995). Improvements in some cognitive functions (increased capacity to use verbal concepts) were positively related to behavioural outcomes (Edwards et al., 2006). Again, comparative data is lacking, and generalisability of the findings is limited by the small samples.

Self-esteem. Self-esteem, a person’s summary evaluation of their worthiness as a human being (Rosenberg, 1979), correlates highly with overall psychological well-being, (Rosenberg, Schooler, Schoenbach & Rosenberg, 1995).

Positive self-image, social acceptance, and good socio-emotional adjustment has been reported by younger children with UCIs (8-9 years old) and their parents (Nicholas & Geers, 2003). Positive outcomes were not restricted to those with good speech or by educational setting. Correlations indicated that child and proxy ratings did not always correspond, again highlighting the importance of collecting both ratings. This study lacks comparison to normative/control group data, making it difficult to ascertain whether their self-esteem is comparable to hearing children or superior to non-implanted peers. A small study with younger children (5-6 years old) reported comparable levels of self-competence to hearing peers (Martin, Bat-Chava, Lalwani & Waltzman, 2010).

Adolescent self-esteem studies have also presented a positive picture. A follow-up of Nicholas and Geers' (2003) study suggested participants maintained positive self-esteem/self-image as adolescents (Moog, Geers, Gustus & Benner, 2011), although again this study lacks comparative data. Two studies with adolescents with UCIs conducted comparisons, and concluded that their self-esteem was comparable to hearing peers (Sahli & Belgin, 2006; Percy-Smith, Caye-Thomasen, Gudman, Jensen & Thomsen, 2008) whereas prior to UCI it was significantly lower (Sahli & Belgin, 2006). Of note, over half of Percy-Smith et al.'s (2008) sample were in specialist education and only 30% used speech, not reflective of most young people with UCIs/BCIs/SCIs. Only one study conducted pre-post UCI comparisons, and found that adolescents reported significantly improved self-esteem following relatively late implantation (around 12 years old; Sahli & Belgin, 2006)

It has been hypothesised that mainstream schooling may mediate the relationship between CIs and psychological well-being, since deaf young people in mainstream education, regardless of UCI status, had higher levels of self-esteem (in relation to schools, friendships and globally; Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2008). Socialisation with deaf peers was negatively related to scholastic self-esteem, it was suggested this was due to subtle messages that value socialisation with hearing peers.

In summary, findings to date suggest that UCIs may improve self-esteem, and that these young people have a positive self-esteem that is comparable to hearing peers. Mainstream schooling and socialisation may also be important factors. These findings are in contrast to findings that deaf adults (mostly without CIs) had lower self-esteem than hearing people (Bat-Chava, 1993), and consistent with the hypothesis that CIs facilitate positive self-esteem. In line with Social Comparison Theory (Festinger, 1954), it could be hypothesised that mainstream schooling provides deaf young people (regardless of CIs) with opportunity to make upward social comparisons to confirm their similarity to ‘better-off’ others (Brunk & Gibbons, 2007), resulting in higher self-esteem. Furthermore, comparable levels of self-esteem in young people with UCIs may be related to the ease of social comparisons to hearing peers.

Other measures of psychological well-being. Some studies have examined psychological well-being of young people with UCI/BCI more generally. Using self-assessment scales (emotional instability, pro-social/aggressive behaviour), projective tests, and parent/teacher interviews, Filipo, Bosco, Marchetta and Mancini, (1999) concluded that young people did not experience adverse psychological effects following UCI and were comparable to hearing peers. Levels of depressive emotions in adolescents with UCI were comparable to hearing peers (Sahli, Arslan & Belgin, 2009). Although these findings present a positive picture, they are limited by their small samples.

The most comprehensive study examining the mental health status of adolescents with UCI/BCI (n = 32; Huber & Kipman, 2011) reported no significant differences between self, parents and teacher ratings of emotional, behavioural, and social difficulties (Strengths and Difficulties Questionnaire) and their hearing peers (n = 212). One exception was teacher ratings of more clinically relevant peer problems, suggesting they may observe subtle difficulties that adolescents may be reluctant to report. A key weakness of this study is the exclusion of children with insufficient speech comprehension (n = 9), who may have experienced more difficulties.

In summary, the literature to date supports the hypothesis that UCI/BCI may improve mental health outcomes, although comparative data to non-implanted peers and studies with young people with SCIs are lacking.

Social Well-Being

Young people with UCIs have significant enhancements in social independence and socialisation when compared to non-implanted deaf children, as rated by parent/teacher questionnaires (Stacey et al., 2006). Parent reported social well-being of young people with UCIs/BCIs was also comparable to hearing peers in a large Danish public health survey (Percy-Smith et al., 2008). Young people with UCIs reported levels of loneliness are comparable to hearing peers (Schorr, 2006) and to a normative sample (Leigh et al., 2008). Although the findings suggest UCIs/BCIs may protect against social exclusion, well documented in deaf young people without implants (e.g. Stinson & Lang, 1994), Leigh et al. (2008) cautioned against generalising their findings, since some young people were in specialist education, so may have been less likely to be socially excluded. There was a positive relationship between higher loneliness and adolescent acceptance by hearing peers, perhaps suggesting that adolescents with CIs feel lonely in ‘hearing’ group situations (Leigh et al., 2008).

Interview studies present a more detailed view of social well-being. Parents of children with UCIs reported continued difficulties in peer and group communication (due to remaining difficulties with speech and hearing), and the level of acceptance required by hearing peers (Bat-Chava & Deignan, 2001). Findings from interviews with young people, parents and teachers indicated a positive experience of psychosocial development since CIs, but continued difficulties with group communication and social skills (Punch & Hyde, 2011). The importance of relationships with other deaf children in addition to hearing peers, as perceived by parents (Bat-Chava & Deignan, 2001) and young people (Punch & Hyde, 2011) were highlighted. These studies do not however define their qualitative approach, nor adhere to Yardley's (2000) criteria.

Two studies have used observational measures (peer entry tasks) to compare the success of children with CIs to their hearing peers. Six to 14 years olds took longer to enter, had less continuous free play interaction, and a higher rate of failure than hearing peers (it is unclear if they had UCIs or BCIs; Boyd, Knutson & Dahlstrom, 2000) whereas five to six year olds with UCIs did as well as their hearing peers in a one-to-one situations but were more likely to be solitary in groups (Martin et al., 2010). Self-esteem was highly correlated with social competence (Martin et al., 2010). One of the studies found longer duration of CI use positively impacted on social competence (Martin et al., 2010), whereas another did not (Boyd et al., 2000). In line with questionnaire and interview studies, these findings suggest groups of hearing peers may present difficulties for young people with CIs, however generalisability is limited by the lack of ecological validity and small samples.

Factors relating to social well-being. Improved oral communication (perception and production) following UCIs has been repeatedly related to improved peer relationships (Bat-Chava & Diegnan, 2001; Bat-Chava, Martin & Kosciw, 2005) and social well-being (Percy-Smith et al., 2008) by parents/teachers in questionnaire/interview studies. However, children were still functioning below what would be expected for their age (Bat-Chava et al., 2005). Importantly, in two studies that have reported positive social adjustment and low levels of loneliness, the young people all communicated well orally (Nicholas & Geers, 2003; Schorr, 2006), perhaps emphasising the role of oral communication in social well-being. Furthermore, loneliness was lower in those who received their UCI earlier, who were likely to have had the best speech (Schorr, 2006). Although successful communication, rather than successful oral communication, has been reported to protect against psychosocial difficulties in deaf young people in general (Dammeyer, 2009), these findings are from deaf schools where signing was likely to be successful. Most young people with CIs go to mainstream schools, some with resourced specialised units, (Archbold, Nikolopoulos, Lutman, & O'Donoghue, 2002), so oral communication may indeed determine their social well-being.

Further studies of social implications of UCIs/BCIs/SCIs are required. Hearing parents may find the hearing world more desirable, highlighting the importance of self-report studies, with comparisons to non-implanted deaf children and hearing peers.

Identity

Empirical studies have established that, rather than lowering self-esteem, minority group 'membership' may in fact buffer self-esteem (Jambor & Elliot, 2005), due to protection against prejudice/discrimination and incorporation of only positive 'in-group' appraisals (Crocker & Major, 1989). For example, Deaf group identification (e.g. having primarily deaf friends, involvement in the Deaf community) is positively related to self-esteem in non-implanted deaf adults (Bat-Chava, 1993). Furthermore, identifying as both Deaf and hearing is associated with the highest self-concept/self-esteem in non-implanted adolescents (Cornell & Lyness, 2005) and adults (Jambor & Elliot, 2005), perhaps because bicultural identification promotes a strong sense of self from being part of two distinct cultures (Cornell & Lyness, 2004). However, caution is required in interpretation of these findings due to the correlational design of these studies. The theoretical underpinnings of identity formation will now be outlined to provide a context for findings with young people with CIs.

Theories of identity. It is proposed that adolescence is a crucial period for identity development (Erikson, 1968). The expansion of Erikson's (1968) model of adolescent identity formation by Marcia (1993) has led to over 500 studies of the adolescent identity formation process (Kroger, 2004). Social Identity Theory (SIT; Tajfel & Turner, 1979) expanded upon Erikson's (1968) assertion that social response is linked to identity development. A recent review of 40 SIT studies suggested that successful competitive intergroup discrimination enhances social identity and thus increases the specific state self-esteem associated with that identity, and low specific social state self-esteem promotes competitive intergroup discrimination (Rubin & Hewstone, 1998).

Theories of deaf identity. Neil Glickman was the first to present a theoretical model of how identification with the Deaf culture and community develops in deaf people, which was based upon cultural and racial development theory (Glickman & Carey, 1993). His model acknowledges the social context of identity development (Erikson, 1968; Tajfel & Turner, 1979) and consists of four developmental stages: (1) Identification with the hearing culture, valuing oral communication and defining deafness as a deficit/disability, therefore minimizing deafness in their identity (culturally hearing); (2) Identification with neither the Deaf nor hearing culture (culturally marginal); (3) Immersion in Deaf culture (using sign language), with a negative view of the hearing culture (immersion); and (4) Identification with, and comfort within, both cultures (bicultural).

The accompanying scale (The Deaf Identity Development Scale [DIDS]) has been used to evidence these four identities in deaf adults, influenced by the onset and severity of deafness (Fischer & McWhirter, 2001). Studies using questionnaire and qualitative methods have also supported Glickman's model by evidencing the existence of hearing, Deaf, and bicultural identities in deaf adults (Bat-Chava, 2000) and adolescents (of whom a few had UCIs; Hardy, 2010). It is predicted that bicultural identification is associated with the most positive outcomes, followed by immersion, hearing and marginal (Glickman & Carey, 1993). Weinberg and Steritt's (1986) finding that bicultural identity was associated with the best psychosocial outcomes in deaf adolescents without implants therefore supports the model. It is suggested that a range of factors will influence Deaf cultural orientation, such as age of onset of deafness, a hearing or Deaf family, and educational and social experiences, and that whether one moves 'forward' or 'backwards' in the model is dependant upon these factors (Glickman & Carey, 1993). However, this model lacks detailed exploration of the development of hearing identify in deaf people.

In response to these perceived limitations of the DIDS the Deaf Acculturation Scale (DAS) was developed to assess acculturation to hearing and Deaf cultures independently (Maxwell-McCaw & Zea, 2011). Its authors highlight that association with one culture is not necessarily exclusive of the other, given the Deaf community is becoming increasingly bicultural, partly due to CIs and technological advances.

Identity in young people with CIs. A limited number of studies have examined identity in young people with UCIs. In the first such study, adolescents with (n = 8) and without (n = 37) UCIs completed the DIDS, and reported rather similar identity beliefs (Wald & Knutson, 2000). The bicultural scale received the most favourable ratings from both groups, indicative of psychological well-being according to Glickman and Carey (1993). Those with CIs rated hearing identity significantly more favourably, and there was a (non-significant) tendency of rating immersion less favourably. Hearing identity was not associated with teacher reported social/emotional difficulties, and it was argued this is contrary to suggestions by those opposed to CIs that having a hearing identity is harmful. However, the small number of CI users may have resulted in insufficient statistical power.

A slightly larger study used the DAS with adolescents with (n= 28) and without (n= 29) UCIs (Leigh et al., 2008). Approximately 40% of each group scored as bicultural, however those with UCIs tended to be more hearing acculturated, whereas those without tended to be more Deaf acculturated. This was understood in the context of those with UCIs being in primarily mainstream settings whereas those without tended to be in deaf settings. It was suggested that school may mediate the relationship between CIs and acculturation, as those in mainstream school (regardless of CI status) tended to have higher hearing and lower Deaf acculturation scores and, as cited earlier, higher self esteem (scholastic, friendship). Number of deaf friends was also positively associated with deaf acculturation and negatively associated with hearing acculturation, regardless of CI status. Conversely, hearing acculturation was positively related to socialisation with and acceptance by hearing peers, and negatively related to deaf peer relationships. Importantly, and in line with Wald and Knutson (2000), adolescents with and without UCIs, regardless of their acculturation, did not differ significantly in terms of self, parent and teacher reported psychosocial well-being. Further support for the hypothesis that hearing identification/acculturation does not negatively impact upon well-being in young people with CIs was provided by Moog et al. (2011). Using the Group Identification Scale (Jambor & Elliot, 2005) they found fairly equal division of hearing, Deaf and mixed Deaf/hearing identities in adolescent UCI users, with no elevated personal or social adjustment problems associated with hearing identity.

An interview study with young people with UCIs supports the above findings (n = 29; Wheeler et al., 2007). Interestingly, many young people recognised themselves as deaf to some degree as they could not hear, but did not demonstrate a culturally Deaf identity. It was suggested that, given the adolescents tended to be flexible with communication mode (using language and signing), identity was “not a fixed concept… but reflects the complexity of their experience” (Wheeler et al., 2007, p. 311).

In summary, the findings indicate that young people with UCIs have deaf, hearing, or bicultural identities, the latter of which seemed to be more common. Hearing identity/acculturation may be slightly more common in deaf young people with UCIs compared to those without. Findings are consistent with the idea that UCIs may impact upon identity formation, since they facilitate access to sound and speech, perhaps allowing a greater choice in identity (Erikson, 1968). Comparisons across findings are somewhat limited by the variation in the measures employed and small samples. Larger studies using a consistent measure, which control for and examine educational setting, and provide comparative data (across UCIs, BCIs, SCIs and non-implanted young people) are required.

Summary and Conclusions

This review indicates that UCIs/BCIs are associated with levels of HRQoL, psychological well-being, self-esteem, and social well-being that are comparable to hearing peers, and with improvements in these areas when compared to pre-implant. However, young people also experience some difficulties in social interaction, and it is apparent that psychosocial outcomes are complex. Methodological limitations have been highlighted, including small sample sizes resulting in poor statistical power, a lack of comparison data and the use of non-validated measures. Most studies included children with UCI, only one compared UCI and BCI, and research with young people with SCIs is lacking.

There is a need for larger, better controlled, detailed studies of psychosocial well-being of young people with CIs. Given the average age of implantation is reducing, pre- and post-implant comparisons will be increasingly difficult, so comparisons to non-implanted deaf children and hearing peers will be most informative. The groups should be matched for age, educational setting and audiological background, since these have been found to be related to psychosocial outcomes. Such data will produce findings that can further inform parents and professionals of the psychological and social outcomes of such an invasive procedure. Given recent changes in NICE (2009) guidance, future studies should compare psychological and social outcomes in children with UCIs and SCIs, to further inform the parental decision-making process regarding whether to opt for BCIs for their baby. There is also a unique opportunity at this current time to explore young people's experiences of SCIs, to provide service-user feedback on the impact of the procedure, and self-reported comparisons to UCIs.

Further research is also needed regarding the nature and prevalence of mental health difficulties in young people with CIs, and there is also a lack of literature on issues for consideration in psychological therapy with these young people. Identity of young people with CIs is also relatively under-researched, given the importance of identity development in psychological well-being (Kroger, 2004).

To conclude, the existing research is consistent with the hypothesis that paediatric CIs lead to improved psychological and social well-being, although further research is needed to explore these issues in more depth.

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KRISTINA M. HILTON BSc Hons

Section B:
Adolescent experiences of receiving and living with sequential cochlear implants: An investigation

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Abstract

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 one cochlear implant (CI) for most of their life. Eleven young people were interviewed. Interpretative Phenomenological Analysis resulted in the identification of six master themes. Most participants enjoyed improved confidence and social well-being following their SCI, and felt that two CIs were superior to one. 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 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.

