Rehabilitation stress in parents of children with cochlear implants

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Rehabilitation efforts and stress in parents of children with cochlear implants

Abstract

This mixed methods study investigated the impact on Australian families of the decision-making process and the ongoing (re)habilitation demands of their children's cochlear implantation. Quantitative results from a survey of 247 parents found that parents experienced stress related to the decision-making and rehabilitation processes at significantly higher levels than they had expected pre-implant. Multiple regression analysis identified factors that were predictive of parents' experiences of rehabilitation efforts and stress. Qualitative data from interviews with 27 of the survey respondents elaborated on the quantitative findings and provided insights into the impact on families' lives, identifying the greatest problem areas and potential stressors for parents. Implications and recommendations for professionals working with families are drawn from the findings.

The process of cochlear implantation, including the decision-making and habilitation or rehabilitation stages, is generally complex, lengthy and demanding for families of deaf children (Christiansen & Leigh, 2002; Most & Zaidman-Zait, 2003). Issues of parental stress and coping with the demands involved in parenting a deaf child with a cochlear implant need to be investigated in order to maximize knowledge that can inform practice in the areas of services and supports for families. In addition, it is important to understand the experiences and needs of parents and families over time, to ensure that the necessary supports are in place not only in the early years post-implant but within the longer time-frame of children's growing years.

Family involvement in the early intervention and language development activities of their deaf or hard of hearing children is typically considered critical to the children's progress, and parents' self-esteem and confidence in helping their deaf children's development has been seen as a factor enhancing family involvement. Luterman (1999) maintained that the self-esteem of the parents, particularly the mother, is the crucial key to the child's success, and that all clinical endeavours should be devoted to empowering and increasing parents' self-confidence. Research has shown that family involvement, and particularly maternal self-efficacy, has a positive influence on deaf children's language development and other outcomes (Moeller, 2000).

A high level of parental involvement in children's rehabilitation and early intervention is generally considered essential for children to gain optimal benefit from their cochlear implants (Geers & Brenner, 2003; Kirkham, et al., 2009; Spencer, 2004; Waltzman, 2006). Studies investigating candidacy profiles for paediatric cochlear implantation have reported that audiologists' pre-implant concerns about the family's

ability to support the child's optimal use of the implant predicted poorer speech perception skills in the early years post-implant (Edwards, Thomas, & Rajput, 2009; Nikolopoulos, Gibbin, & Dyar, 2004). Other research has suggested that maternal factors such as involvement and self-efficacy related to managing their children's cochlear implants and working with their children to develop speech and language can contribute to the variability in the language outcomes of children with cochlear implants (DesJardin & Eisenberg, 2007; DesJardin, Eisenberg, & Hodapp, 2006; Kirkham et al., 2009).

Thus, research indicates that parents of children receiving cochlear implants should be as involved as possible and that their participation is likely to be enhanced if they feel competent to deal with the demands related to their children's deafness and cochlear implantation. It is, therefore, important that professionals working in cochlear implant programs, early intervention centres and education systems have as full an understanding as possible of the stresses and demands that parents face and that strategies are designed to best support and empower parents so that feelings of stress or psychological distress are minimised.

Stress may be defined as a mental state of tension or arousal, usually triggered by external stimuli or stressors, that results in behavioural, emotional, cognitive, and physiological indicators or symptoms (Rice, 1999). Although external events may act as stressors, different individuals vary in their reactions to the same external event. Individuals' cognitive appraisal of events influences their stress responses to those events. An individual's resources are also paramount in his or her reactions to potential stressors. Personal traits such as self-efficacy, perception of control, and self-esteem can enhance coping with potential stressors. Social support, including family, friends, and

local agency networks, is another important resource (Lazarus, 1999; Rice, 1999). There is an important relationship between such resources and potential stressors; psychological stress occurs when “environmental and/or internal demands tax or exceed the individual’s resources for managing them” (Holroyd & Lazarus, 1982, p. 22).

Deafness in children of hearing parents generally has a considerable impact on families, and a diagnosis of deafness brings with it many immediate and longer-term challenges for parents. Parents generally need to deal with their feelings about their child’s deafness, learn and make decisions about communication and educational options for their child, become involved in the child’s early intervention and language development, manage family interactions in the presence of the needs and communication difficulties of the deaf child, educate others about their child’s hearing loss, and, often, advocate for their child (Eriks-Brophy, et al., 2007; Hintermair, 2006; Jackson, Traub, & Turnbull, 2008; Jackson & Turnbull, 2004).

Researchers have sought to determine whether these challenges are associated with increased stress or other psychological states such as depression and anxiety. Studies comparing parental stress levels of mothers of deaf and mothers of hearing children have reported varied results. The most commonly used measure of stress in these studies is the Parenting Stress Index (PSI, Abidin, 1990, 1995). Using the PSI and additional measures, a Canadian study (Quittner, Glueckauf, & Jackson, 1990) compared 96 mothers of children with severe or profound hearing losses with a matched sample of 118 mothers of normally hearing children. They found significant mean differences on levels of parenting stress and depression, anxiety, and anger, with the mothers of deaf children group having higher levels than the control group. However, other studies have found

parents of deaf children to have levels of parenting stress no higher than parents of hearing children (Asberg, Vogel, & Bowers, 2008; Hintermair, 2006; Lederberg & Golbach, 2002; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). In Lederberg and Golbach's study, although the group of 23 mothers of deaf children did not significantly differ from a matched sample of mothers of hearing children on the PSI, they did indicate higher levels of stress than the comparison group on the Questionnaire on Resources and Stress – Short Form (QRS-F; Friedrich, Greenberg, & Crnic, 1983). The authors pointed out that the QRS-F has items related to children's communication difficulties and parents' concerns about their children's future life, potential sources of stress not measured by the PSI, and it was largely on those items that the mothers indicated higher levels of stress.