Introduction

Children and adolescents (hereon referred to as young people) who are severely or profoundly deaf are eligible to receive cochlear implants (CIs), a technological device that provide a sensation of hearing and ultimately provide access to speech perception and production. Prior to a revision of the National Institute of Health and Clinical Excellence (NICE, 2009) guidelines, young people received a unilateral cochlear implant (UCI). However, due to the possibility of further audiological benefits young people are now eligible to receive simultaneous bilateral cochlear implants (BCIs). Young people with an existing UCI are eligible to receive a second, sequential cochlear (SCI) implant until the end of their eighteenth year.

CIs and Psychosocial Well-Being

Given that rates of emotional and behavioural 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 and quality of life (QoL) with young people with UCIs indicate that, in addition to a positive experience of hearing and speech perception/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 has 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/BCIs are mostly comparable to hearing controls (Warner-Czyz, Loy, Roland, Tong & Tobey, 2009; Loy, Warner-Czyz, Tong, Tobey & Roland, 2010; Huber, 2005). However, concerns and disadvantages of UCIs have also been reported, including continued difficulties hearing in noisy environments and groups and the restrictiveness of CIs (e.g. exclusion from some sports).With the exception of Wheeler et al.'s (2007) interview study, 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, behavioural and social well-being reported by adolescents with UCI/BCI was comparable to 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 pre-school were also found to have positive self-esteem and good social integration in mainstream education, using spoken language to communicate (Moog, Geers, Christus & 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 to hearing peers. Levels of loneliness comparable to hearing peers (Schorr, 2006) and to a normative sample (Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2008) have also been reported. A more detailed picture was presented in a recent interview study with young people with UCIs, who described difficulties in group communication due to listening challenges, and in adolescence felt self-conscious about deafness/CIs and fitting in and worried about friendships, dating and the future, even though they also spoke about a positive psychosocial development (Punch & Hyde, 2011).

In summary, despite a generally positive picture, it is evident that young people with UCIs may experience psychosocial difficulties.

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: (1) Culturally hearing, where oral communication is valued and deafness is perceived as a disability (2) Culturally marginal, where neither culture is identified with (3) Immersion in Deaf culture/sign language, with negative views of the hearing culture (4) 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 impact upon Deaf cultural orientation, and whether one moves ‘forward’ or ‘backwards’ in the model will be dependant upon these factors (Glickman & Carey, 1993).

In response to 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 behavioural change occur in line with ongoing contact with a new culture. The DAS addresses a perceived need to assesses 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 (Wald & Knutson, 2000; Moog et al., 2011; Leigh et al., 2008).

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 favourably by those with UCIs. In line with this, using the DAS, adolescents with and without UCIs also 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., 2008). A later study using the Group Identification Scale (Jambor & Elliot, 2005) found adolescents with UCIs identified as hearing, Deaf and mixed Deaf/hearing (Moog et al., 2011).

Importantly, none of these studies found that hearing identification or acculturation were associated with increased psychosocial difficulties. This is in contrast to studies that have shown associations between bicultural or culturally deaf identities and more positive psychosocial well-being in non-implanted deaf adults (Bat-Chava, 2000; Hintermair, 2007; Jambor & Elliott, 2005) and adolescents (Cornell & Lyness, 2004; Weinberg & Steritt, 1986). It could be hypothesised 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/acculturation, although the variation in measures across studies limits comparisons. It is also important to consider interview findings, that adolescents with

UCIs identified themselves as deaf (in terms of their hearing), but not culturally Deaf, and for many who used speech 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). To date only two studies have been conducted with young people who received a SCI (Mather, Gregory & Archbold, 2011; Redfern & McKinley, 2011), both of which focused mainly on audiological benefits (sound localisation, general ease of listening) with only brief evaluation of psychosocial implications. Of note in a questionnaire study, 68% of users felt the SCI enhanced their QoL, and 84% felt more confident in group conversations (Redfern & McKinley, 2011), and 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.

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 that can compare having one versus having two CIs, 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 a 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 understand and represent the experiences and actions of people as they encounter, engage and live through situations (Elliot, Fischer & Rennie, 1999).

It was hoped that the findings would inform clinical provision and provide useful information for parents considering UCI or BCI, and for young people contemplating a 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 to, for example, grounded theory methods (Glaser & Strauss, 1967) that are concerned with theory generation.

Participants

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

(1) Had received a SCI since the revision of the NICE (2009) guidelines.

(2) Aged between 12 and 18 years of age at the time of the interview (since it was hypothesised that identity formation occurs in adolescence [Erikson, 1968], the minimum age of 12 aimed to facilitate discussion of these issues).

(3) Received the SCI a minimum of six months prior to the interview, to allow for initial adjustment and experience using the SCI.

(4) No other disability (e.g. severe physical/learning disability) that would impact upon homogeneity.

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

Table 1

Individual and demographic characteristics

Characteristics		Number of participants	
Gender	Male	4	
	Female	7	
Age	12-13 years	7	
	17-18 years	4	
Deafness	Congenital	9	
	Acquired	3	
Communication	Speech	7	
	Speech and BSL	4	
Age at CI1	1-3 years	3	
	4-6 years	5	
	7-9 years	3	
Age at CI2	7-9 years	1	
	10-12 years	5	
	13-15 years	2	
	16-18 years	3	
Duration between implants	1-3 years	0	
	4-6 years	4	
	7-9 years	5	
	10-12 years	1	
	13-15 years	1	(Mean = 7.2 years)
Ethnicity	White British	8	
	Bangladeshi (Asian)	1	
	Indian (Asian)	1	
	Mixed White/Black African	1	
Religion	Christian	3	
	Catholic	1	
	Muslim	1	
	Sikh	1	
	Atheist/no religious group	5	

Recruitment

Participants were recruited from three National Health Service (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 covering letter (Appendix D) and the young person and parent information sheets (Appendices E and F) were provided, or posted if verbal consent was sought over the telephone. Interested participants and their parent(s) were contacted two weeks later to discuss any questions and arrange a time for the interview. Eleven of the twelve 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 semi-structured interview schedule (Appendix G) 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 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 socialisation and 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 (Appendix H). The BPS code of human research ethics was adhered to throughout (BPS, 2010).

Interview Procedure

Nine of the eleven 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 (Appendices I, J, and K). Most interviews lasted around one hour. 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 transcript and all participants wanted to receive a summary of the findings (Appendix L).

Data Analysis

In line with IPA, the first three transcripts (see the example transcript, Appendix M) were read and re-read, initial comments were noted regarding descriptive, linguistic and conceptual issues, and emergent themes were recorded (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 sub-themes.

Quality Assurance

Yardley's (2000) guidelines for qualitative research were applied throughout the study. IPA emphasises 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 sub-themes, transcripts were coded according to support for each possible emerging theme (Appendix N). 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 supervisor 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 rigour’ 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 (Appendix O), and using a reflective diary throughout the research process (Appendix P).

Results

The analysis resulted in six master themes and 22 sub-themes, outlined in Table 2, which will be explained with illustrative quotations (see Appendix Q for further example quotations).

Table 2.

Master themes and sub-themes

Master themes	Sub-themes
Consideration and commitment to the second implant	• An important decision • Fear and discomfort • Excitement • Adjustment and effort
Contentment with two CIs	• The benefits of hearing with two ears • An even brighter future with two • Social gains • Improved confidence

The importance of being in the hearing world	• Speech: value and commitment • Inclusion and integration • A better future • Normality versus disability • Being a hearing person
Connections to deafness	• Deafness as a valued part of the self • BSL means understanding • The importance of a shared experience of deafness and CIs
Bicultural identity	• Being deaf, being hearing and being in the middle • Sameness and difference
Feeling different in a hearing world	• Frustration and confusion at not hearing and understanding • Feelings of isolation and difference in a hearing world • Unfairness of prejudice and difference • Looking different

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*[1]), seemingly due to the important prospect of better hearing, which needed weighing up against the risks. Whilst most participants made the decision with their parent(s), a few made the choice alone or their parents decided for them. Although two participants had no doubts about their SCI, 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 the SCI may not work:

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

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

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).

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[1] P(x, x, x,) Participant name, page number, line number.

[2] (…) Material omitted for clarity or confidentiality.

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).

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 SCI.

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 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. One participant was conflicted about SCI 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).

An even brighter future with two. Most participants felt their future prospects improved following their SCI, *'It's made my future more stable and guaranteed' (P8, 17, 497),* with some feeling that without their SCI they would not have been able to access their chosen career. The majority of 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-wellbeing with their SCI. They felt able to engage in conversations with more ease, mishearing less, making socialising 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 can understand what they was talking about I'm 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 lear*nt 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 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).

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 its 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 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. 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 cos 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/SCIs had allowed them to aspire towards:

‘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 dependant 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 o*nly 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 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 lip-read. 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 then perceiving it is a negative and limiting aspect of the self. For example, some participants spoke playfully used deafness to their advantage, one participant would say '*I didn't hear you' (P6, 2, 49)* if she hadn't tided her room or done her homework.

BSL means understanding. Although only a minority of participants used BSL, it is important to acknowledge its value to them. Three were fluent BSL users, and they described the ease of communication and understanding it provides, in comparison to 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. The majority of 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 i*n *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 a 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).

The majority of participants were not in fact aware of the Deaf culture/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 dependant on when they experienced difficulties understanding others. It seemed that difficulties in communication emphasised 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 al*so 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 dependant 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 lik*e 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).*

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 and difference to 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 to 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).

It seemed that participants perhaps wanted to feel distant from deaf people who could not hear or talk, and 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 didn't 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 ex*plain 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, since 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 towards 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 under half of participants, all female, felt CIs were a visual sign of their difference to 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 m*e more obvious that I’m really really like feels like I’m really alone I don’t know why I feel like that is juts 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 beca*use 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/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 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 people’s decision to proceed with a 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, and parents often had a role in this important decision.

In terms of the impact of the SCI on participants’ psychological and social well-being, the theme ‘contentment with two cochlear implants’ 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 is the first study to rigorously examine psychosocial experiences of a SCI, building upon earlier, briefer, interview and questionnaire studies (Mather et al., 2011; Redfern & McKinley, 2011). These findings occur in the context of existing literature of psychosocial well-being reported by young people with UCIs, hence it could be hypothesised 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’), 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 to

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 their social comparisons (Festinger, 1954) left them feeling neither fully deaf nor fully hearing. This is in line with a grounded theory study that theorised 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 Wheeler et al's (2007) assertion 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 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 dependant on the level of interactions with the cultural environments (Leigh, 2009). Since young people with UCIs whose speech perception and language are close to hearing peers have been found to identify most strongly with the hearing world (Moog et al., 2011), it could be hypothesised 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 reported to be an important mediating factor on self-esteem in deaf young people, regardless of UCI status (Leigh et al., 2008). It could be hypothesised 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 Social Identity Theory (Tajfel, 1981) Bat-Chava (2000) suggested that members of the deaf minority achieve positive social identity by attempting to access the mainstream. It could be hypothesised 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 dependant on connections to 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 non-implanted deaf adults and adolescents (Bat-Chava, 2000; Cornell & Lyness, 2004; Hintermair, 2007; Jambor & Elliott, 200; Weinberg & Steritt, 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 deaf as well as hearing was important in maintaining 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 non-implanted deaf teenagers and adults, who had more positive self-esteem when they associated more closely with other deaf people (Bat-Chava, 1993). These relationships may have provided a normalising experience of being deaf with CIs, helping with feelings of loneliness that may have been experience in hearing groups (Leigh et al., 2008).

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

While 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 will allow comparisons between young people with UCIs, BCIs and SCIs and their non-implanted deaf and hearing peers, and consideration of factors such as schooling, that 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. The identities of young Asian deaf people with UCIs are reportedly complex, multiple and contingent (Ahmad, Atkin &

Jones, 2002), and adolescents are in a period of identify formation (Erikson, 1968), therefore future studies should further explore identity issues (e.g. religion, culture).

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 a SCI, since 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 were also grappling 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 clinical psychologist’s (CPs) role 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. CPs have a role in promoting psychological thinking in a medical setting, for example in considering the psychological experience of the surgery. It will be important for psychology provision to focus upon exploration of issues of identity with young people prior to, and following, receiving a SCI. CPs have a role in the assessment and formulation with young people who feel different and isolated, with provision of therapeutic support where necessary. These implications may also be pertinent to young people with UCIs and BCIs.

Conclusions

This is the first study to examine the experience of young people with SCIs using rigorous qualitative methodology. Adjustment to the SCI required considerable effort, and on the whole, most participants were extremely pleased to have a 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 (NICE, 2009). Moreover, these findings have important clinical implications in terms of the role of CPs in CI clinics.

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Section C:
Critical Appraisal

Word Count: 1994

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Doctor of Clinical Psychology

SEPTEMBER 2012

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1. **What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?**

Prior to embarking on this project I had worked only as an assistant in research projects, mainly involving collecting quantitative questionnaire data from children, adolescents and their parents. I feel have learnt how to design a research project, starting with the very basics, since I was not at all experienced in the field of deafness and cochlear implants (CIs). I have gained experience in first establishing the state of research in a particular area, before planning a study. I feel that the National Health Service (NHS) research ethics process, which although at times felt challenging due to the comprehensiveness of the application, was a valuable experience given the importance of clinical psychologists' conducting research projects within NHS settings.

I was pleased that my research questions indicated a qualitative approach, as I wanted to engage with the depth of participant experiences, given I had previously worked mainly with quantitative data. I had used Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) as an assistant psychologist whilst working in an adult neuropsychology setting, although the project I worked on felt somewhat limited since data was collected using fairly brief telephone interviews. Hence in conducting this project I was keen to learn more about the underpinnings of IPA and engage at a deeper level with participant experiences.

Conducting this research has allowed me to build upon my skills of recruiting participants in an NHS setting and has enabled me to develop skills in gaining Research and Development approval, and recruiting across multiple sites.

I also utilised service-user involvement in designing the interview schedule, which was an extremely valuable experience since it was not something I had done previously. I would like to develop these skills further, by involving service-users at an earlier stage in project design and in the process of data analysis.

I have learnt how to design a semi-structured interview schedule, with consideration of issues pertinent to a deaf sample. I think these skills would be transferable to designing interview schedules for clients with other difficulties in communication or understanding. Although it has been suggested that students produce interview schedules that are too long (Hefferon & Gil-Rodriguex, 2011), deaf participants, who at times found it difficult to express their experiences, did require additional prompt questions which ultimately lengthened my interview schedule. This is in line with Smith's (2004) assertion that children, and individuals who have difficulty with English, may need the researcher to take a stronger role than the general open question stance of interviewing common with IPA. I would like to gain more experience of designing interview schedules across different client groups.

It felt difficult at points during the interviews to resist taking on a 'therapist role', particularly when participants spoke about feelings of exclusion which they experienced as distressing. This pull felt particularly strong in an interview with a participant who was anxious about anyone seeing her CIs, which seemed to be further exacerbated by her continued avoidance. I managed to remain in an 'interviewer role', by listening and being empathic, and being mindful not to act as a therapist. My feelings were perhaps inevitable given that the interviews involved exploring sensitive issues. On the other hand, I also found it quite 'freeing' being able to explore participant experiences without having to focus upon formulating and intervening. I felt that taking on a ‘curious’ stance enabled participants to give a rich first hand account of their experiences (Smith et al., 2009).

Smith et al. (2009) suggest that one challenge of novice researchers is tending to be too cautious and produce analyses that are too descriptive, and indeed at the beginning of my analysis I struggled with these concerns. I think that as the analysis progressed I became more skilled in engaging with a deeper level of interpretation. I gained experience and skills in engaging with the ‘double hermeneutic’ (Smith et al., 2009), requiring me for the first time to engage in a reflexive research process, including using a research diary and actively attending to my assumptions as a hearing person as part of the process of ‘bracketing’ my assumptions (Fischer, 2009; Smith et al., 2009). I have learnt a great deal about the need to consider issues pertinent to qualitative research, such as validity, and through exploring relevant literature I have learnt about key issues related to producing good quality, trustworthy, and publishable qualitative research (Elliott, Fischer & Rennie, 1999; Nutt Williams & Morrow, 2009; Yardley, 2009).

I have learnt more about the intricacies of confidentiality in conducting research. For example, my sample was small so I became aware of the importance of not separately displaying the demographic characteristics of each participant, given that recruiting clinicians would have been able to identify participant quotations.

Through the research process I attended a trainee IPA discussion group. This experience allowed me to utilise peer support and knowledge in the research process, a skill which I think will be vital when conducting research as a qualified clinical psychologist.

Having used IPA, I would like to further develop my skills in qualitative analysis. I am particularly interested in learning about Grounded Theory (Glaser &

Strauss, 1967). I had initially considered a project using this type of design during the planning stages of this study, and I am keen to learn more about engaging with qualitative data with the aim of generating a theory in relation to the topic being studied. I am also keen to conduct quantitative research studies, given I have not had the opportunity to devise and run such projects.

2. **If you were able to do this project again, what would you do differently and why?**

A few of the participants (who used British Sign Language [BSL] and speech) found using spoken language quite challenging, which I felt affected the richness and usefulness of their transcripts. On the one hand I feel it was extremely important to hear the voices of these participants, given that excluding them would have led to a rather biased sample of sequential cochlear implant (SCI) users. On the other hand, it was difficult to conduct these interviews and I feel these young people were not fully able to express a rich first person account. It has been suggested that phenomenological research methods may not be suitable for studying the experiences of those who may not be able to express themselves in the sophisticated manner required by the method (Willig, 2001). If I were to conduct the study again, I would spend more time talking with participants to explore the use of a BSL interpreter, perhaps discussing whether it may allow them to discuss complex issues with more ease. This may allow participants to give a more rich and detailed account. This analysis would be complex given its impact upon the double hermeneutic (J. A. Smith, personal communication, December 4, 2010), although it feels integral to allowing these young people a means of describing their experiences.

I think it would also be important to further consider specific issues of homogeneity in the sample, as although participants had all experienced having a sequential cochlear implant (SCI), their experience of deafness and communication was somewhat variable. It would be important to consider whether the data of young people who used BSL and speech should be considered separately to highlight themes particularly pertinent to communication mode. Similarly, participants varied in whether their deafness was congenital or acquired, which may have impacted upon their identity development, which again would be something I may need to further refine if I were to conduct the project again.

As recently highlighted in a paper discussing the implications of an increase in popularity of IPA, students consistently appear to experience pressure to include too many participants (Hefferon & Gil-Rodriguez, 2011). On reflection I think I experienced this pressure when designing the project, feeling that perhaps my study would be more credible and publishable with a larger sample. Although it is recognised that is not possible to conduct such a detailed analysis with larger samples (Smith et al., 2009), I think I felt the need to engage with each transcript in depth so as to honour all of the participant experiences, which was extremely time consuming.
I think if I conducted the project again I may have aimed for around eight participants, in line with Smith et al.'s (2009) guidance for professional doctorates.

3. **As a consequence of doing this study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?**

As outlined in the clinical implications in Section B, I think it is important for deaf young people to be given the opportunity to explore issues of identity as part of the service they receive from their cochlear implant clinic. The provision of clinical psychology at many clinics indicates that young people can access such input. I understand from my contact with these psychologists that some medical clinicians may not privilege issues such as identity in the decision making of parents and young people, for example in considering the reasons why young people may not wish to proceed with a SCI given the potential hearing improvements on offer. Clinical psychologists therefore have an educative and consultative role, as well as a direct clinical role, in working with these young people and their families.

In future I hope to work with clients who are deaf, who may or may not have CIs. I feel that the knowledge I have gained regarding issues of mental health in the deaf population would be extremely valuable should I work in this area. More widely, I feel that the experience of taking a curious stance, sitting back and listening to participants tell the story of their experience is a valuable lesson for my clinical work. In clinical work I often find myself very focused on the particular goal for that session, and I do feel that using the experience of allowing clients more freedom to tell their stories would ultimately allow me to develop richer psychological formulations in my clinical work.

4. **If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?**

The experience of young people who decline an SCI requires further exploration, since this may raise issues pertinent to parents' decision about whether to proceed with the bilateral cochlear implantation now offered to infants following the revision of guidance from the National Institute of Health and Clinical Excellence (NICE, 2009). An IPA methodology would be well suited to exploring the experiences of these young people.

Furthermore, issues of identity were pertinent in my study and require further exploration. I would like to use a quantitative measures of identity, such as the Deaf Acculturation Scale (Maxwell-McCaw & Zea, 2011), to explore patterns of identity in young people with unilateral, bilateral and sequential implants. This study would use a multi-group cross-sectional design (Clark-Carter, 1997), where the DAS would be completed by young people with unilateral, bilateral and sequential implants. The research questions would include the following: (1) How do young people with unilateral, bilateral and sequential implants identify themselves in relation to the deaf and hearing worlds? (2) What are the similarities and differences in cultural identity in young people with unilateral, bilateral and sequential implants? Additional research questions would relate to consideration of factors such as schooling, communication mode, and audiological backgrounds. This information that would be gathered using questionnaires designed for the purpose of the study, and associations would be explored using statistical methods. This study would require a number of participants, which could be accessible through the network of CI clinics across the United Kingdom. The findings would be informative on a psychological and societal level, in thinking about changes in the deaf community following continuing technological advances.

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Section D:
Appendices of supporting material

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Appendix A: Literature search methodology for Section A

Inclusion criteria

Studies were required to investigate an aspect of the psychological and/or social impact of unilateral cochlear implants or simultaneous/sequential bilateral cochlear implants for children and adolescents (aged 0-18 years of age). Therefore studies were included if they examined health related quality of life, quality of life, psychological well-being (mood, self-esteem), social well-being and identity.

Studies were included if they included deaf children and/or adolescents who were aged between 0 and 18 years of age when they underwent unilateral, bilateral or sequential cochlear implantation, or collected data from the parents/guardians of these young people.

Studies were not included if their sample included children or adolescents with significant additional disabilities, given the variation in the outcomes for these young people.

Search strategy

The following electronic data bases were searched from the earliest year of publication available up to the end of March 2012: EBM Reviews (2005- present), Medline (1948 to present), PsychInfo (1806-present).

Key words CHILD* or ADOLESCEN* and COCHLEAR IMPLAN* were combined with the following; PSYCHOLOGICAL, PSYCHOSOCIAL, PSCYH*,

SELF-ESTEEM, SELF-CONCEPT, SOCIAL, PEER, FAMIL*, OUTCOME, QUALITY OF LIFE, EXPERIENCE, IDENTITY, and CULTURE,

The key words CHILD* or ADOLESCEN* and DEAF were also combined with IDENTITY and QUALITY OF LIFE to capture broader literature.

Study selection

Abstracts were screened to ascertain whether they met the inclusion criteria, and full references were collected where the inclusion criteria were met. The reference lists of the selected studies were checked for additional articles not found in the searches. Forty-nine studies met the inclusion criteria.

Study categorisation

The studies were categorised according to key factors pertaining to mental health; health-related quality of life (HRQoL), quality of life (QoL), psychological well-being (e.g. mood, self-esteem), social well-being and identity. Some studies were included in more than one category as they investigated more than one of the key factors.

Appendix B: Tabular presentation of review of findings from HRQoL studies

Table 1
Studies of HRQoL in young people with UCI/BCI

Study	Country	Sample Size and Characteristics	Respondent	Comparisons	Control group?	Measure	Results of comparisons	Results of associations between HRQoL and background variables
Cheng et al. (2000)	America	N = 78 Mean age (years): 7.5 Mean use (years) of implants: 1.9 Unilateral implants only	Parents	Retrospective ratings of pre- and post-implant	No	Health Utilities Index – Mark III Visual Analog Scale (from death to perfect health)	HUI scores from 0.25 (before implant) to 0.64 (post implant) 92% improved (due to hearing & speech domains) (For n = 22) Mean gain associated with implantation = 0.39 VAS scores from 0.59 (before implant) to 0.86 (post implant) 95% improved (For n = 78) Mean gain associated with implantation = 0.27	**n/a**

Huber (2005)	Austria	N = 44 Mean age at assessment in 8-12/13-16 year olds: 10.5/14.5 Mean age (years) at implant in 8-12/13-16 year olds: 4.3/7.6 Mean use (years) of UCI in 8-12/13-16 year olds: 6.3/6.9 Unilateral implants only	Parents and Children	Parent and child data Data from 8-12 and 13-16 year old age group	Hearing children	KINDLr	Comparison to Hearing Control: 8-12 year olds HRQoL significantly below that of hearing children. Girls were lower in physical well-being, psychological well-being, self-esteem, family, friends and school. Boys were lower in the psychological well-being and self-esteem. 13-16 year olds HRQoL within the norm in comparison to hearing children, although self-esteem was lower in girls. Comparison to parent ratings: 8-12 year old HRQoL was significantly lower than parent ratings. 13-16 year olds ratings did not significantly differ from the parent ratings.	Self-rated ability to hear and understand spoken language correlated positively with HRQoL, although this was not found in parent ratings. In terms of parent ratings, the length of time of deafness, the age at implantation, the length of time with an implant, capability to hear and understand, and chronological age do not influence HRQoL.

Sach & Barton (2007)	United Kingdom	N = 222 Mean age (years) : 9.26 Mean age (years) at implant ≥4: n = 108 <4: n = 114 Mean use (years) of implant ≥4: n = 112 <4: n = 110 Unilateral implants only	Parents	Reterospective ratings of pre- and post-implant. Comparision of HRQoL and QoL ratings.	No	EuroQol EQ-5D EuroQol Visual Analog Scales (best and worst imaginable health states) Visual Analog Scales (best and worst imaginable QoL) Categories of auditory performance Parent Interview	Child EQ-5D Mean = 0.88 EuroQol VAS mean gain associated with implantation = 0.14. However, 67% of parents reported the same ratings pre- and post-implant, leading to questions about the usefulness of HRQoL ratings. VAS QoL mean gain associated with implantation = 0.35. 59% of parents conceptualised deafness as a QoL, but not a health issue.	Lower EQ-5D scores associated with: Additional disability, being male, lower level of auditory perception, parents leaving school before 18 years of age. No differences associated with: Age of onset of deafness Age at implantation Duration of implant use

Warner-Czyz et al. (2009)	America	N = 44 Age of sample: 4-7 years Mean age (years) of identification of deafness : 0.79 (range birth – 3 years) Mean age (years) at implant: 2.52 (range 7 months - 7 years) Mean use (years) of implants: 3.27 (range 6 months – 5 years and 7 months) Unilateral and Bilateral Implants – details not provided	Parents and children	Parent and child data	Hearing children	Kiddy KINDL	Comparison to hearing control: 4-7 year old children rated HRQoL similarly to hearing peers (no significantly differences) Comparison to parent ratings: 4-7 year old children rated HRQoL significantly more positively than their parents, specifically in terms of self-esteem, family and friends.	Shorter durations of cochlear implant use were related to more positive overall HRQoL. Younger chronological age was related to more positive overall HRQoL. There were no relationships between age at implantation and HRQoL ratings.

Loy et al. (2010)	America	N = 88 Mean age (years) in 8-11/12-16 year olds: 9.1/13.7 Mean age of onset of deafness (years) in 8-11/12-16 year olds: 1.11/1.18 Mean age (years) at implantation in 8-11/12-16 year olds: 3.37/5.83 Mean use of implant (years) in 8-11/12-16 year olds: 5.17/ 7.87 Unilateral and Bilateral Implants – details not	Parents and Children	Parent and child data 8-11 year old and 12-16 year old group	Hearing children	KINDLr	Comparison to hearing control: 8-11 year old and 12-16 year olds scored similarly to hearing peers. However, 8-11 year olds scored lower in the family domain than hearing peers. Comparison to parent ratings: 8-11 year old and 12-16 year olds scored similarly to their parents. However, 12-16 year olds scored the school domain lower then their parents Age group	In the 8-11 year old group a later onset of deafness was associated with more positive HRQoL in emotional well-being and self-esteem in 8-11 year olds, and more positive overall HRQoL in 12-16 year olds Adolescents who were younger at age of activation rated their HRQoL more positively than those with an older age at activation. Adolescents with a longer duration of implant use rated their HRQoL more

	provided		comparisons: 8-11 year olds scored their overall HRQoL significantly higher than the 12-16 year old group.	positively than those with a shorter duration of use.

Warner-Czyz et al. (2011)	America	N = 138 Mean age (years) at assessment in 4-7/8-11/12-16 year olds: 5.8/9.1/13.7 Mean age (years) of identification of hearing loss in 4-7/8-11/12-16 year olds: 0.8/1.1/1.2 Age(years) of implant activation in 4-7/8-11/12-16 year olds: 2.5/3.4/5.7 Duration of implant use (years) in 4-7/8-11/12-16 year olds: 3.5/5.7/7.9 Unilateral Implants in 4-	Children only	4-7 years old 8-11 years old 12-16 years old	No Control	KINDLr Preliminary Cochlear Implant specific module (6 item) developed for the study, relating to peer acceptance, self-image, and satisfaction.	Age group comparison: 4-7 year olds rated HRQoL significantly more positively than the 8-11 and 12-16 year olds 4-7 year olds rated CI specific HRQoL significantly more positively than the 8-11 and 12-16 year olds 4-7 year olds rated cochlear implant specific items of friends and self-image more positively than older groups, but reported greater difficulties in hearing teachers The oldest group (12-16 year	n/a

7/8-11/12-16 year olds: 42%/46%/76%

Bilateral Implants in 4-7/8-11/12-16 year olds: 58%/54%/24%

olds) score more consistently on the cochlear implant specific module.

Table 2

Studies of HRQoL in young people that compare UCI and BCI

Study	Sample Size	Comparisons	Control	Measure	Respondent	Results
Beijen, Snik & Mylanus (2007) Netherlands	N = 10 5 unilaterally implanted children 5 bilaterally implanted children	Unilateral versus bilateral	No	PedsQL	Parents	No significant difference between unilaterally and bilaterally implanted children on the PedsQL Of note, bilaterally implanted children scored higher on sound localisation, but not in speech and quality of hearing.
Lovett et al. (2010) United Kingdom	N = 50 20 unilaterally implanted children 30 bilaterally implanted children	Unilateral versus bilateral	Hearing children N = 56	Health Utilities Index- Mark III QOL Visual Analog Scale	Parents	No significant difference between unilaterally and bilaterally implanted children in terms of health utility or QoL. Of note, bilaterally implanted children scored higher on sound localisation and speech perception in noise, although on average they did not perform as well as hearing children

Appendix C: Characteristics of good qualitative research (Yardley, 2000)

Reproduced from Yardley (2000)

Essential qualities are in bold, with examples of the form each could take shown below.

Sensitivity to context

Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.

Commitment and rigour

In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.

Transparency and coherence

Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.

Impact and importance

Theoretical (enriching and understanding); socio-cultural; practical (for community, policy makers, health workers).

Appendix D: Recruitment cover letter

Canterbury Christ Church University
Department of Applied Psychology
Broomhill Road
Tunbridge Wells
TN3 0TG

Dear ……………………………………………………………………………………

I (Kristina Hilton, Trainee Clinical Psychologist) would like to invite you to participate in an interview about your experience of having a second cochlear implant.

I am contacting you via *(clinic name)* who are supporting the project and helping me find young people who would like to take part. The project is based at *(removed to maintain confidentiality)*, but I can travel to your clinic or home to do the interview.

The research project aims to find out what it is like for young people to have a second cochlear implant. There is no research that has asked young people what this has been like.

The enclosed information sheets will tell you about the project. The consent forms enclosed are what you would need to sign if you decide to take part in an interview.

The clinic will have asked you if it's OK for me to telephone/email you and your parents/guardian. I will contact you in a few weeks to answer any questions you may have and see if you are happy to meet me and discuss your experience of having a second cochlear implant.

If you would like to contact me, or if you have changed your mind and do not want to discuss taking part, please contact me either by telephone or email:

k.hilton240@canterbury.ac.uk
01892 507673

Yours sincerely,

Kristina Hilton	Dr Jenny Cropper
Trainee Clinical Psychologist	Clinical Psychologist
Canterbury Christ Church University	

Appendix E: Young person information sheet

YOUNG PERSON INFORMATION SHEET

Adolescent experience of a sequential cochlear implant

I (Kristina Hilton) am asking you to take part in this research project.
Research projects are done to try and find out more about something. This is sometimes with people who use hospitals or clinics and sometimes with other members of the public. Research aims to find out new information to try and make things better for people.

Participation in the project is completely voluntary (it is your choice whether to take part or not). If you decide not to take part your ongoing care at the clinic will not be affected in any way.