Certain factors have been found to be correlated with or predictors of stress in parents of deaf children. Social support, particularly support specifically related to the family's needs with their deaf child, has been shown to predict lower levels of parental stress (Asberg et al., 2008; Hintermair, 2006; Lederberg & Golbach, 2002; Pipp-Siegel et al., 2002). Pipp-Siegel and colleagues also reported that frequency and intensity of daily hassles predicted parental stress. The presence of additional disabilities in the deaf children was found to be associated with higher levels of stress in the studies by Hintermair (2006) and Pipp-Siegel et al. (2002). Communication mode did not influence stress levels in Hintermair's or Pipp-Siegel et al.'s studies, but Asberg et al. (2008) reported that parents using Total Communication with their children were significantly less stressed than parents using only oral communication or only sign language. It may be

that it is communicative effectiveness, rather than communication mode per se, that has a beneficial effect on stress levels, as suggested by findings in Hintermair's study.

Parents of children with cochlear implants may face similar demands and potential stressors to those faced by parents of deaf children without implants, along with additional ones, the first of which is making the decision to implant, and then the implant surgery itself. This can take place at increasingly young ages; in recent years, cochlear implant surgery has been performed on infants aged 6 to 12 months and sometimes even younger (Birman, 2009; Dettman, Pinder, Briggs, Dowell, & Leigh, 2007; Holt & Svirsky, 2008; Lesinski-Schiedat, Illg, Heermann, Bertram, & Lenarz, 2009; Waltzman & Roland, 2005). The growing incidence of early detection of congenital deafness through newborn hearing screening programs means that parents are likely to be faced with making a decision about cochlear implantation very early in the lives of their deaf children. Several studies have found that parents experience considerable stress and anxiety in the process of making the decision to implant (Burger, et al., 2005; Christiansen & Leigh, 2002; Hyde, Punch, & Komesaroff, 2010; Most & Zaidman-Zait, 2003; Perold, 2001; Sach, Whynes, Archbold, & O'Donoghue, 2005; Spahn, Burger, Loschmann, & Richter, 2004; Weisel, Most, & Michael, 2007; Zaidman-Zait & Most, 2005).

Some parents have reported high levels of satisfaction with the outcomes of their children's implantation, but have also reported ongoing concerns about aspects of their children's progress with the implant, as well as stressors involved in the ongoing demands of their children's (re)habilitation. (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Archbold, Sach, O'Neill, Lutman, & Gregory, 2008; Christiansen &

Leigh, 2002; Sach & Whynes, 2005; Zaidman-Zait, 2007). After the difficult period of decision-making and their children's surgery, ongoing demands for families include not only the early intervention sessions and home activities needed for speech and language development, but also a large number of appointments for audiological and technological follow-up related to the device and its accompanying equipment. In addition, parents must learn to manage the maintenance and troubleshooting of the device equipment (Archbold et al., 2002; Archbold & O'Donoghue, 2007; Sach & Whynes, 2005; Zaidman-Zait, 2008), which is more difficult to handle and maintain than hearing aids (Lesinski-Schiedat et al., 2009). For children's outcomes to be optimal, it is necessary that children gain access to the technological advances involved in the rapidly evolving field of electronic speech processing, as well as the most appropriate and well-fitted map (Geers, Brenner, & Davidson, 2003). It is therefore important that parents feel competent and have a sense of self-efficacy in their involvement with the technological, audiological, and educational aspects of their children's ongoing rehabilitation and development after implantation.

Several studies have investigated the stress experienced by parents of children with cochlear implants. In a study of mothers' stress and expectations of cochlear implantation, Weisel, Most, and Michael (2007) found that mothers' stress levels did not decrease as time passed, and mothers whose children had been implanted for at least three years indicated some disappointment in the areas of their children's communication and academic outcomes and lower expectations for these outcomes than mothers whose children had been more recently implanted or whose children were candidates for implantation. The authors concluded that the initial period of high hopes and expectations

can give way, over some years, to a realisation that their child is still deaf and that intensive rehabilitation efforts are still needed. Zaidman-Zait and Most (2005) found that higher stress levels in mothers of implanted children were associated with less satisfaction and more communication difficulties with rehabilitation professionals, illustrating the importance of good relationships between parents and professionals.

A study conducted in Germany compared parents of 57 children with cochlear implants and parents of 90 children with hearing aids on measures of distress and psychological wellbeing. Both groups felt distress at the time of diagnosis. The parents of the children with implants had reduced levels of distress on first receiving information about cochlear implants, but felt heightened distress at the time of their children's surgery. The parents of children with implants indicated more distress on measures of family climate (measuring levels of factors including support, tension, and conflict within the family) than the parents of aided children, who were within the norms for the instrument. The authors concluded that fitting with hearing aids versus cochlear implants leads to different demands on parents and consequently to differing reactions within families (Spahn, Richter, Burger, Lohle, & Wirsching, 2003). Investigation of the psychosocial support needs of the parents of the children with cochlear implants revealed that parents indicated a strong desire for psychosocial supports in the form of parent groups as well as therapeutic supports such as counselling and family therapy (Spahn, Richter, Zschocke, Lohle, & Wirsching, 2001).

Using an open-ended questionnaire as well as established measures of parenting stress and life satisfaction, Zaidman-Zait (2008) investigated the everyday problems and stress experienced by 31 parents of children with cochlear implants in Canada. From the

open-ended responses, she identified nine categories of everyday problems related to the children's deafness, habilitation, and implant drawbacks. Parents most commonly reported problems related to the implant and its external parts, especially the maintenance of equipment and dealing with breakdowns. Parents were also concerned about their children's communication difficulties, behaviour, and socialization. The study's findings indicated that 16% of the parents scored at or above the clinical cut-off for the Parenting Stress Index (Abidin, 1995). Parents' satisfaction with their lives was strongly associated with parenting-related stress, which encompassed feelings of incompetence, lack of support, and depression.

In an interview study with over 200 parents of children with implants in England, parents reported that the amount of time and attention necessary to devote to their deaf child meant that the marital relationship was strained, it was sometimes difficult to attend to siblings' needs, and mothers worked less in paid employment (Sach & Whynes, 2005). Other studies have reported that parents of children with cochlear implants would forego paid work in England (Sach & Whynes, 2005; Sach et al., 2005) and Germany (Spahn et al., 2001).

While findings about parents' stress and symptomatology based on clinical measures have been inconsistent, most studies have suggested that parents of children with cochlear implants face challenges and demands that often result in experiences of stress. There are limitations in using measures which do not include or reflect particular types of stressors relevant to parents of deaf children to assess stress in this population. The current study used parental reports to investigate parents' expectations and experiences of the effect of their children's cochlear implantation on themselves and their

families across a range of locations in eastern Australia. It included parents of children with varying lengths of time since implantation and thus gained the perspectives of parents about the lived experience for families of children with cochlear implants over time. The findings reported here are part of a larger study that also investigated parents' decision-making and children's outcomes, as reported elsewhere (Hyde, Punch, & Grimbeek, in press; Hyde et al., 2010; Hyde, Punch, & Komesaroff, in press).

METHOD

A mixed methods approach to data collection and analysis was used that enables research questions to be addressed more fully and accurately than the adoption of only a quantitative or qualitative approach permits. A combination of quantitative and qualitative approaches was adopted in a sequential strategy in which one method is used to further explore and expand the findings of another (Creswell, 2003). Thus, parents' expectations and experiences of their rehabilitation efforts and stress were measured by a quantitative survey instrument, followed by in-depth interviews with a subsample of the survey participants in order to extend and elaborate on the survey data.

Participants

Parents of children who had received cochlear implants before the age of 18 years participated in the study. Of the 247 survey respondents, 30.7% lived in Queensland, 47.3% in NSW, and 21.8% in Victoria. The majority (88.3%) of respondents were mothers, 10.1% were fathers, and the remaining 1.6% included 2 grandmothers, 1 foster parent and 1 step-father. Most of the children lived in households with 2 parents (88.1%), and 11.9% lived in single- parent households. Nearly all parents were hearing (96.7%), 2.8% were hard of hearing, and 1 parent (0.4%) was Deaf. Although 9.7% of parents

indicated that English was not their first language, only 4.0% reported that English was not the language they used most each day.

Of the 247 surveys in the analysis, 49.8% reported on a male child. For the majority of the children, parents reported that hearing loss was congenital (69.2%) or had occurred before the age of 2 years (11.1%), while 7.8% had lost their hearing over the age of 2, and 12.6% of parents reported that they did not know when their children's hearing loss had occurred. One quarter of the parents (25.3%) indicated that their children had additional difficulties or disabilities. Sixty-five of the children (26.3%) had a sequential bilateral implant. As Table 1 indicates, there was a wide range of ages, ages at implantation, and duration of implant use in the group.

Insert Table 1 about here

Families' geographical locations were categorised by postcode and compared to Australian Bureau of Statistics information which classifies postcodes into an accessibility to services/remoteness index of regions termed Major Cities, Inner Regional, Outer Regional, Remote, and Very Remote (Australian Bureau of Statistics, 2006). The proportion of survey respondents living in each locality category reflected quite closely the 1996 Census population figures reporting percentages of people living in regions ranked on accessibility/remoteness (Australian Bureau of Statistics, 2001).

Postcodes were also used to ascertain socioeconomic status (SES). Each postcode was assigned to one of ten decile positions according to the Index of Relative Socio-economic Advantage and Disadvantage which ranks postcode areas on a continuum of social and economic advantage to disadvantage (Australian Bureau of Statistics, 2008).

The majority of parents lived in areas ranked in the highest deciles: 75.1% lived in areas ranked in the top five deciles.