Before you decide we will talk about this information sheet. I will answer any questions you have about taking part.

What's the project for?

Young people who have had one cochlear implant are now being offered an operation to have a second cochlear implant.

Research has been done to look at what it is like having one cochlear implant, and how young people think about themselves in terms of how they fit in with people who are deaf, and people who are hearing, and the Deaf and hearing communities.

I want to find out what it is like having a second cochlear implant after having the first one, and how this affects what young people think about themselves in terms of the Deaf and hearing worlds

Why have I been asked to take part? Do I have to take part?

You have been invited to take part in this study because you had a second cochlear implant. It is up to you whether you take part or not. If you agree to taking part you will be asked to sign a form, a parent/guardian also has to agree and sign a form if you are under 16 years old.

What does taking part involve?

You will have an interview with me (Kristina Hilton). This will last for up to an hour and a half.

It involves talking to me, using either speech or British Sign Language via an interpreter, or a combination of speech and British Sign Language. You will be asked questions about:

- Your decision to have a second cochlear implant.
- How you think about yourself in terms of the Deaf and hearing worlds.

- How the second cochlear implant has affected or changed they way you think about yourself.
- How the second cochlear implant has affected your life.

The interview will be voice and video recorded so that the interview can be written down afterwards, and then the recordings will be erased.

To participate in this research your must:

- Have received a sequential cochlear implant since the NHS started offering them.
- Have acquired your deafness (if applicable) prior to starting school at age 4-5.
- Be aged 18 years or under when you had your second cochlear implant.
- Be aged between 12 and 21 years old at the time of the interview.

Will taking part help me?

You will have a chance to take part in research into cochlear implants, which you may find interesting.

Are there any bad things about taking part?

If you talk about sensitive feelings about being deaf or your cochlear implant you may feel upset. You will not have to answer any questions that you do not want to. You can stop the interview at any time, or take a break. You can decide not to take part at any point. I will be able to talk to you and answer any questions after the interview, and/or someone from the clinic will be able to talk to you within a week of the interview if you need to do this.

Expenses

You can claim up to £10 towards the cost of travel to the interview.

Confidentiality

If you agree to take part the clinic where you had your cochlear implant will be told that you are coming for an interview. What you talk about in your interview remains confidential unless you tell me something that makes me worry about your safety or the safety of others. Then I may have to talk to the clinic and your parents. The interview will be typed up and will be stored securely at the university, without your name on it. Only I (Kristina Hilton) and two research supervisors can look at the typed interview, but the research supervisors will not be told your name. Your name and contact details will be stored separately to the printed copy of our interview. After the study your name and contact details will be removed completely.

What will happen with the results?

You and your parents/guardians will be sent a brief summary of the findings of the study.

Your cochlear implant clinic will also be sent a summary of the findings of the study and the study will be written up as an article, and published in an academic journal (which is a like a magazine for people who do research, so that other researchers can read about what I found out) . Your name and other identifying information will not be included. I may want to quote something you said to me but no-one will be able to tell that it was you who said it.

Who has reviewed the study?

This study has been approved by a Research Ethics Committee for the NHS, and my University (Canterbury Christ Church University). They did not have worries about me doing this research.

Do you want to take part?

It is up to you whether you take part. Please email me or talk to me if you have any questions.

If you take part you can change your mind and stop taking part at any time without having to give a reason. Your treatment at the clinic will not be affected in any way.

Any questions? Please contact Kristina Hilton (Trainee Clinical Psychologist):

k.hilton240@canterbury.ac.uk or 01892 507673
Canterbury Christ Church University, Salomons Campus at Tunbridge Wells
Broomhill Road, Southborough, Tunbridge Wells, Kent, TN3 0TG

If you would like to speak to someone outside of the research team for advice about taking part in a research project or taking part in this project you can telephone *(site clinical psychologist / team member details – removed to maintain confidentiality)*

If you are unhappy with the research project or the care you have received please talk to the researcher and/or the cochlear implant clinic and we will do our best to solve the problem. There are also two other options available to you and your parent(s)/guardian(s):

[Site specific Patient Advice and Liaison Service (PALS) information – removed to maintain confidentiality]

If would like to make a formal complaint you can contact the complaints department:

[Site specific complaints department information - removed to maintain confidentiality]

Appendix F: Parent information sheet

PARENT/GUARDIAN INFORMATION SHEET

Adolescent experience of a sequential cochlear implant

This research study is being sponsored by the Department of Applied Psychology at Canterbury Christ Church University (CCCU). I (Kristina Hilton) would like to invite your child to take part in this research study. Your child's participation is completely voluntary, if you decide they are not going to take part this will not affect their ongoing care at the clinic in any way. Before you decide I will go through this information sheet with you and answer any questions you may have.

Purpose of the study

Young people who have had one cochlear implant are now being offered an operation to have a second cochlear implant, following a revision of the guidelines from the National Institute for Health and Clinical Excellence (NICE).

Research has been done to look at how one cochlear implant affects young peoples' lives and how they think about themselves in terms of the Deaf and hearing worlds. This project aims to see how having a second cochlear when a young person already has one (a sequential implant) affects their life and how they think about themselves in terms of the Deaf and hearing worlds. Your child has been invited to take part in this study because they have received a sequential cochlear implant. Your child's participation is voluntary.

What will your child be required to do?

Your child will take part in an interview with me (Kristina Hilton), which will last for up to an hour and a half. This involves talking to me, using either speech or British Sign Language via an interpreter, or a combination of speech and British Sign Language. Your child will be asked questions about:

- Their decision to have a sequential cochlear implant.
- How they think about themselves in terms of the Deaf and hearing worlds.
- How the sequential cochlear implant has affected or changed they way they think about themselves.
- How the sequential cochlear implant has affected their life.

The interview will be voice and video recorded so that the interview can be written down afterwards, and then the recordings be erased.

To participate in this research your child must:

- Have received a sequential cochlear implant as a result of the revision of the NICE guidelines (2009).

- Have acquired their deafness (if applicable) prior to starting school at age 4-5.
- Be aged 18 years or under when they had their sequential cochlear implant.
- Be aged between 12 and 21 years old at the time of the interview.
- Have no other disability (e.g. severe physical or learning disability) that would either mean they couldn't participate in the interview or that their experience of their cochlear implant(s) would be complicated by multiple issues.

What are the benefits and risks of my child taking part?

Your child will have an opportunity to contribute to research into cochlear implants. Your child will be told that they can choose what they want to tell me, and they do not have to answer questions if they do not want to. If your child chooses to discuss sensitive topics regarding deafness or cochlear implants they may become upset. They will be informed that they are free to stop the interview at any time, or take a break. I will be available to answer any of yours or your child's concerns after the interview, and/or a member of their clinical team will be also available within a week of the interview if required.

Expenses

Travel expenses of up to £10 can be claimed to contribute to the cost of travel to the interview.

Confidentiality

If your child takes part the clinic where they had their cochlear implant will be told that they are coming for an interview. The contents of the interview will remain confidential unless your child tells me something that makes me worry about their safety or the safety of others. In this case I may need to discuss the issue with the cochlear implant clinic, and you, the parent(s)/guardian(s). Data will be stored securely within CCCU premises and the chief investigators office in accordance with the Data Protection Act 1998 and the University's own data protection requirements. The anonymised transcripts of the interviews will be accessed only by me (Kristina Hilton) and two research supervisors. Your child's name and contact details will be stored separately to the printed copy of the interview. After completion of the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed).

Feedback and Dissemination of results

You and your child will be sent a brief summary of the findings of the study.

The cochlear implant clinic will also be sent a summary of the findings of the study and the research study will be written up as an article, and submitted to an academic journal for publication. Participants' names and other identifying information will not be included in any dissemination of the results. I may want to quote something your child said to me but no-one will be able to tell that it was them who said it.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of participants. This study has been reviewed and given favourable opinion by the *(Research Ethics Committee details removed to maintain confidentiality).* The study has also been approved by the Department of Applied Psychology at Canterbury Christ Church University (CCCU).

Deciding whether to participate

If you have any questions or concerns about the nature, procedures or requirements of the study please discuss these with me. Should you decide that your child is going to participate in the study, you or they will be free to withdraw from the study at any time without having to give a reason. Their treatment regarding their cochlear implant clinic will not be affected in any way.

Any questions? Please contact Kristina Hilton (Trainee Clinical Psychologist):

k.hilton240@canterbury.ac.uk or 01892 507673
Canterbury Christ Church University, Salomons Campus at Tunbridge Wells
Broomhill Road, Southborough. Tunbridge Wells, Kent, TN3 0TG

If you would like to speak to someone outside of the research team for advice about taking part in a research project or taking part in this project you and/or your child can telephone *(site clinical psychologist / team member details – removed to maintain confidentiality)*

If you are unhappy with the research project or the care you have received please talk to the researcher and/or the cochlear implant clinic and we will do our best to solve the problem. There are also two other options available to you and your child.

The Patient Advice and Liaison Service (PALS) provide a confidential service to help patients get the most out of the NHS. If you would like to get advice or more information you can contact them:

[Site specific Patient Advice and Liaison Service (PALS) information – removed to maintain confidentiality]

If would like to make a formal complaint you can contact the complaints department:

[Site specific complaints department information - removed to maintain confidentiality]

Appendix G: Semi-structured interview schedule

Section A: Background information

A1 What is your date of birth?

A2 From this list of ethnic backgrounds *(use NHS ethnicity categories)*, please can you tick which you feel applies to you.

A3 Do you use speech or British Sign Language, or both, to communicate?

A4 Do you have a preferred way of communicating?

(If yes) Tell me about why you prefer that way?
(or if they do not understand, How do you like to communicate? And why?)

A5 Have you always been deaf?
(If no) What happened to make you deaf? How old were you?

A6 Are your parents hearing or deaf?

A7 Do you have any brothers or sisters? Are they hearing or deaf?

A8 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?

A9 How old were you when you had your first cochlear implant?

A10 Did you use your first cochlear implant everyday? Why?

A11 How old were you when you had your second cochlear implant?

A12 How long have you been using your second cochlear implant? (or, When was your second cochlear implant switched on?)

A13 Do you use your second cochlear implant everyday? Why?

A14 Are there any time's where you do not use your first or second cochlear implant? (If yes) Why?

Section B: What factors were involved in the young people's decision to proceed with the second CI?

B1 When did you find out that you could have a second cochlear implant? What did you think about that?

B2 How did you decide?
Prompt Q: What did you think would be good about a second cochlear implant?
Prompt Q: What did you think would be bad about a second cochlear implant?

B3 Did anyone help you decide?
(If yes) Who helped you decide?
How did they help?

B4 What was it like making the decision?

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

C1 In what ways do you see yourself as a Deaf person?

(or if they do 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?

C2 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??)

C3 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?

C4 How do you communicate with your parents/siblings/wider family? How do you feel about that?

C5 Do you have deaf friends, or hearing friends, or both?

C6 How do you communicate your deaf/hearing friends?

C7 In what ways is it different spending time with deaf and hearing friends?

C8 Do you prefer spending time with one group or another? Tell me about that.

C9 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?

Section D: Has the second CI changed or affected their identity?

D1 How do you see yourself? / How would you describe yourself as a person?

D2 How did the first cochlear implant affect or change the way you see yourself?

D3 How has the second cochlear implant affected or changed the way you see yourself?

D4 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?

Section E: Has the second CI impacted on their quality of life?

E1 How has the second cochlear implant changed your life, either in a good or bad way?
Prompt Q: What have some of the positive changes been?
Prompt Q: What have some of the difficult changes been?

E2 Is there anything you can do now that you couldn’t do before the second cochlear implant? What’s that like?

E3 Is there anything you need help with because of being deaf?
Who helps?
What do they do?
What’s that like for you?

E4 Have there been any difficult times with your second cochlear implant?

E5 What are the advantages and disadvantages of your second cochlear implant?

E6 What are your expectations (hopes and fears) about the future? Tell me about that.

E7 Where would you hope to see yourself in five years time?
How will having a second cochlear implant help you get there?
What things do you worry might get in your way?

Appendix H

This has been removed from the electronic copy

Appendix I: Consent form – young person aged 16 years and over

Canterbury
Christ Church
University

CONSENT FORM FOR YOUNG PERSON (16 years and over)

Title of Project: Adolescent experience of a sequential cochlear implant

Name of Researcher: Kristina Hilton

Contact details:

Address:
Canterbury Christ Church University
Salomons Campus at Tunbridge Wells
Broomhill Road
Southborough, Tunbridge Wells
Kent, TN3 0TG

Tel: 01892 507673

Email: k.hilton240@canterbury.ac.uk

Please initial box

1. I confirm that the above study has been explained to me by the researcher. ☐
2. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐
3. I understand that it is up to me whether I take part (my participation is voluntary). I can change my mind any time, without giving any reason, and this will not affect my treatment at the clinic in any way. ☐
4. I agree to the interview being voice recorded. ☐
5. I agree to the interview being video recorded. ☐
6. I understand that any personal information that I provide to the researcher will be kept strictly confidential. ☐
7. I agree to take part in the above study. ☐

______________________	______________	__________________
Name of young person	Date	Signature
______________________	______________	__________________
Name of researcher	Date	Signature

Copies: 1 for young person
1 for researcher

Appendix J: Consent form – parent/guardian of young people aged under 16 years

Canterbury
Christ Church
University

PARENT/GUARDIAN CONSENT FORM

Title of Project: Adolescent experience of a sequential cochlear implant

Name of Researcher: Kristina Hilton

Contact details:

Address:
Canterbury Christ Church University
Salomons Campus at Tunbridge Wells
Broomhill Road
Southborough, Tunbridge Wells
Kent, TN3 0TG

Tel: 01892 507673
Email: k.hilton240@canterbury.ac.uk

Please initial box

1. I confirm that the above study has been explained to me by the researcher. ☐
2. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
3. I understand that my child’s participation is voluntary and that they are free to withdraw at any time, without giving any reason, and this will not affect their treatment at the clinic in any way. ☐
4. I agree to the interview being voice recorded. ☐
5. I agree to the interview being video recorded. ☐
6. I understand that any personal information that we provide to the researchers will be kept strictly confidential ☐
7. I agree to my child taking part in take part in the above study. ☐

____________________ __________________________
Name of young person Age of young person

________________________ ________________ ____________________
Name of Parent/Guardian Date Signature

_________________________ ________________ ____________________
Name of Researcher Date Signature

Copies: 1 for parent/guardian
1 for researcher

Appendix K: Assent form – young people aged under 16 years

Canterbury
Christ Church
University

AGREEMENT TO TAKE PART FORM
FOR YOUNG PERSON (aged under 16 years)

Title of Project: Adolescent experience of a sequential cochlear implant

Name of Researcher: Kristina Hilton

Contact details:

Address:
Canterbury Christ Church University
Salomons Campus at Tunbridge Wells
Broomhill Road
Southborough, Tunbridge Wells
Kent, TN3 0TG

Tel: 01892 507673
Email: k.hilton240@canterbury.ac.uk

Please initial box

1. The researcher (Kristina Hilton) has explained the study to me. ☐
2. I have read and understood the information sheet for the above study. I have asked questions if I needed to. ☐
3. I understand that it is up to me whether I take part. I can change my mind any time, without giving any reason, and this will not affect my treatment at the clinic. ☐
4. I agree to the interview being voice recorded. ☐
5. I agree to the interview being video recorded. ☐
6. I understand that any personal information that I provide to the researcher will be kept strictly confidential. ☐
7. I agree to take part in the above study. ☐

Name of young person	Date	Signature
Name of researcher	Date	Signature

Copies: 1 for young person
1 for researcher

Appendix L: End of study letter and summary for participants and their parent(s)

Canterbury Christ Church University
Department of Applied Psychology
Broomhill Road
Tunbridge Wells
TN3 0TG

July 2012

Dear ……………………………………………………..

Firstly, I am writing to say a big 'Thank you' for taking part in my research project. I interviewed eleven young people who received a second cochlear implant, and the project is now finished.

I am sending a summary of the findings of the project for you and your parent(s). If you would like any further details, or would like to receive a copy of the study once it is published, please contact me before the end of September 2012 by email or telephone:

k.hilton240@canterbury.ac.uk
01892 507673

Once again, thanks so much for taking part.

Best Wishes,

Kristina Hilton Trainee Clinical Psychologist *Canterbury Christ Church University*	Dr Jenny Cropper Clinical Psychologist

Canterbury
Christ Church
University

Summary of findings: Young people's experiences of a second cochlear implant

July 2012

Background

The research project aimed to find out what it is like for young people to have a second cochlear implant.

What did I do?

I interviewed eleven young people. In the interviews I talked with young people about what it was like deciding to have a second implant, and what it was like using two implants. I also talked with young people about the way they saw themselves as 'feeling hearing' and 'feeling deaf', and what having cochlear implants had meant to how they thought about this.

After the interviews I typed up what was talked about, and then spent time reading and understanding what everyone said. I decided on 'themes' in the interviews that summed up young people's experiences.

What did I find?

I found six main themes:

Consideration and commitment to the second implant

Young people talked about the important decision they made. The surgery was frightening for some of them, and many spoke about needing to learn to adjust to using the second implant.

Contentment with two cochlear implants

Most young people were really happy with their second implant. They could hear better which meant feeling more happy and confident and finding it easier to be with friends and cope at school. Many young people felt that having two cochlear implants would make life easier in future.

The importance of being in the hearing world

Being able to hear and talk was really important to the young people I spoke to, and they felt that life was easier than it would be if they didn't have cochlear implants. Most young people felt that they fit in with their hearing friends, and many felt that they were a hearing person. Some young people felt more hearing since having a second cochlear implant.

Connections to deafness

Although many young people felt hearing, being deaf was also important to some people. Many young people had a friend who also had one or two cochlear implants, which helped them to feel they weren't the only one. A few of the young people I spoke to used sign language, which they found fun to use with deaf friends, and really helped when talking was hard.

Bicultural identity

All of the young people talked about feeling hearing and feeling deaf (which is sometimes called 'bicultural identity'), and sometimes feeling in the middle between being hearing and deaf. Some young people talked about having better hearing and speech than deaf young people without cochlear implants, and feeling more similar to hearing people because their cochlear implants meant they could hear and speak more like them.

Feeling different in a hearing world

Although many young people were really happy with having two cochlear implants, many young people also sometimes felt different to hearing people. Young people spoke about sometimes feeling left out when they couldn't hear what others were saying, and feeling lonely as they were the only deaf person. Some young people didn't like the appearance of their cochlear implants, and tried to cover them up as they felt they looked different. Some young people also worried that others would judge them if they knew they were deaf, so some people tried to hide it until people got to know them better.

Summary

These findings are really important as we now know more about what it is like for young people who have a second cochlear implant. The findings will be interesting for parents and young people making decisions about cochlear implants, and for the cochlear implant clinics who provide support for young people.

These findings will be sent to the Journal of Deaf Studies and Deaf education (which is like a magazine for findings of projects like this) so that others can read about young people's experiences of deciding to have, and living with, a second cochlear implant. As we talked about, the findings will be written about anonymously, so no-one will know which young people took part.

Kristina Hilton
Trainee Clinical Psychologist
Canterbury Christ Church University

Appendix M

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Appendix N: Table documenting the theme development process

Master theme	Sub-theme	Initial theme related to sub-theme	Participants with initial theme	Total number of references to initial theme
Consideration and commitment to the second implant	An important decision	2.1. Own CI2 decision vs joint vs parent dominated	(1, 11) vs (2, 3, 4, 6, 8, 9, 10) vs (5, 7)	2 vs 7 vs 2
		2.2. Initial uncertainty about CI2 vs certainty	3, 6, 7, 8, 9, 10, 11 vs 1, 2, 4	7 vs 3
		2.3. The time and careful consideration of the CI2 decision	3, 4, 6, 8, 9, 10, 11	7
	Fear and discomfort	2.5. Fear of CI2 operation	3, 4, 5, 6, 7, 8, 10, 11	8
		2.6. Frightening experience of anaesthetic	6, 8, 10, 11	4
		2.7. Experience of pain/discomfort after CI2 operation	1, 6, 8, 9, 10, 11	6
		2.8. Discomfort of the sound from CI2	3, 5	2
	Excitement	2.4. Excitement about having CI2	1,3, 4, 6, 11	5
	Adjustment and effort	2.9. The adjustment time to the sound of CI2 – effort and practice	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	10
		2.10. The effort and responsibility of having two	3, 6, 7, 8	4
Contentment with two cochlear implants	The benefits of hearing with two ears	1.8. The role of anticipated better hearing in the decision for the second implant	1, 2, 3, 4, 6, 8, 9, 10, 11	9
		1.9. Contentment with the hearing benefits of CI2 - a better life	1, 2, 3, 5, 6, 8, 10, 11 (not 7)	8
		1.11.CI2 gives better directional hearing	1, 2, 3, 4, 6, 7, 8, 10, 11	9
		1.12.CI2 makes hearing better and easier	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
		1.15. Hearing with two ears	1, 2, 6, 7, 8, 11	6
		6.2. CI2 made me feel more hearing	6, 8, 9, 10	4
	An even brighter future with two	3.2. CI2 improved the future even more	2, 3, 6, 7, 8, 9, 10	7
		3.5. Additional educational benefit of CI2	1, 2, 3, 4, 5, 6, 7, 8, 10, 11	10
	Social gains	3.3. The social benefit of a second CI (hearing, talking, friendships)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
		1.14. CI2 will help me speak clearly	5, 10	2
	Improved confidence	3.4. Confidence and self belief after having CI2 (hearing and hearing my own voice)	1, 2, 6, 7, 8, 9, 10, 11	8

The importance of being in the hearing world	Speech: value and commitment	1.16. Commitment to speech – the practice and effort required	1, 2, 3, 5, 11	5
		1.17. The importance and value of speech	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
		1.18. BSL is a (communication) barrier – I don’t understand it and no-one would understand me	2, 4, 6, 8, 9	5
	Inclusion and integration	1.1. CIs mean you can integrate into the hearing world, have hearing friends and be socially included	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
		1.7. CIs have meant accessing mainstream education (eventually for some)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
	A better future	1.3. Happiness and joy of hearing with CIs – a better life	1, 2, 3, 4, 6, 7, 8, 11	8
		3.1. A better and different future with CIs	1, 2, 3, 4, 6, 7, 8, 9, 10, 11	10
		1.5. Contentment with parents decision re CI1	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
	Normality vs disability	1.4. Hearing is the normality – so deafness should be fixed	2, 3, 4, 6, 7, 8, 9	7
		1.6. CIs mean I’m normal	3, 4, 6, 7, 9	5
	Being a hearing person	6.1. Distance from the Deaf community/world	2, 3, 4, 5, 6, 7, 8, 9	8
		6.3. A strong sense of feeling hearing	2, 3, 4, 6, 7, 8, 9, 10	8
		7.3. A wish to be less deaf	1, 3, 7, 2	4
		6.2. CI2 made me feel more hearing	6, 8, 9, 10	4
		1.2. Hearing is desirable	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11	11
Connections to deafness	Deafness as a valued part of the self	4.8. Deafness as a part of the self	2, 3, 7, 8, 11	5
		5.5.Valuing deafness	2, 3, 6, 11	4
	BSL means understanding	5.1. BSL means feeling understood/understanding- a natural way to communicate	1, 9, 10, 11	4
	The importance of a shared experience of deafness and cochlear implants	5.2. The importance of a shared experience of deafness and CIs	1, 3 , 4, 6, 8, 9, 10, 11	8
		5.3. Part of the Deaf community/world	1, 8, 11	3
Bicultural Identity	Being deaf, being hearing and being in the middle	4.1. Feeling deaf and hearing – fluidity of identity	1, 2, 3, 5, 6, 8, 9, 10, 11	9
		4.7. Without my implant on – I’m deaf	6, 8, 9, 10	4
	Sameness and difference	4.2. I am more able then the deaf vs I am less able than the hearing	1, 2, 3	3
		4.3. Feelings of sameness to hearing people vs feelings of difference to hearing people	(2, 3, 4, 6, 8, 10) vs (1, 2, 3, 7, 9, 10)	8
		4.4. Feelings of sameness to deaf people vs feelings of difference to deaf people	(1, 9, 10) vs (1, 3, 4, 6, 7, 8, 11)	9
		4.5. Changing deafness – the individuality of deafness	1, 2, 3, 4, 6, 7, 8, 9, 11	9

Feeling different in a hearing world	Frustration and confusion of not hearing and understanding	7.2. Frustration and confusion of not hearing and understanding	1, 3, 5, 7, 8, 9, 10, 11	8
		7.11. Confusion/not understanding at school/college	5, 6, 7	3
		7.12. The need for educational support vs not needing support	(1, 3, 5, 6, 7, 10, 11) vs (2, 4, 8, 9)	6 vs 4
	Feelings of isolation and difference in a hearing world	7.1. Feelings of isolation and difference in a hearing world	1, 2, 3, 5, 6, 7, 8, 9, 10, 11	10
	Unfairness of prejudice and difference	7.4. Unfairness of deafness	3, 11	2
		7.5. Fear of discrimination with future needs at work	1, 3, 5, 10, 11	5
		7.6. The prejudice of deafness	1, 3, 6, 7, 9, 10	6
	Looking different	7.7. Letting others discover deafness – I don't want to be treated differently	3, 6, 7, 9	4
		7.8. Covering CIs as I don't like the appearance	3, 6, 7	3
		7.9. Two CIs made me look more different	1, 3, 6, 7, 9	5
		7.10. CI2 made me look/feel more deaf	3, 6, 7, 8,	4

Appendix O

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Appendix P: Reflective research diary (abridged)

13th January 2011
I'm nearly at the point of submitting my ethics and I'm starting to think about how I am going to use my research diary. I think it's important to start thinking about my prior ideas and assumptions as part of the process of 'bracketing'. I have been thinking about what I am 'bringing' to the research and why I was interested in deafness in the first place.

In the past I was always fascinated by seeing glimpses of British Sign Language (BSL). I worked as a Learning Support Assistant (2005-2006) in a mainstream school that had a hearing impairment unit. Although I did not support children who used BSL I worked with two deaf young people, both were hearing aid users and one used BSL - I think this is when I started to become interested in the impact of deafness, particularly in seeing the young people face certain challenges in communication with their peers. Going to a lunchtime signing club helped me to learn some BSL basics. Some time later when working as an Assistant I completed the Level one in BSL (2008-09) – thinking about it, it is hard to pin down what it was about BSL that made me want to learn it. I wonder if it was in part about being able to communicate with BSL users should this opportunity arise in my social/work life. I also went with my friend and her father who had a progressive hearing loss, so it was able about enabling me to communicate with him.

The BSL course was I think my first real experience of Deaf culture, as the teacher was a profoundly deaf adult who did not communicate orally at all. I was fascinated by the expression of BSL, as well as being amazed at how many obstacles being a deaf person presents you with, like when we all went for dinner, you can't eat and talk at the same time!

Thinking about when I started clinical training, I did start to think about how deaf children and adults access psychology services. I looked on the internet and saw there is some provision, through national services. When I got the list of MRP projects areas the project with deaf adolescents jumped right out at me, I guess because of a building interest and curiosity in deafness. No-one else on the course has sought this supervisor and project, and I have been thinking about how deafness and psychology isn't an interest which other trainees seem to have, not necessarily a 'mainstream' project.

I'm going to be doing an interview with a fellow trainee about my assumptions about the project soon, I think I need to be thinking about answering the following questions:
Is deafness a disability?
How do I feel about cochlear implants?
Thoughts on the Deaf culture and community?

10th May 2011
I did an assumptions interview with a fellow trainee a few days ago. I think it really helped me to map out what perhaps I am 'expecting' to find, so I can check when I am doing my analyses that I am not being influenced by my assumptions, some of which I

think are coming from the literature I've read. I've transcribed the interview and had a look over at what I think are my main assumptions and expectations:

- I think that the type of school attended may influence the young people's mode of communication, so if they are at mainstream I think I would assume they would use speech more.
- I guess I'm assuming from my reading and conversations with my supervisor that the children may be at mainstream school? In the interview I seemed to be thinking that this may present some challenges for young people – maybe this is based on my experiences from being at school and working at a school that difference is not always accepted.
- I have a number of assumptions about how a young persons' context will affect their communication choices, for example if they are immersed in the Deaf community I seem to be thinking that they may prioritise BSL.
- As a hearing person, I do think I am quite positively biased in terms of cochlear implants, in that I seem to think it is the 'right' thing to do, that children should be given the possibility of hearing – I need to make sure this doesn't cloud me being able to see any negatives of cochlear implants or of hearing that come up in the interviews.
- The assumptions interview suggests that I do see deafness as a disability, which is not how it is viewed by the Deaf community, again perhaps reflecting my position as hearing.
- I seem to be expecting young people to report a range of benefits of their implants, including better hearing and sound localisation, as suggested by the literature, but also I seem to be assuming that the operation and adjustment may be hard.
- In terms of identity, the assumptions interview suggests that I expect identity to be related to preferred mode of communication. I seem to be thinking that the young people may have a fluid identity, given their experiences of being deaf and having cochlear implants, an assumption which I think is based on what I have read so far. I need to make sure I keep an open mind and be open to all possibilities in the interview.
- I seem to be also expecting a sense of proudness from the young people of being deaf, but maybe also difference, disadvantage and challenges- maybe again this is a bias from my hearing position? - because I assume that deafness would be difficult from my perspective of being able to hear.
- I also spoke about BSL, I seem to be thinking that the young people will wish that they used BSL, if speech is a challenge for them.
- Another of my assumptions seemed to be that having two implants may make them lean more towards the hearing world.
- Based on some anecdotal reports I have heard from psychologists in CI clinics, I seem to be also expecting that the expectations of some young people have not been met.

I'm feeling pleased I have done this interview, I think I'm reflecting on how being a hearing person could impact my interpretation, and bracketing the above assumptions and allowing what the young people say in the interviews to guide the analysis will be really important. I guess I'm also thinking that some of these assumptions may turn out to be the case, but I'm pleased I have them down first to make sure they don't bias my thinking.

September 2011 – December 2011: Experience of interviews

Interview one

I was struck by how positive this participant was about cochlear implants. I don't know if I was expecting participants to talk about more challenges. It seemed the decision to have a sequential was made by her alone, not with her parents as I think I expected. It seemed she was really motivated to access the 'hearing world', but she used BSL and she spoke about being part of both the Deaf and hearing worlds, making me think about Wald and Knutson's (2000) bicultural identity findings. Deaf club seemed really important to her, like she 'fit' in there. It was interesting though as her deaf friends (without implants) joked she was a 'robot' because of her implants, making me wonder if she didn't feel she fit wholly with these friends. Although on the other hand she spoke about her deaf friends thinking she was funny and humorous, whereas her hearing friends do not. I'm left wondering about how easy it actually is to feel you fit with Deaf and hearing friends?? It was hard to understand her speech at times, which I found challenging as a hearing person, particularly because I wanted her to feel heard and understood. I did not want to re-enact what happens when she finds it difficult in the hearing world by asking her to repeat all the time. Yet she was really determined to be in the hearing world.

I was surprised that the SCI hadn't had a great impact on her sense of identity or made her feel more hearing, which I think I thought it might have. Although she was an older adolescent so maybe it came too late to be part of her developing identity. The SCI did seem to help her believe they she could go to university and get a job.

Interview two

Throughout this interview I was really struck by how opposed he seems towards the Deaf community. I wondered about how issues of bullying in a deaf school may have influenced these feelings for him. It made me really think about how he identified himself as deaf and how that was a part of him, but he did not see himself as culturally Deaf in the sense of being part of a community. He came across as very confident and content with his deafness, living very much in the hearing world with hearing friends. He was so happy with having had a second implant! I was left thinking about how very important speech was to this young man.

Interview three

I felt again in this interview that this girl was very much in the hearing world, and even said that sometimes she felt like a hearing person and would forget she was deaf. It also seemed that she was positive about her deafness, she liked being able to take her implants off at the end of the day and it seemed it gave her the best of both worlds. She really liked having two implants. I was struck by how clear she was at being 'in-between' the two worlds, which made me think about the literature on bicultural identity. It seemed she really valued the hearing community, and I it was really clear how upset she felt when she couldn't hear or felt left out. She spoke about sometimes feeling alone, which made me wonder about the danger of being in-between two worlds.

Interview four
I was really struck in this interview by how much of a ‘hearing identity’ she seemed to have, which I guess says something about my preconceptions that these young people would identify as deaf in some way. It was as if she had been able to access the hearing world just fine and therefore never had to consider her deafness. It really seemed that implants gave her the ease of communication meaning she never really needed to consider her deafness. She really seemed she had been so certain about having the second implant. She even kept one implant on at night, which made me wonder if it was in fact quite frightening to be deaf, and that maybe her implants made her hearing therefore they could not be taken off….? Again she didn’t really know about the Deaf community, it seems a bit of a pattern is emerging, with the exception of interview one. It felt that being deaf wasn’t even part of her identity at all, which isn’t really something I’ve thought about too much.