Measures

Parental expectations and experiences. This measure was adapted from Zaidman-Zait and Most's (2005) scale that was used to assess expectations of the rehabilitation demands on mothers of children with cochlear implants. Zaidman-Zait and Most reported Cronbach alpha coefficients for internal reliability for their scale as .65. In the current study, this 7-item scale is called Rehabilitation Efforts, and a further 3 items asking about parents' level of stress in the areas of making the decision to implant, the rehabilitation process, and generally with their deaf children formed a second scale, called Rehabilitation Stress. In the current study, the internal reliability coefficient was .76 for Rehabilitation Efforts and .62 for Rehabilitation Stress. The scale items can be seen in Tables 2 and 3.

Parents were asked to rate their level of agreement or disagreement about their *expectations before* their child had received the cochlear implant with items with the stem "I expected that...." A following section of the questionnaire asked parents to report on their *experiences since* their child's implantation, with the stem "Now I find that...." Respondents were asked to rate their level of agreement with each item on a 5-point scale with responses *strongly disagree, disagree, neither agree nor disagree, agree* and *strongly agree*.

Parents were also invited to write an open-ended response to the question “If there is one central message that you would like to convey to us about the experiences you have had with your deaf child and his/her cochlear implantation, what would that be?”

Interviews

Follow-up interviews with approximately 10% of parents who completed surveys were planned. Almost 80% of the survey respondents agreed to be contacted for an interview, so it was necessary to make a selection of parents to contact and invite to be interviewed. In keeping with the aims and qualitative approach of this phase of the study, sampling was purposeful. Purposeful sampling is designed to select information-rich cases likely to best illuminate the questions being investigated and yield insights and in-depth understanding, rather than empirical generalizations (Patton, 2002). Nevertheless, a range of parents in terms of location (metropolitan, regional, rural), current age of child, age of child at implantation, and the type of educational setting the child attended was interviewed, so that there would be structured representation across the range of situations of families.

Twenty-seven parents were interviewed. Five of these parents had 2 children with cochlear implants, and so the number of children discussed in the interviews was 32 (16 girls and 16 boys). The children’s ages ranged from 1 year 8 months to 25 years. The large majority of these had been implanted before 3 years of age: Five of the children had been implanted before the age of 1 year, 18 between the ages of 1 and 3, 5 between the ages of 3 and 12, and 4 between the ages of 12 and 17. Despite an attempt to arrange interviews with several fathers, only one interview with a father eventuated; the other interviewees were all mothers. One interviewee was deaf; the others were hearing.

The interviews incorporated an initial list of questions serving as a guideline only, allowing unanticipated information to emerge. The use of a semi-structured interview schedule does not pre-empt the open-ended nature of the qualitative interview, as within each question the opportunity for unstructured responses remains. Rather, the schedule ensures that previously identified areas of interest will be explored even if they do not emerge spontaneously during the course of the interview (McCracken, 1988). Thus, the format and sequence of each interview was determined as the session proceeded. In addition, further questions were asked as necessary to probe or clarify particular answers.

The questions included in the interview guide covered the parents' decision-making process, the expectations they had before their child's implantation, and their own experiences and their perceptions of their child's outcomes since implantation. Interviews were conducted over the telephone and ranged in length from 35 minutes to one hour 45 minutes, with most taking around one hour. All interviews were audio-taped, with the parents' prior consent, and transcribed in full for analysis. The interview data were analysed according to the constant comparative method (Glaser & Strauss, 1967; Lincoln & Guba, 1985). Analysis involved the coding of data in order to generate categories, with the constant comparison of units of data in order to discover similarities, differences, patterns and consistencies of meaning that identified themes. As a validity check, a selection of interview transcripts was reviewed and coded by an informed academic external to the research team (Creswell & Plano Clark, 2007). The interview data analysis was facilitated by the use of the NVivo 8 computer program.

Procedure

Approval for the project was gained from the Human Research Ethics Committees of the universities, state government Departments of Education, early intervention centres, and hospitals with cochlear implant clinics participating in the study. Cochlear implant clinics, early intervention centres and Departments of Education facilitated distribution of copies of the survey to all families of implanted children on their data-bases. In addition, organisations for parents of deaf children disseminated information about the project to their members. All parents who received an invitation to participate in the study were informed of the option of completing and submitting the survey online at the project's web-site.

QUANTITATIVE RESULTS

Expectations and experiences of rehabilitation efforts and stress

To examine levels of parents' expectations and experiences, scores were averaged for each of the two subscales, with higher scores indicating higher expectations and experiences (after reversing the relevant items), and the means and standard deviations for each subscale were calculated.

The means for the Rehabilitation Efforts subscale were 3.21 (SD=0.53) for parents' expectations and 3.20 (SD=0.58) for their experiences. Means for the Rehabilitation Stress subscale were 1.07 (SD=0.88) for expectations and 1.18 (SD=0.95) for experiences. Thus, parents indicated relatively high expectations of the rehabilitation demands on themselves, and relatively low expectations of the stress involved in the decision-making and rehabilitation process. Similarly, they indicated relatively high

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experiences for the rehabilitation demands on themselves, and relatively low experiences of the stress involved in the decision-making and rehabilitation process.

Paired sample t-tests were conducted to compare the mean scores of the subscales for expected versus experienced outcomes. The rehabilitation efforts scores did not vary significantly in terms of expected versus experienced responses. There was a significant difference between expectations and experiences on rehabilitation stress scores ($t=-2.41$ ($df=246$), $p<0.05$). Thus, the parents' experienced levels of stress were significantly greater than they had expected before the implant.

Rehabilitation efforts

To report frequencies of parents' responses to the expectations and experiences items, the *agree* and *strongly agree* responses have been summed to indicate agreement, and *disagree* and *strongly disagree* responses summed to indicate disagreement. As Table 2 indicates, the large majority of parents agreed that their children needed intensive listening training and that they, as parents, had needed to work a lot and had been heavily involved in communication teaching activities with their children. Most of the parents felt that they were primarily responsible for their child's rehabilitation process, and that their child needed a lot of family support.

Insert Table 2 about here

Rehabilitation stress

Table 3 shows parents' levels of expectations and experiences of the stress involved in making the decision for their children to be implanted, with almost half indicating that their experience of making the decision was extremely stressful Approximately four

tenths of parents agreed that their child's rehabilitation following their cochlear implantation had been extremely stressful, and half of the parents disagreed with the statement that their level of stress with their CI child was no greater than for any other child of the same age.

Insert Table 3 about here

Multiple regression analysis

The degree of association between the two dependent variables (average “experienced” scores for rehabilitation efforts [RE] and rehabilitation stress [RS]) and the following variables were examined via a series of step-wise regression analyses. Independent variables included in the analysis were family- and child-related demographic factors (urban or regional/remote location, SES, State of residence, number of other children in the family, and child's age), factors related to the child's deafness and implantation (age at onset of deafness, age at identification of hearing loss, age at implantation, length of time using hearing aids before implantation, implantation after the age of two years, and the presence of additional disabilities), factors related to the child's development post-implant (mainstream or special educational placement, communication modes used by the parent and in the educational setting, use of bilateral implants, and use of hearing aid in the non-implanted ear), and factors related to the parents' decision-making and expectations pre-implant (length of time considering the decision to implant, communication mode wanted for child, awareness of possible negative outcomes, and expectations in regard to communication, social, academic, and future life outcomes).

Tables 4 and 5 show the significant outcomes from the multiple regressions related to RE and RS respectively. Age at questionnaire, age at implant and residing in

Victoria were associated with less RE. Parental expectations of high RE and the child having an additional disability were associated with higher RE (Table 4). Expectations of positive social outcomes and the child using a spoken language communication approach in their educational setting were associated with lower RS. Parents living in a regional/remote location and having expectations of higher RS were associated with higher RS (Table 5).

Insert Tables 4 and 5 about here

QUALITATIVE RESULTS

In the interviews and in the open-ended responses written on the surveys, parents repeatedly used words and phrases such as *hard work, effort, work and time, commitment, dedication, demanding, exhausting, challenges, stress, worry, and sacrifices* that described the type and extent of the rehabilitation demands they faced and their feelings about these. Several major themes were identified in the qualitative findings. These inter-related themes are: a) the assumption by mothers of roles as their children's therapists or teachers, b) the continuing educative and advocacy roles parents needed to undertake in order to inform other people about their children's needs, c) the nature of post-implant services and supports and ongoing difficulties related to the maintenance of the device equipment, and d) the effect of their children's deafness and implantation on mothers' working lives. Most of the direct quotations of parents' words in the following section come from the interviews; where a quotation is from a written response, this is indicated in the text.

Professionalisation of parenting

The qualitative findings indicated that mothers often adopted a role not unlike that of a professional – therapist or teacher - in their daily interactions with their children. In describing her child's Auditory-Verbal Therapy program, this mother said:

There was an awful lot of teaching of the parent to take control of the program and be aware that they were the one to make the biggest difference in the child's language development. A lot of teaching of things....Every day, our whole day really – that was what life was.

Some of the mothers had recognised that this could be detrimental to their relationships with their children, as this comment indicates:

I forgot to be a mother for a long time, I was just a therapist. Taking him here, taking him there, and doing as much therapy as I could. I just lived to do what I had to do, I didn't live to enjoy the beautiful little boy that [name of child] is. I didn't realise that for a long time, because I got so caught up in all the therapy that he had to have.

It was also recognised by this participant's teenage daughter following her reimplantation at age 13:

I don't do any specific lessons with her anymore. When she got to about Year 9, I'd say, she didn't really want a bar of it because she just wanted me to be her mother.

Some parents described effects on the family as a whole or siblings in particular. This mother of two implanted children spoke of the effect on her other children:

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It [having the two children implanted] just impacted completely. It's never been the same, I feel like I'm just starting to recover. It just consumed everyone. The [older] boys get jealous because it's been such a big job for me. I sort of had to say "OK guys, please just hang tight, I'll be back." But you do feel you drop everything and it's all about the ears, definitely the ears.

Continuing educative and advocacy role

After their children started school, the mothers generally continued their attempts to ensure the best outcomes for their children through their own involvement and efforts. Mothers described how they sorted out problems with speech processors and FMs and how they tried to educate class teachers about their children's needs. Asked if there was direct contact between the school and the implant centre, this mother replied:

No, they don't have anything to do with the teachers, like, if a teacher asks me a question I usually go to [name of implant centre] and ask them and then they will tell me and I'll get back to the teacher....I think I shouldn't have to do it in this day and age, but if there's no one there to do it, you know what I mean, I have to do it.

Difficulties resulting from the assumptions and expectations of other people, both within the educational system and in other areas, formed a recurring theme in the qualitative findings. Particularly when children had good speech, people expected them to be able to hear easily. As this mother said:

I think even my parents and my husband's parents still think he can hear everything. Most people think if he's got them on he can hear perfectly well.