Interview five
This interview felt the trickiest so far, he found speech harder than the other participants had, and it felt he didn’t understand some of the complex questions. Throughout the interview I was worried I was misunderstanding him. He used BSL and speech, and I wondered about his identity, which was hard for him to describe. It seemed he was pleased with his sequential implant, although it was quite noisy when he was getting used to it which makes me think about adjustment.

Interview six
After this interview the phrase “proper hearing person” has really stuck in my head – it really seems that having two cochlear implants allowed her to feel properly hearing. She seems to identify as a normal hearing person, making me think about this emerging theme around what’s normal. It seemed that her one deaf friend was really important to her in terms of sharing and not feeling alone. Being deaf didn’t seem very desirable to her, and she didn’t feel like she had a disability, making me think about possible themes about normality and disability. It did also feel that the second implant had allowed her to acknowledge her deafness more, since she described improved confidence with herself.

Interview seven
I came away from this interview feeling quite sad for the first time in all of the interviews so far. It really seemed the emotional consequences of the implant were quite difficult for this girl, she was uncertain about the second implant in terms of the difference it made to her appearance and self-esteem and confidence seemed to be an issue. I felt she was quite conflicted between, on the one hand, being pleased with the hearing benefits of the second, and on the other hand, struggling with feeling she looked more deaf and difference. This makes me think about the ideas of difference that have come up for other participants, they are all striving to be the same as their hearing peers….

Interview eight

I was really struck by how eloquent this boy was in his speech, although most of the participants I have interviewed have spoken so well - for some if you hadn't have seen the implants you wouldn't have known they were deaf - this young man really sounded hearing. This boy made me think of participant four, in that he seemed he fit in with hearing friends and was immersed in a hearing world. There were hints of times when he felt his cochlear implants restricted him, like in sports, and I again was thinking about this idea of difference. He was quite sure of his second implant.

Interview nine

This young girl again spoke about being 'normal', which again made me think about this idea of what normality is to these young people, it seems that deafness is not their normality - being hearing is. She spoke about feeling normal with her cochlear implants on and without them feeling deaf, making me think again about this changeable notion of feeling deaf and hearing. She seemed to want to disguise her implants, making me think about issues of appearance to other people and what it means to appear to be deaf. Ideas of being both deaf and hearing came up, she liked sometimes going to deaf club as she felt the same as the other deaf young people, but she also talked about feeling the same as her hearing friends, again making me think about the bicultural literature. The second, more than the first, made her feel like a hearing person, making me think about how it may be easier to feel hearing if you feel more able to compare yourself to hearing people. I am starting to think about how these young people with cochlear implants have a new type of 'deaf identity', not the same as being immersed in the Deaf signing world, but not like being fully hearing either.

Interview ten

This was the second interview with a participant who was also a fluent BSL user. I found it really interesting how she really seemed to prioritise the development of her speech and hearing, even though she had a way of communicating using BSL with her family and close friends who were deaf. BSL was fun to her, and it made me think about how it was something unique to her relationships with deaf friends, even though they could probably talk to each other, they enjoyed the signing. In a way this girl seemed to want to widen her contact with hearing peers, even thought she had a deaf best friend and a deaf boyfriend, she had wanted to make more hearing friends at college and found the second implant helped her to do this. It seems that maybe it's a mixture of deaf and hearing friends that allowed this participant to feel integrated in the hearing world, yet not feel alone in being deaf?

Interview eleven

It was hard at times to understand the speech of this participant, he used BSL and speech, though he did persevere at making sure I understood. It seemed he was integrated with both deaf and hearing peers, as he was in a mainstream school with a deaf unit. It made me think about the issue of mainstream education for deaf children, and children with disabilities in general, it seemed that for him this structure meant he could integrate into both sets of friends, and there seemed to be real integration of deaf and hearing. There was a feeling from him that he was more capable than some of his deaf friends who didn't have implants and use speech, meaning he could be friends with hearing peers whereas some of his other friends found that more difficult. It really seemed that his implants had made this possible.

I can't really believe I've got to the end of the interviews...! I'm feeling quite daunted about starting to analyse the data, I've got so many thoughts and ideas in my head about possible themes…. !

4th January 2012
Having just done notes and emerging themes for transcript one, I am completely overwhelmed. I seem to have a massive list of themes, which is good I suppose, although I am wondering if I'm being interpretative enough.

5th January 2012
I've just done my notes and emerging themes for transcripts two and three, I am wondering if I'm just describing what they've said and trying to strike the balance between interpretation but not loosing the essence of what they are saying. It is feeling hard with deciding on emerging themes that I'm loosing something of the depth and detail of the young people's narratives.

19th April 2012
Well I'm back to the MRP…. ! After spending time focusing on my other assignments and Section A, I am now again feeling overwhelmed with the amount of data that I need to analyse. I'm worried I'll be calling similar aspects the same things and that it'll just end up being messy. I'm thinking that I need to take real care to track the process of what I am doing, I think that'll help me feel a bit more confident about ensuring the emergent themes are grounded in the data.

What is striking me in the moment in thinking back to the interviews is the real range of individuals, cochlear implants certainly don't seem to make young people feel the same about deafness and being hearing. It feels that maybe speech outcomes are a factor, maybe this has an impact on communication which in turn affects identity and psychosocial outcomes. I know IPA isn't at all about causality, but I am finding myself thinking about the differences in the participant reports as well as the similarities.

20th April 2012
I'm writing as I've just been going through participant seven's transcript and I find myself feeling quite sad. I was really struck by how embarrassed and insecure she talked about feeling about her implants. It's making me wonder if there is a pressure for these young people to feel the same as her hearing peers, in being mainstreamed are these children just being pressured into wanting to feel and be the same as the majority? Is deafness not valued and respected? I guess that brings me to thinking about the bigger picture about disability and difference, and I don't think I have the answers to that. Certainly, participant seven didn't seem to place value on being deaf, she just seemed to want it to go away so she could feel the same as her friends.

In reading, noting and thinking about themes on some of the other transcripts, I am also feeling struck by the ambition these young people have. It does feel that without cochlear implants, and especially the second for some, they wouldn't be able to do the same things. I guess I'm quite biased by being a hearing person, but I feel that should have the option and opportunity to choose their future, rather than being restricted.

3rd May 2012
I met with Jenny today, she'd carried about the supervisor audit of a transcript. It felt really reassuring as Jenny picked up the key themes that I had – it makes me feel a bit more confident in the analysis!

4th May 2012
Right so I've grouped together emergent themes into categories as part of the cross-case comparison- there seems to be quite a lot there! I am pleased the analysis is detailed and rich, but it is feeling hard to hold everyone's experiences in mind and draw together sub-theme that capture everything. I'm still feeling a bit worried about the level of interpretation, thinking I may need to step it up even more. Smith talks about the analytic shift of working with my notes rather than the transcripts, which I am trying to hold in mind to reassure myself not to worry that I feel a step removed from the transcripts at this point.

6th May 2012
Having spent all day comparing themes across cases I'm feeling anxious that I will have missed references to themes with some participants. I think what I am going to do is group the sub-themes and create master themes, and then go back through each transcript and code them according to the themes, as part of a quality check really. I'm feeling I really want to get it right for my participants, to make sure the themes reflect their true experience.

19th May 2012
Now I've come to a point where I've created my master and sub-themes, and I've met Fergal to talk about them. I am feeling more confident now that the themes reflect the data. What's been quite hard is making sure each participants voice is heard. I do feel now that the themes have allowed the data to take on a more conceptual meaning, rather than being descriptive of what they've said. As I talked about in my last entry, to make sure I didn't miss anything important I trawled the trancripts and coded them according to my themes, this has helped me feel more certain about the quality of the analysis, and I feel the themes 'fit' the data.

Now for the task of writing it up, this does feel quite daunting and final – it means I'm really committed to the analysis now, whereas up to this point it felt quite fluid, now it's near to being completed.

25th May 2012
I've just finished the first very rough draft of my results, I'm 2500 words over what I need to be. I'm feeling quite worried about cutting this amount of words, I don't want to loose the voices of the participants.

30th May 2012
I'm trying to pull the discussion together, I'm really conscious that I don't want to loose the voices of the participants who felt quite strongly hearing (e.g. participant 4,

participant 8), since I’m talking about the bicultural experience of the majority. Think I’ll have another look at my write-up and check I’m happy with this.

24th June 2012
So I think I’m there!! I’ve spent the last three weeks or so really focusing on the write-up, checking back that the results and discussion reflect the themes and I think I’m at a point where I feel the write-up really reflects the participant voices. When I’m reading over the final draft I can still hear the participants’’ voices and I remember the interviews very vividly, which I guess is what qualitative research is all about. I feel like I internalised their voices which have stayed with me throughout the whole project, which has really helped when reading over, as I feel what I’m seeing on the page reflects the interviews.

Appendix Q: Example supporting quotes for each sub-theme

Consideration and commitment to the second implant

An important decision

‘Probably my mother certainly helped me decide but it wasn’t entirely her decision’ (P2, 8, 217)

It was a big decision cos I don’t really know what to go for and in the end I chose my choice (P3, 14, 402)

‘I was like I don’t really know and then they had this thing opened up and say people who want to know more about second implant come here and that so I went there and I was like really interesting helps a lot and the peoples been saying how horrible they thought at first like don’t even want it and then when they have it done they like that is amazing’ (P3, 10, 289).

‘I went there and I was like really interesting helps a lot and the peoples been saying how horrible they thought at first like don’t even want it and then when they have it done they like that is amazing’ (P3, 10, 295).

‘Umm well we umm went to see some other people that had got the second one and umm my parents were deciding whether we should get a second one and they decided we should cos it would the people said it was better because you could hear from both sides and stuff’ (P4, 7, 188).

‘Well like um my Mum had told my Mum and Dad had told me the advantages of having this and then um my other friend the one who’s deaf well um she was also deciding if she wanted a second implant or not so then we both have kind of made our minds up together and um I was the one who said well I think it would be good and she kind of like made her mind up from me as well’ (P6, 11, 318)

‘[Researcher: Ok so how did you make that final decision did anyone help you decide?]
Mum did and the hospital we had one big meeting to talk about it and I think we had a book information about it it helped me to change my mind yeh’ (P10, 10, 292)

‘Err um everyday err yes or no errr yes or no I tried say yes yeh I say yes to my Mum and she shocked and she called the hospital I go to hospital have operation’ (P11, 7, 194)

Fear and discomfort

‘I was scared about just in case if something went wrong and er but of course I do have another one I just think cos if something went wrong with it’ (P3, 11, 313)

‘I’m just dunno its scared hospital scared (…) I’m scared sometime it kill me I’m scared’ (P5, 8, 227).

‘But um I just remember crying I was really scared and my Mum was like if you don’t wanna have it we’ll go home but I’m glad I went into the operating theatre and had it done’ (P6, 9, 252)

‘I was just petrified of the operation like I’d be scared in case I woke up in the middle of what they was doing and but there was nothing really bad that I thought about having it’ (P6, 9, 246)

‘Yeh it’s cos I was sposed to go like back home like the next day after the operation but because I was like sick almost all the time when I woke up cos I fell asleep a lot um I ended up having another week off staying at the hospital and then I went home that’s it’ (P9, 8, 230)

‘Cos I’m when I read it Mum explained what its mean and I was thinking no I don’t want a second one cos it I thought it might not work or I thought I wont be able to like wake up when they do my operation or I end up like more ill or that sort of thing really’ (P10, 9, 244)

‘My scar was a bit sore and when I wear it it kind of little bit rubbing it (….) and sometime the cochlear bit wouldn’t stick to my head I getting stressed with it and I told Mum wish I didn’t have it done [Researcher: So how do you feel now about it?]Much better getting used to it’ (P10, 12, 331).

‘Yeh not now when I put it on wake up ooh I got second one when I wake up yeh there’s nothing there I press yeh I feel pain so I get second implant in bout ten hours or two hours and then eight days later yeh about ten days later they put a special thing in yeh so I stop the blood come out they put special thing in so’ (P11, 8, 211)

Excitement

‘It’s like I’ve had operation I excited’ (P1, 7, 198)

‘That day I wasn’t even scared I was like yep yep and then I’m ready I’m excited it’s like really weird cos from the actual before it was like different then on that day I’m like really excited’ (P3, 11, 315)

‘I was excited to get my one’ (P4, 9, 244)

‘[Researcher: And when did you find out you could have a second cochlear implant do you remember?]
Um I think it was the beginning of year six and um I was really happy to find that our because I thought well we have two ears so I should able to listen out of two ears and not one so I was really happy to find out’ (P6, 7, 198)

‘Yeh it was an amazing thing’ (P6, 8, 208)

Adjustment and effort

‘I had the implant its very very good I have to get used to listen try very it getting better and me might make me hear more benefit yah’ (P1, 10, 283)

‘umm I was aware umm that there may be difficulties in adjusting to the yeh which umm new implant which umm was quite a prevalent theme umm expressed but umm that was understood that I’d have to get used to that that I’d have to practice with it I’d have to have time with it umm but there weren’t any worries about something going worse’ (P2, 8, 209)

‘I have two lots on it sometimes give me a headache and um cos after swimming (…) I don’t bother to put both of them on cos I’m going to bed afterwards (…) cos I can’t be bothered it’s too much uhhhh’ (P3, 7, 183).

‘Because then it’s easier to get used to them as in now umm I just got my new one it’s harder to get used to it cos I’ve always had this one and I’m not used to this one so much’ (P4, 5, 123)

‘there’s obviously going up to the hospital and having to have tests and that’s been a bit draining really but other than that it’s been fine’ (P6, 25, 716)

‘Um… I think well what’s different is um when I had to change my batteries for that one it’s like I don’t like wasting time changing my batteries and if when I have two it’s like it takes up more time to do it that’s one thing that I don’t really like that I find quite annoying and different um but things that’s easier is just sound wise really and where I am’ (P7, 13, 365)

‘Um it was really weird like it was really weird having beeping sounds in your head but like we’d like kind of work though it and then they’d turn into speech and stuff’ (P6, 11, 298)

Contentment with two cochlear implants

The benefits of hearing with two ears

‘I can hear everything I can even hear people talking to behind my back I can understand so its really helps’ (P1, 23, 642)

‘Its good to have a second implant because you can hear ..which side come from direction…(name) oh that way.. if my Mum called my name, the other side and look about my.. if someone called my left (look) left really good’ (P1, 6, 162)

‘You get more hearing and errm one of the one of the benefits you also get from the second cochlear implant is that by that time technology had advanced quite a lot umm there was a 9 year gap between the two implants so this one is just umm a significantly improved model as well as being another ear but having two implants is just better’ (P2, 7, 185)

‘With my first implant I can’t um do directions where the noise is coming from I can hear the noise but I think it’s all over the place but since I’ve got a second one um I’ve said what was it like hearing direction (…) especially when I played netball (P3, 12, 337).

‘Um well that I’d be able to hear like say if I took my second implant off it’d be a bit more quieter with my first one but if I put it on then it seems louder and I can hear everything better so that’s what I thought’ (P6, 8, 227)

‘Well it’s like it’s easier to hear having two implants I don’t know how it just is it’s like I can hear more louder’ (P6, 23, 656)

‘Yeh yeh sense of direction from where the person’s speaking is a lot better as well’ (P8, 13, 361)

‘The first one will always be a lot better than the second one whereas if you get them at the same time you’re it’s gonna be a lot easier to get started’ (P8, 18, 531).

‘Much better now I can hear more than I had first one I can hear a bit more sound and much better really’(P10, 5, 124)

‘Yeh cos the first one I was worried about when I talked to someone I come out say wrong and its not right one its not the right speak language when I had the second one it helped me to speak a bit clearer and more speak language properly’ (P10, 21, 603).

Conflicting feelings:
‘I have days when I was like oh I wish I hadn’t had a second one but I still have to think having a second one was a better choice than not having one cos if I didn’t have one it would be a lot difficult’ (P7, 24, 704).

An even brighter future with two
‘[Researcher: So if you only had one cochlear implant what would you be thinking about university umm would that be different to how you feel having two?]
Yes much different because university if the teacher call my name I don’t know where it come from they attention walking around’ (P1, 24, 660).