Many parents felt that their children's mainstream teachers lacked training in or understanding of deafness and cochlear implants. In a written comment, this mother described her role in educating her child's teachers:

Their expectation when she started preschool this year was that she has the CI therefore she will be just like the other kids and they now express surprise to me that she doesn't seem to hear as much as they expected and they request more info on what to do about it which I have to follow up and request and liaise about rather than it being automatic in the school system.

A few parents mentioned that unrealistic media portrayals of cochlear implants for children were unhelpful and led to a public perception of deafness being "cured" by implantation. This parent explained:

The media perception of it is hard. People think, OK, he's got an implant, he can hear now, he's just a normal child, but they don't realise how much work goes into it and that he's not a regular child.... And people are quite surprised at the amount of time he doesn't wear it because of the rain or the wind or the static electricity, and things like that, nobody knows anything about that.

Similarly, another parent said "It's a lot more than the media portray, they don't portray the ever-ongoing side."

Post-implant services and supports

The necessity to attend appointments – with the cochlear implant team, early intervention centre, and a range of professionals for mapping of the implant, therapy and education - constituted a major demand on families. Not only did these appointments take a lot of

time in themselves, but also they involved, for many families, a great deal of travelling. This travel produced extra stresses, including financial strains, on families. These two parents explained:

I had lots of trips to [name of city], it was exhausting. I had a breakdown, I was just in tears. I could not do the [name of city] trip anymore..... We still have to go there every three months for mapping.

It's highly stressful. Just the whole surgery alone was frightening, and that sort of thing, and we were travelling every week down to [name of city]. That takes its toll because it's five hours each way and we were doing it in one day.

Some families had moved residence to major cities or even interstate in order to be nearer to educational facilities or cochlear implant centres.

A common theme in the interviews, and also mentioned frequently in the open-ended survey responses, was the difficulty of dealing with the implant equipment, as well as managing additional devices such as FM systems. Damage to speech processors, broken cords and coils, and microphone covers was common, especially with curious and active babies and young children. One mother said of her toddler, "He was a machine for breaking parts!" Again, living at a distance from services exacerbated the problem, as this written response illustrates:

We live in [name of region] where it is very hot and humid, the equipment simply cannot stand this environment and is often sent away for repairs. He is often left without any equipment.

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Some parents reported that difficulty establishing stable maps meant a necessity for frequent mapping appointments involving travel to the city; often this led to their children missing a lot of time at school. One mother expressed her frustration in this written response:

Lack of explanation of why my child requires frequent mapping i.e. 6-8 weeks after 3 years implanted. My child still favours the hearing aid ear and often tests that his hearing aid ear is better than the CI ear. I am fearful of the future (when he is an adult) if mapping is a constant requirement.

Parents found it particularly helpful when there was ready communication between the cochlear implant centre and other professionals working with their children; for instance, one parent said that their child's teacher of the deaf accompanied them to sessions at the cochlear implant clinic, and others spoke of a good exchange of information between the implant centre and the school. Parents praised service providers, including cochlear implant clinics and early intervention centres, with statements such as this:

The [early intervention] centre is an oasis. We couldn't have done it without them; they take so much stress out of the situation. They should get more government funding.

However, for some parents the level of ongoing support was problematic, as this written response indicates:

After a couple of years, trying to get information/parts/appointments is quite difficult (from the clinic). Their initial participation is terrific but future follow up seems to be lacking.

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Parents whose children did not do well with the implant or had ongoing problems with the device went through particularly stressful periods. In cases where auditory-oral approaches were not working well and parents moved towards using signed communication, they often lost a support base. Where early intervention centres followed auditory-oral approaches only, families were often unable to continue their involvement with the centre, losing that source of support and needing to try to establish other supports to replace it. When children are not progressing well orally, mothers can feel a sense of personal failure or feel that others are blaming them. One mother whose child's spoken language communication did not develop optimally wrote:

I'm lucky that the [cochlear implant] clinic gave me fairly reasonable expectations, however I know several mothers who have become severely depressed post-implant; there's really too much pressure on mothers to become 'speech therapists' and blame attached when/if the child doesn't meet expectations.

Impact on mothers' working lives

Many mothers said that they had decided not to go back to work, or had left their jobs, because of the extra demands of their children's deafness and cochlear implantation. This mother of two implanted children said:

I made the decision that I would have to be at home. Feed all that information into them, all that language, make sure they got to where they had to be.

Another mother who had to travel an hour each way to the city for appointments said:

Rehabilitation stress in parents of children with cochlear implants

I had to resign from my job to do this because they wouldn't give me time off work and I'm a single mum. You know, it was a big thing even leading up to the cochlear implant, so I resigned from my job.

Other mothers balanced part-time work with their children's habilitation needs, as this mother described:

I look back and I've had days where I've worked, and gone to the appointments in [name of city], and come home and been absolutely exhausted and fallen in a heap, but I'm doing this for her.

It is important to stress that, in discussing their efforts with their children, these parents were not complaining; rather they were happy to do all that they could for their children, and were in fact determined to do so in order for their children to have the best possible opportunities for full and happy lives. Parents often spoke about the positive aspects of their experiences with their deaf children, and parents' feelings of love for and pride in their children were very evident in the interview data. When asked if the cochlear implant experience had been worthwhile for her family, this mother of two implanted children said:

Absolutely, I just love it. It just warms my heart when I hear [name of child] just talk and talk and talk and talk....You just know that they are going to cope better than they would have without it.

DISCUSSION AND INTEGRATION OF QUANTITATIVE AND QUALITATIVE FINDINGS

The multiple regression analyses indicated that certain family and child-related variables predicted parental stress and rehabilitation efforts. The child using spoken language communication approaches in the educational setting was associated with less rehabilitation stress. It appeared from the qualitative findings that a move to the use of Auslan or Signed English entailed issues of finding new supports and services and feelings of failure or being blamed for some parents, at least in the early stages. It was clear in the qualitative findings that parents whose children did not progress as expected with the implant and whose spoken language development was limited went through particularly stressful periods. It is important for service providers to sustain and encourage parents' hopes and to respond with flexibility when children's and parents' needs change over time, particularly when expected outcomes are not achieved and it becomes apparent that alternative strategies and approaches are necessary.

The findings also showed that parents' pre-implant expectations were associated with their experiences of stress. Parents having held high pre-implant expectations of positive social outcomes for their children predicted less parental stress. As well, the parent having had high expectations that the rehabilitation process would be stressful strongly predicted more rehabilitation stress. Overall, these findings could suggest that parents who are generally optimistic have high motivation to dedicate the time, work, and effort needed for optimal outcomes from cochlear implantation for children and may find these efforts more manageable than other parents.

The survey respondents and interview participants represented a wide range of geographical locations, and it was particularly valuable to include the experiences of families living in regional and remote areas. In the regression analysis, living in a regional or remote, rather than major city, location was associated with greater levels of parental stress. Consistent with this finding, a recurring theme throughout the qualitative data was of the difficulties and stress experienced by parents living some distance from implant, rehabilitation, or early intervention services. In Australia, cochlear implantation is undertaken in hospitals in major cities only, and most of the providers of early intervention services for deaf children are based in the major cities, although some have centres or therapists in regional areas. Some provide an outreach service for remote families, usually involving video or webcam conferencing to link parent and child with teachers or therapists. In general, it is more difficult for families living some distance from major city centres to access the ongoing therapy, educational, and implant equipment maintenance services that their children need. Spencer (2004) reported similar problems for some of the Australian families in her study. The findings from the current study suggest that, for the demands and stress on parents to be reduced, it is necessary that the current efforts of cochlear implant centres, early intervention programs, and educational authorities to expand their services to distant locations be continued and extended.

Variables predictive of less rehabilitation effort included the child's current age; the child being older predicted less rehabilitation effort. In addition, the child being older when implanted predicted lower levels of parental stress. These findings are intuitively consistent, as it is likely that parents of older children would be past the most difficult

period of having to adjust to the realities of having a deaf child and learning to negotiate a world previously unknown to them. In addition, a child implanted at an older age is likely to already have some speech and, possibly, some language development through a sign language. In the interviews, parents of some of the children who were implanted after the age of 5 years explained that their children had developed speech quite well in their early years with the help of hearing aids before a further loss in their hearing led to the decision to have a cochlear implant. It may be that the parents of such children would experience fewer demands than are faced by parents of children implanted at a younger age.

It is not entirely clear why being resident in Victoria predicted lower rehabilitation efforts. (No predictor values were found for the states of NSW or Queensland.) An explanation could be that the smaller size of Victoria compared to NSW and, particularly, Queensland meant that parents had easier access to implant, habilitation and ongoing educational services and supports.

Past studies have indicated that the presence of additional disabilities was associated with greater stress in parents of deaf children (Hintermair, 2006; Pipp-Siegel et al., 2002). The current study, however, found an association between additional disabilities and parents' rehabilitation efforts, but not stress.

While the quantitative findings indicated that parents' expectations of the rehabilitation efforts they would make following their children's cochlear implantation did not vary significantly from their experiences of these efforts, their experience of stress was significantly higher than their pre-implant expectations of stress. The qualitative findings revealed more about this, as many parents spoke in detail about the

stress of the decision-making process and the impact on the family of the resources, both personal and financial, that they needed to invest following their children's implantation. The stress associated with gathering information and making the decision to implant was highlighted by many parents, and is reported in more detail in another paper (Hyde et al., 2010). These findings are consistent with those of previous studies which have reported high levels of stress among parents when deciding about cochlear implantation for their children (Burger et al., 2005; Christiansen & Leigh, 2002; Sach & Whynes, 2005; Spahn et al., 2004; Spahn et al., 2003; Weisel et al., 2007).

The qualitative findings showed that mothers devoted large amounts of time and energy to their children's early intervention, cochlear implant rehabilitation, and ongoing mapping appointments. Indeed, most of the mothers interviewed had left work, reduced their hours of employment, or decided not to return to work in order to devote the necessary time to their deaf children. This may have financial implications for some families, as some of the parents described. These findings are consistent with several others in the literature reporting that mothers of children with cochlear implants decided to forego paid work for similar reasons (Sach & Whynes, 2005; Sach et al., 2005; Spahn et al., 2001). There are families for whom financial constraints preclude this parental choice and for whom additional supports may be needed in order to minimize family stress and maximize implant benefits.