‘It is hard to say um mmmm well I would say I probably be done less in my English with the first one now I got my second one I would know more cos I could never heard I could never hear the word the s I can hear it a bit more (….) when I um had my second one I can hear it a bit more and in my English career I hope I get better standard to it’ (P3, 29, 856).

‘I’d just like to be the first person to um finish university and it give me something to be proud of [Researcher: Yeh and do you think having a second cochlear implant would help you do that is that something you’d you would have felt able to do if you had one?] Well um I’d be able to understand more what people are saying like to socialise with all the friends at my uni my future university and things like that really [Researcher: So do you think you would still have um gone if you had one cochlear implant?] Yeh I still I definitely still would have gone but it’s just like having two will just make life that bit easier (P6, 28, 826)

‘In the classroom it’s a lot easier so if my friends talking to me about problem I could easily hear the teacher from that side and then listen to my friend on this side’ (P7, 14, 387)

‘When I was hearing in a noisy classroom I found that really hard but then when I got my second one I found it a lot better and a lot easier’ (P8, 4, 107).

‘Well it made me feel like my future’s a lot better it was going to be a lot more I was a lot more confident about it but apart from that that’s it’ (P8, 15, 432)

‘When I was hearing in a noisy classroom I found that really hard but then when I got my second one I found it a lot better and a lot easier’ (P8, 4, 107)

Social gains

‘I only really felt when I went to (sixth form) and got the full use out of my second cochlear socially which um which um had ended up to a self-image of being rather indebted to these things both of them of being able to use them to their fullest potential’ (P2, 17, 491)

‘Since I had one well when I had that problem the other day and I only wore one and I went to school yeh my friends were going shhh shhh you’re speaking really loud and I was like oh am I? cos I thought I wasn’t cos I can’t really hear how loud I am cos I think it’s just normal to me and umm when I had the second implant on and I do my voice a little bit quieter and I'm like ohh is that how loud I was being compare I was like oh ooops…. especially if it's like private stuff to my friends I don't really wanna go OH PRIVATE TALKING so that'd be like really embarrassing' (P3, 14, 408)

'Yeh whereas before I was always turning my head and now it's a lot easier I can just sit down and listen to both of my friends talking in conversation at the same time whereas before I had to like move my head most of the time' (P7, 13, 382)

'I felt I was more able to socialise with other people and yeh I think that's it I just felt I could just be more social' (P8, 16, 451).

Improved confidence

'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 (…)I've literally told people that I'm deaf whereas before I'd be like I wouldn't tell people I was deaf and I'd be a bit shy about it but I'm really upfront about it and if anyone wanted to ask me questions I'd be happy to answer them and I'm quite confident to be honest' (P6, 19, 544).

'Yeh when I had one I could do a lot of things really but having two implants has made me feel like I can do things a lot better than I used to' (P6, 25, 732)

'It'd made me feel I fit in even more so it makes me feel that I'm even more fun and things like that' (P8, 15, 423)

'It made me more confident [Researcher: How's it make you more confident do you think?]
Well because I can like hear my voice better and know what I'm saying and like change my voice levels' (P9, 24, 691)

The importance of being in the hearing world

Speech: value and commitment

'Ummm 99 I mean less than 1 percent of the population use sign language so using sign language seems a bit impractical' (P2, 5, 125)

‘I went to work experience in hearing world I did not use my sign language at all talk talk talk I feel it good’ (P1, 9, 255)

‘So umm I’ve pretty much ummm for a significant portion of my life been in an exclusively hearing community which means that ummm the main mode of communication has always been speech and everybody else around me has used speech’ (P2, 1, 9).

‘Yeh easier practice talking [Researcher: You practice talking?] Yeh’ (P5, 20, 597)

‘I’ll find it really hard to understand them and they might use sign language and try and get me into doing sign language but I don’t really wanna learn how to sign language because I’m just all about talking really’ (P6, 21, 603)

‘Well um I’m very pleased that I’m not using sign language cos it would make me cos I’d feel rather limited in who I can talk to cos if I was talking to a shopkeeper or someone who didn’t know sign language at school they aren’t I wouldn’t be able to talk to them whereas when I can talk I can just talk to them and not have to sign to them’ (P8, 13, 378).

‘Like speaking a bit more so it can help me learning to speak bit more and sometime I do signing if I can’t if I can’t say the word it be easier me to sign it cos I just not’ (P10, 1, 15).

Inclusion and integration

‘I’ve been in a hearing community for a large section of my life so going into something which is exclusively hearing community isn’t something which worries me that was part of the reason why I moved schools to (sixth form) in order to get into a hearing community before going to uni’ (P2, 6, 160)

‘[Researcher: Ok so how do you feel about the fact that you’ve gone to schools for hearing people] Um I think it’s good because I think that I should be treated as a hearing person cos I can do everything that a hearing person does and know I feel good about that’ (P6, 4, 106)

‘When I had hearing aids I don’t think I actually noticed that I was I thought it was quite normal to not really understand as much cos I and then as soon as I got my cochlear implant I realised how much I’ve just missed when I had conversations with my friends so like it would have been easier and I think I would be able to like talk more and not talk something that is completely not what my friends are talking about’ (P7, 3, 60).

‘Well I just see myself as one of them and I don’t really see myself as much of an outsider cos they all know me they have fun with me and I enjoy myself with them we have fun together so’ (P8, 13, 371)

A better future

‘Because well if I don’t have implant its hard for my friends deaf friends because hear my hearing aids can’t hear at all just sign sign sign my friend told me that she studied studied a degree everything went for a job the boss said no she a deaf person because you can’t talk like you cant hear anything at all so sorry I don’t want you my friend ohhhh upset wasted time for degree everything my friend work at (supermarket) all his life’ (P1, 28, 805).

‘I’ve also been able to umm because of the cochlears been able to expand go to new activities do more things umm live my life more widely’ (P2, 14, 397)

‘I don’t mind being deaf as long as I can hear with these cos I actually quite like being deaf cos probably if I didn’t had any implant I probably would be like of deaf will like make my life the worst thing ever and then since the implants come along I’ve like at least I can hear something that’s like really nice’ (P3, 17, 493)

‘I can remember when I was little I couldn’t even speak I’m hardly to speak so if I didn’t have it done I’d probably be signing more…. I probably will be a little bit sad or (pause) that’s all I can think really’ (P10, 19, 544)

‘If I didn’t get these I don’t think I would have had such you know a successful life’ (P4, 21, 590)

Normality versus disability
‘The idea of umm 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)

‘Like say with our school I’d have to go in for like meetings of how I’m doing at school and it’ll say um disability meetings and I say to my Mum why do they put disability on the top cos I’m not disabled at all I’m perfectly normal’ (P6, 29, 847).

‘Everyone treats me as I’m a normal hearing child like my Mum will even treat me she’ll be like say if I didn’t hear something she’ll be like are you deaf and I’ll be like yeh I am everyone’s so used to me talking and they don’t really think of me as a deaf child [Researcher: Yeh and do you think of yourself as a deaf child?] No not at all like I just think of myself as a normal hearing child (P6, 3, 63

‘Errm I love about (…) school is that I just feel normal like anyone else like I don’t have to go to a certain school just cos I’m deaf cos that’s not really fair and it’s like I like to be round everyone else and be really friends with them and it’s nice’ (P3, 6, 150)

Being a hearing person

‘If I could tomorrow be able to take both these off and umm have completely umm hearing or umm in fact just have completely good hearing with these I then that would be a bit odd but I’d take it’ (P2, 10, 277).

‘If my Mum and Dad didn’t made that decision I wouldn’t be able to hear at all not a thing so that’d be really horrible’ (P3, 2, 40).

It’d just be really weird like I just think if it as being really strange just to like not having these at all and just being deaf all the time and I wouldn’t really like that (P6, 19, 541).

‘Yeh because they help me to hear and um I’m not I don’t I’m not really deaf if you think about it like I don’t feel deaf I just feel like a normal child and I’m glad that their that they invented them so that I could hear’ (P6, 14, 388)

‘I can hear out of both ears whereas before I could only hear out of one ear so now I feel more like a hearing person’ (P6, 17, 488)

‘[Researcher: do you see yourself as part of the Deaf community?] Not really cos I’m not I’m not round with deaf people most of the time um I don’t go to a deaf school and I only know two people who are deaf but I just don’t I don’t talk to them a lot I just say hi once in a while people who are at school’ (P7, 15, 435).

‘ 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)

‘What thinking of me being deaf?[Researcher: Yeh] Yeh sometime not really often but sometime I thinking of myself pretend to being hearing people really’ (P10, 13, 377).

‘Well I think having two made me feel more hearing hearing person(…..)cos I can hear much louder and hear some things that I couldn’t when I had one implant’ (P9, 14, 407).

Connections to deafness

Deafness as a valued part of the self

‘ I do see myself as a deaf person in the fact that had I not become deaf at this point my life would have gone in a completely different direction so umm its impossible to deny that I am a different person because I’m umm deaf cos I had my implants because umm I moved school umm because before I went to (name of school) I was in a different school so my life has completely umm taken a different direction so this person is completely different well probably not completely from the boy who never became deaf so in that sense umm I am defined by my deafness’ (P2, 9, 254)

‘What I love about I actually do like being deaf because um when my friends like whisper yeh well they whisper to someone ear but they wouldn’t do it at me but I lip-read cos I can lip-read and er I catch them out (laughs) that’s what I love doing’ (P3, 4, 97).

‘Sometimes use my excuses if say I um I know this is really bad but I do my excuses at school like say um I don’t even listen what they’re saying and I just drift off into daydream or chat to my friends then my teacher comes along and says why haven’t you been doing your work and I go cos I didn’t hear what you said but that’s really bad my Mum even tells me off for saying that but I don’t do it anymore I did it when I was at middle school but now I’m in high school I gotta be more serious about it (P3, 6, 153)

BSL means understanding

‘I can understand my friend deaf friends easily hearing friend I sort of have difficult communicating with my hearing friends and of yeh and I feel more comfortable with my deaf friends’ (P1, 15, 441)

‘Because I find it difficult to speak with hearing people because my speech is not very clear…I don’t know…I speak too fast or can’t say properly’ (P1, 1, 6).

‘When do I use it I use speak all the time and I do signing I do it at college with my helper and I got best friend who’s she is deaf and my partner is deaf sometime I sign them a bit and one of my mates from school I sign with her most the time’ (P10, 1, 3)

‘I use sign sign language because when the teacher talking to the class its like (shows me someone talking but with no sound coming out) yeh sign language you can be able to if it’s a I don’t understand what that mean yeh interrupt Mrs the teacher so sign language’ (P11, 1, 8)

The importance of a shared experience of deafness and cochlear implants

‘Deaf school, deaf club, umm deaf activities week deaf club yah (…) deaf club is about all deaf people to meet them and have activity to organise like theme park, park, bowling lots of activities’ (P1, 10, 288).

‘You know at my school most of my deaf friends have one implant and they want have second implant having operation soon….. we talk about cochlear how it helps you’ (P1, 19, 516)

‘It’s really nice actually to have another deaf friend (…) because I’m not the only one whose deaf and its like really nice (…) it does always it always felt like that because I don’t I never see one (…) before and it makes me feel I’m the only one (…) who’s deaf there that’s what is makes me feel like and then when I have a deaf friend it makes me feel really happy cos I’m not the only one and I’m like enjoying my life of them and it feels happy’ (P3, 23, 674).

‘We can understand what’s going on with each other and if we find it hard to explain if something’s gone wrong or something we can both kind of tell her like cos we know what’s going wrong’ (P4, 2, 46)

‘I have a best friend and um I met her when I was two years old and she’s older than me and she’s also deaf and um I’ve know her literally my whole life and we’re like sisters really’ (P6, 3, 80)

‘It’s kind of nice to have someone to talk to about being deaf about cos I don’t really know anyone who’s deaf apart from her so it’s quite nice to have someone else whose deaf (…) like sometimes um we’ll talk about like if you got any bullies like if you got bullied for being deaf or like people usually say that my voice sounds weird so then we’d ask each other about do does people say that’ (P6, 4, 94).

‘Sometime I do feel like it is my important friend who is deaf more than hearing people (…) that’s all I can think really’ (P10, 23, 654)

‘I spend more with the deaf friends (…) just mess about yeh more um more time with like like with my best deaf friends’ (P11, 15, 419).

Bicultural identity

Being deaf, being hearing and being in the middle

‘Yes well I see myself I think as fit in both worlds deaf and hearing worlds because I can sign and speak and I can communicate to hearing kind of well yah that’s why I think I fit in both worlds’ (P1, 9, 248).

‘[Researcher: So in terms of the Deaf community, how are you involved in the Deaf community, can you tell me a bit about that?] Deaf school, deaf club, umm deaf activities week deaf club yah [Researcher: Yeh, so what’s deaf club?] Deaf club is like youth club for summer holidays half term the deaf club is about all deaf people to meet them and have activity to organise like theme park, park, bowling lots of activities' (P1, 10, 288).

'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 I don't umm even so logically they are I don't think there are actually mutually contradictory but umm (pause) like I said my life's split there and I don't have a tendency to think about the person who didn't become deaf in a theoretical lifeline as the hearing person so I see myself as a deaf person as is that is a significant portion of what I am it has defined my life so the conclusion to that is that I probably do see myself as a deaf person as opposed to a hearing person but I don't think that's actually incredibly important or at all important when dealing with people unless they try and make an issue out of it issue out of it' (P2, 11, 301)

I know I'm deaf and I can hear that's how I feel (P3, 23, 654)

'When I look in the mirror its on but sometimes its off in the morning I sit down put it on and before I put it on I look in the mirror and I go I don't look like a deaf person there that looks like me without being deaf and I go like that and then when I put an implant on I go ohhhh I'm deaf I'm not saying it's a bad thing' (P3, 17, 489)

'I don't mind being deaf as long as I can hear with these cos I actually quite like being deaf cos probably if I didn't had any implant I probably would be like of deaf will like make my life the worst thing ever and then since the implants come along I've like at least I can hear something that's like really nice' (P3, 17, 493).

'Um I don't really see myself as a deaf person to be honest but like it'd just be like if I take my implants off and then I'll just see myself as a deaf child then but even then people would still just talk to me normally and I'd just lip-read them' (P6, 13, 377)

'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)

'I think it's a bit of both because my because when I feel like I'm a hearing person and a deaf person it goes up and down up and down really so there are times when I feel like more of a hearing person and there are times when I don't' (P7, 17, 501)

‘When I’m signing to my friends I feel like that I am like really deaf yeh’ (P10, 14, 405).

‘I mostly feel sometime I’m deaf sometime I’m hearing people’ (P10, 18, 527)

Sameness and difference

‘ I feel I am equal to my deaf friends because I am deaf but I can hear though but my deaf friends who can’t hear at all can sign language so bit different though I can speak they can’t speak’ (P1, 16, 464)

‘Some of them can’t speak as much as I can cos of they problems they have and I go oh and then I look at them and I go I feel really sorry for them and I’m like I’m deaf as well but still feel sorry’ (P3, 21, 612).

‘When I see stuff like that it feels like I’m just a hearing person I can hear and that makes me feel I’m not deaf and I look at other people and I’m like I feel really sorry for them and then I forget that I’m deaf cos I can hear and I’m like staring at them like they do sign language and I’m like ohh interesting’ (P3, 21, 619)

‘Like if makes me feel like left out like I’m not involved with hearing that people can hear and it makes me like well I can hear but still I’m not I can’t hear as well as them and that makes me feel mmmmm’ (P3, 24, 692)

‘Umm I’ve never really like thought that I was deaf I’m just the same as everyone else who are hearing people’ (P4, 3, 70)

‘ I don’t really wanna be like in deaf communities cos then people would be like cos I always think of other deaf children as like who have no implants they can’t talk properly and I’m scared in case like if I go to them it’ll make me a bit upset that I’ll be that I’ve been given the chance to have hearing aids and they haven’t so it just makes me feel a bit’ (P6, 14, 405)

‘ 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 and um that’s about it’ (P6, 17, 496)

‘Well it just made me have like closer hearing to their hearing so it made me feel like I really fit in’ (P8, 2, 47).

Feeling different in a hearing world

Frustration and confusion of not hearing and understanding

‘With my family the hearing world I feel like I’m being left out because they all talk and talk and talk and talk and I do not understand and I was bored walking around’ (P1, 11, 300)

‘Um there is in the fact that group conversations I said are the trickiest aspect I mean the radio aid I’ve currently got um has a multi directional mic on the direction which points in all directions which um helps with that I just put it on the table um the main problem then the major problem left is um group conversations in background noise background noise is general generally in general a problem but um in one on one its quite manageable because I only have concentrate on one person but in group conversations conversations shift from person to person and they microphone doesn’t help so much with that because um it also picks up the background noise which is not much help at all’ (P2, 19, 553)

‘The other thing they not care about is when I when they speak to me and I say what sorry didn’t catch that and they go don’t worry and when people say don’t worry I get really angry cos that really defends me cos like my sister say it and my Mum tells her off cos she cos my Mum knows that really defends me cos its not fair’ (P3, 3, 61)

‘I don’t understanding talking people at all’ (P5, 2, 51)

‘What I don’t like about it I think I have some bad days when I don’t want to go to school and it’s well I feel like if I’m the only one struggling in class I don’t sometimes like it because everyone seems to be getting on fine and listening to the teacher and everything so I yeh I don’t think I have any bad points about the school’ (P7, 6, 155)

Feelings of isolation and difference in a hearing world

‘I’m going to university (date) but I feel excited bit embarrassed bit because I’m having interpreter coming but I feel quite uncomfortable interpreter there signing to me what teacher saying but hearing people look that she signing to me feel like embarrassed mmm and my effort to me for not have friends because they think I’m really odd with signer person worried worried yeh’(P1, 20, 546)

‘I say what sorry didn’t catch that and they go don’t worry and when people say don’t worry I get really angry’ (P3, 3, 61).

‘I have helpers like from all the way to school I have helpers that’s nice’ (P3, 7, 180).

‘My friend says it’s really noisy in the pool and I’m like well I don’t know cos I actually never been in the pool with able to hear (…) they talk yeh and they forgot that I’m deaf and I’m like and I’m like oh so I can’t hear what you’re saying’ (P3, 5, 130).

‘In primary school there was like boys who used to like tease me but it was just like minor and they used to get like tin foil and put it behind their ear and be like oh I’m deaf too and they used to just laugh it off and we used to like have a go at each other really so boys would be kind of nasty about it but I’ve learnt to like forget about them and like say if they tease me now or in the future I’ve learned to just ignore them and get on with things really’ (P6, 15, 438).

‘I got a bit annoyed about that and a bit embarrassed so then I talked to the head of the um people and I’ve told her like I oh I don’t really want someone following me and she was like ok then and she didn’t really follow me that much’ (P6, 27, 775).

‘Sometimes people say that I talk weird so then I get a bit like you know like its just some boys but they bully they like take the mickey out of everyone so’(P6, 4, 106)

‘I find it quite annoying cos I sometimes feel like oh I feel independent enough to do my own work but still I still need I have to be reasonable and I still need some help but if I didn’t have any help I would like fall behind my school work and I don’t really want to do that’ (P7, 23, 662).

‘I think I was worried about both but more when I actually had it and also I was a bit uncomfortable in having I just don’t I just don’t like having I dunno as soon as I got my first one I felt like a bit like I was a robot when I had a magnet in my head and I um with when the reason I didn’t really want the second one was cos I didn’t really want another magnet in me I didn’t want to be I didn’t want to go through an operation and have something put into me that I don’t really want’ (P7, 9, 241)

‘[Researcher: I just wondered in what ways if any do you see yourself as a deaf person?]Well when I can’t do some activities that normal people can do like I can’t do rugby or I can’t well I can do swimming but it’s a lot harder to talk with people when swimming I can’t hear them but I think those are the only occasions’ (P8, 8, 214).

‘Sometimes makes me feel left out if I can’t do things like other people can ….. I mean um last year no last year at my old school errr we went on a holiday to (place) that’s it and um they’re having a secret water fight which Miss (name) told me but I wasn’t allowed to tell anyone else and umm I couldn’t join in cos of the implants cos can’t get wet’ (P9, 15, 433)

‘Err when people say new people say say oh what is that thingy say ohh I’m deaf oh sorry oh so sorry people say sorry so I just fine fine’ (P11, 19, 557)

Unfairness of prejudice and deafness

‘Bad thing is that how do they think of being as deaf that they might think I’m dumb dumb’ (P1, 21, 572).

‘Well I think more challenging because to be fit with hearing colleagues for (…) design yeh I going to tell them that I’m deaf might forgot that I’m deaf like if for example if my boss call my name (…) why you can’t hear me excuse me I’m deaf oh sorry (P1, 27, 773)

‘[Researcher: You said you’d have to go to a specialist school and is that not really something you’d have liked?] No because its not fair cos er what if some deaf people do want to go to public school they should cos you get to make friends with like non- hearing people because I got friends that not deaf at all and that’s actually really nice’ (P3, 2, 50)

‘If someone else is saying that you look like a hearing person and that makes you actually feel really happy and that makes me really happy when they say that cos I don’t like cos it’s not nice when they say oh I thought you’re a deaf person like that and I’m like well I am deaf but I can hear but still’ (P3, 17, 498).

‘There’s some people out there in the world who like use like don’t take people with a disabilities and um I don’t want ever want to come across that in my life to be honest it’s like people will be like if you’re in a wheelchair you can’t do this and 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).

‘They might think oh she’s deaf how could I talk to her or something or like um I don’t know I think it’s just I’m think more worried about how they talk to me and how they’re going to approach me and things like that’ (P7, 11, 326)

‘What I was been thinking they think that I’m think that I can’t even speak that I’m stupid errrm keep thinking they might take the mickey out of me being nasty that’s all I can think of’ (P10, 21, 610).

Looking different

‘Robot yes because they make magnet me look like a robot ahh funny’ (P1, 17, 481)

‘I just can’t do what I want with my hair’ (P3, 10, 275).

‘If I’m having a picture taken I wouldn’t really like want them showing cos it kind of ruins the whole picture because I didn’t really want them to show so I’ll just cover my hair up like cover them with my hair’ (P6, 17, 477).

‘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)

‘Well I went to this new school I wore my hair down for a reason is to I didn’t want people to look at me didn’t want people to be taking mickey out of me and all of that then my Mum said don’t just show the world that you’ve got these in and you just get it over and done with that’s all and I’m like that is true Mum even my friends said that but I’m like but that’s what you think but it’s about what I think and it’s just makes me feel uncomfortable’ (P3, 18, 520).

‘Well sometimes like say if I tie my hair up I’ll try and put my hair over them so it doesn’t look as noticeable because my whole school doesn’t know that I’m deaf there’s only really the people in my class and like the whole year so then I would be scared in case like people would keep staring at them and so sometimes I'd cover my hair with my ears but other times I'll just tie my hair back and not care what people say' (P6, 16, 448).

'Um when I had one it was just when I had one cochlear implant I didn't have anything on this ear and I felt a bit oh I only got one cochlear implant and that's fine but as soon as I got two it was like I don't really want two and I just didn't really want people to think oh she's got two that mean's she has more problems so I just didn't really like the feeling of having two' (P7, 10, 271)

Appendix R: Research process letter to recruiting clinics

Canterbury Christ Church University
Department of Applied Psychology
Broomhill Road
Tunbridge Wells
TN3 0TG

1st July 2011

Re: Research project examining Adolescents experience of sequential cochlear implantation'

Dear clinicians,

Thank you for agreeing to help recruit participants for this research project. Please find below an outline of the recruitment process for the project. This recruitment process has been approved by NHS ethics.

STEP 1

From all of the young people who attend your clinic, please identify which young people meet the inclusion criteria:

- The young person received a sequential cochlear implant as a result of the revision of the NICE guidelines (2009)
- If the young person acquired their deafness, that this was prior to starting school at age 4-5.
- The young person was 18 years or under at the time of the sequential cochlear implant operation.
- The young person will be aged between 12-21 years at the time of the interview.
- The young person does not have disability in addition to being deaf (e.g. severe physical or learning disability) that would either mean they couldn't participate in the interview or that their experience of their cochlear implant(s) is complicated by multiple issues (which would therefore reduce homogeneity).

STEP 2

- If you are due to see the young person, or it is possible to arrange this, please have the initial conversation about the project face-to-face.

- If you are not due to see the young person please contact the young person and their parents via telephone/email.

- Briefly explain the project to the young person (and their parents if they are under 16), saying 'Is it OK to give you some information about a project that's been carried out that you may like to take part in. Kristina Hilton is a trainee Clinical Psychologist who would like to interview young people about their experience of having a second cochlear implant. Would it be ok for Kristina Hilton to contact you and your parents/guardians to talk about whether you would like to take part? If that's OK, would you prefer telephone or email contact?

- If you see the young person face-to-face give the young person and their parent/guardian the pack containing the cover letter, information sheets and consent forms. If you are contacting the young person and their parents/guardians via telephone/email, please get their verbal consent for their address to be given to Kristina Hilton so they can be sent the information pack.

STEP 3

Contact me (Kristina Hilton) and give me the following information;

- Names of the young person and their parent/guardian
- The young person's age
- Contact details and preference
- Address if applicable

STEP 4

I will follow-up with family. If they consent to participate I will liaise with you regarding booking a clinic room for the interview (if applicable).

I hope this recruitment process is clear. Please do not hesitate to contact me if you have any queries.

Yours sincerely,

Kristina Hilton
Trainee Clinical Psychologist
Canterbury Christ Church University

Dr Jenny Cropper
Clinical Psychologist

k.hilton240@canterbury.ac.uk

Appendix S: End of study report for Research Ethics Committee (REC) and Research and Development (R & D) departments at research sites

End of study report – July 2012
Full title of study: Adolescent experience of a sequential cochlear implant
REC reference number: 11/LO/0069

Background

Prior to a revision of the National Institute of Health and Clinical Excellence (NICE, 2009) guidelines, severely or profoundly deaf young people received a unilateral cochlear implant (UCI). However, due to the possibility of further audiological benefits young people are now eligible to receive simultaneous bilateral cochlear implants (BCIs). Young people with an existing UCI are eligible to receive a second sequential cochlear (SCI) implant until the end of their eighteenth year.

Given that rates of emotional and behavioural disorders and social exclusion 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 cochlear implants (CIs). Although in the past studies have typically been conducted with parents, there is an emerging evidence-base with young people. A literature review indicated that findings from questionnaire and interview studies of satisfaction, quality of life (QoL) and health related QoL (HRQoL), and more rigorous studies of psychological and social implications of CIs, suggest a mainly positive picture. Young people feel more confident and less frustrated due to their ability to communicate orally, with improved or extended social/family relationships, and levels of HRQoL, mental health, self-esteem, social integration and loneliness that are comparable to hearing peers. However, concerns and disadvantages have also been reported in some of these studies, including the restrictiveness of CIs (e.g. exclusion from some sports), continued difficulties hearing in noisy environments and groups, feeling of self-consciousness about deafness/CIs and fitting in, and worries about friendships, dating and the future.

Adolescents with UCIs have tended to report bicultural or hearing identity/acculturation, and those without CIs have tended to report Deaf identity/acculturation. However, the variation in measures used across the studies limits the comparability of the findings and interview studies suggest identity is complex for these young people. Most studies to date have included only young people with UCIs, therefore research into the psychosocial implications of SCIs and BCIs are lacking.

In summary, despite a generally positive picture, it is evident that these young people with CIs may experience some psychosocial difficulties and are dealing with complex issues regarding their identity.

Research aims

Given that no studies have rigorously examined issues of psychosocial well-being and identity development in young people who opt to receive SCIs, this study aimed to examine the young people's decision, their identity in relation to the Deaf and hearing worlds and their experience of the impact of the SCI on their identity and psychological and social well-being.

Method

Eleven young people with a SCI who met the study inclusion criteria were interviewed. Interpretative Phenomenological Analysis (IPA) was selected as it is concerned with how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009).

Findings

Six master themes were identified; ‘consideration and commitment to the second implant’, ‘contentment with two cochlear implants’, ‘the importance of being in the hearing world’, ‘connections to deafness’, ‘bicultural identity’ and ‘feeling different in a hearing world’. Most participants enjoyed improved confidence and social well-being following their SCI, and felt that two CIs were superior to one. The majority of participants 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 and were also grappling with their identity as a deaf person who is able to hear. These findings add to the emergent deaf identity development literature in young people with CIs.

These findings are perhaps transferable to the wider population of young people who receive SCIs, and therefore support the clinical psychologist’s role in CI clinics. This provision allows young people to have psychological input in relation to SCI decision making, and for exploration of issues of identity and therapeutic input if required. These implications may also be pertinent to young people with UCIs and BCIs, and in providing useful information for parents and young people making decisions about CIs.

Feedback to participants

Participants and their parents were sent a ‘Thank you’ letter for taking part in the study and a brief summary of the research findings. Copies of these documents are included with this report.

Publication and dissemination of findings

The findings of this study will be disseminated to the research sites and will be submitted to the Journal of Deaf Studies and Deaf Education for publication.

References

National Institute for Health and Clinical Excellence (2009). Cochlear implants for children and adults with severe to profound deafness. Retrieved from http://www.nice.org.uk/nicemedia/pdf/TA166Guidancev2.pdf

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Written by Kristina Hilton, Trainee Clinical Psychologist,
Canterbury Christ Church University

Appendix T: Publication guidelines for journal chosen for publication – Journal of Deaf Studies and Deaf Education

Retrieved from: http://www.oxfordjournals.org/our_journals/deafed/for_authors/general.html

The Journal of Deaf Studies and Deaf Education (JDSDE) publishes original, scholarly manuscripts relevant to children or adults who are deaf, including topics such as development, education, communication, culture, and clinical or legal issues. Although most of the articles published will make both empirical and theoretical contributions, purely theoretical or review articles are also welcome. The overriding criterion for acceptance of an article for publication is that it must make a significant contribution to the field. The evaluation of an article's quality takes into consideration the significance of the issue that it addresses and the appropriateness of the methodology. Empirical articles should clearly state their relevance for application and, similarly, articles that are primarily of an applied nature should address the broader theoretical issues.

Manuscripts are accepted for review with the understanding that the same work has not been and will not be submitted elsewhere, and that its submission for publication has been approved by all of the authors and necessary institutional officials. It is assumed that any person cited as a source of personal communication has approved such citation; written authorization may be required at the Editor's discretion.

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- Marc Marschark, Editor
  Journal of Deaf Studies and Deaf Education
  National Technical Institute for the Deaf
  Rochester Institute of Technology
  52 Lomb Memorial Drive
  Rochester, NY 14623
  USA

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The names of authors will be witheld from all referees. Manuscripts should be prepared accordingly; all names and author notes should be included on the title page only.

All submissions should conform to the Publication Manual of the American Psychological Association, Sixth Edition.

MANUSCRIPT PREPARATION

Form. Manuscripts should conform to the conventions specified in the Publication Manual of the American Psychological Association (6th Edition) (1200 Seventeenth Street, N.W., Washington, D.C.

20036). Printed manuscripts must be typewritten, double-spaced on 81/2 x 11-inch (or A4) white paper, with numbered pages. Page 1 should contain the title of the article, author(s) name(s) (without degrees), affiliation(s), a short title not exceeding 45 characters and spaces, and the complete mailing address of the person to whom correspondence should be sent. Page 2 should contain an abstract of 100-150 words. Language should be accessible for a wide range of readers of English wherever possible.

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References. The following examples show style of capitalization and punctuation for journal articles, books, and edited books. See APA Manual Edition 6 for further information on references. Please note that the references have been updated to reflect APA Edition 6. Please ensure that you include the city AND state of publication for all books, and please include the DOI number for all journal articles.

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Please go to the manuscript preparation guidelines for further instruction regarding preparing a manuscript for publication.

Funding. Details of all funding sources for the work in question should be given in a separate section entitled 'Funding."

The following rules should be followed:

- The sentence should begin: ‘This work was supported by …’

- The full official funding agency name should be given, i.e. ‘National Institutes of Health’, not ‘NIH’ (full RIN-approved list of UK funding agencies) Grant numbers should be given in brackets as follows: ‘[grant number xxxx]’

- Multiple grant numbers should be separated by a comma as follows: ‘[grant numbers xxxx, yyyy]’

- Agencies should be separated by a semi-colon (plus ‘and’ before the last funding agency)

- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number 'to [author initials]'.

An example is given here: ‘This work was supported by the National Institutes of Health [AA123456 to C.S., BB765432 to M.H.]; and the Alcohol & Education Research Council [hfygr667789].’

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