The parents interviewed were well aware that the amount of work and time they dedicated to their children's speech and language training was an important factor in their children's progress with the cochlear implant. However, some mothers pointed out that this meant they became more of a teacher or a therapist than a mother to their deaf child,

a situation which could have negative effects on family dynamics (Power & Hyde, 1997).

While parents' dedication to their children's speech and language development is important for children to receive optimal benefit from their cochlear implants (DesJardin & Eisenberg, 2007; DesJardin et al., 2006; Edwards et al., 2009; Kirkham et al., 2009; Nikolopoulos et al., 2004), this "professionalization of parenting" is of concern. It is important for professionals to be aware of this and try to support parents in their role of provider of language input to their children while also encouraging them to understand that sometimes it is alright to "just be a mum."

Mothers also described their continuing involvement with teachers in their children's schools, seeing it as essential to ensuring that their deaf children's needs were recognised and met in their educational settings. Some parents expended considerable efforts on educating other people and advocating for their children's needs. Similar parental efforts have been reported by Spencer (2004) and Zaitman-Zait (2008). The reports by parents in our study that regular class teachers knew little about cochlear implants and their implications for deaf children suggest the need for professional development for teachers and strong links between implant clinics and schools. As Archbold and colleagues pointed out within the UK context, these links are especially important at times of device problems and changes to individual children's technology, as well as changes of the child's school or class teacher (Archbold et al., 2002).

The extent and quality of support in practical, functional ways was an issue for many parents. A common theme in the interview data was the amount of time and effort parents (again, usually mothers) spent on the care and maintenance of the implant equipment, organising repairs of parts, and the difficulties experienced by their children if

repairs or replacements were not immediately available. Similarly, Zaidman-Zait (2008) reported that the everyday problem most frequently cited by the parents in their study involved equipment breakdowns. It was clear in our interview findings that parents greatly appreciated when replacement parts, loaner speech processors, or repairs were delivered expeditiously. It was worrying for parents and difficult and frustrating for their children to be unable to use their implant and thus be without their means of hearing, sometimes for several days in the case of families living long distances from appropriate services.

If, as our findings indicated and researchers and clinicians have suggested, the coping of mothers of deaf children is assisted by personal resources such as their confidence and feelings of self-efficacy in managing the demands involved in the habilitation and language development of deaf children (DesJardin, 2005; DesJardin & Eisenberg, 2007; DesJardin et al., 2006; Luterman, 1999), it is important that professionals nurture these resources in parents of deaf children who have cochlear implants. Ways in which this can be achieved include the principles and skills associated with family-centred practice, which for some time has been the recommended style of practice for families of deaf children (DesJardin, 2006; Luterman, 1999; Roush, 2001). Professionals need to be skilled in basic counselling skills and be able to actively listen to parents' concerns, offer empathic understanding, and work with parents in a collaborative partnership (Luterman & Kurtzer-White, 1999).

Limitations and strengths of the study

Indications of stress and the impact on families of children's cochlear implantation are derived in the present study from parental self-report, and not from clinical measures.

However, commonly used measures of parenting stress such as the Parenting Stress Index (Abidin, 1990, 1995) do not include or reflect particular types of stressors relevant to parents of deaf children and so may have limited usefulness to assess stress in this population (Lederberg & Golbach, 2002). In the current study, the qualitative findings served to increase the relevance of the quantitative findings by enabling a deeper understanding of parents' experiences. As well, the study involved a relatively large sample size compared to other research of parents' perspectives.

As parents self-selected to participate in this study, they may not be representative of the whole group of parents of children with cochlear implants in eastern Australia. It is not possible to know if responding parents differed from non-responders in demographic characteristics. However, the breakdown of socioeconomic level by respondents' postcodes indicated that three quarters of families lived in areas included in the five highest deciles ranking socio-economic advantage and disadvantage (Australian Bureau of Statistics, 2008). The parents who participated in the study may have been better resourced financially and educationally than the whole population of parents whose children have cochlear implants. Issues of stress and coping with the demands of parenting a child with a cochlear implant may be even more problematic for less well-resourced families. Despite the best attempts, the inclusion of lower SES families in this type of survey-based research remains a challenge for future research.

As well, our parent group differed from the Australian population as a whole in its household structure. According to the 2006 Australian census figures, 22.5% of families with children were one-parent families, the remaining 77.5% being families with couples living together, either married or in a de facto marriage (Australian Bureau of Statistics,

2009). Of our study's respondents, 11.9% reported that they lived in one-parent families and 88.1% were in a two-parent household. Single parents are more likely to experience financial hardship and may find it difficult to devote the requisite amounts of time to their children's habilitation, therapy and education needs.

Most of the participants in the study were mothers, and the findings are likely to more closely represent the experiences of mothers rather than fathers of children with cochlear implants. Despite the high rate of participation of women in the workforce that exists today, it seems that mothers of deaf children continue to be the primary providers of daily care and involvement in their children's early intervention and language development activities (Eriks-Brophy et al., 2007). Certainly, it appeared from the current study's qualitative findings that this was the case. The perspectives of fathers, and of other family members such as grandparents, could extend the understanding of families' experiences and it would be beneficial to seek them in future research.

Conclusion

The findings from the combined quantitative and qualitative methods used in this study showed how extensive and life-changing the demands involved in parenting a deaf child with a cochlear implant can be, particularly for families living outside of major metropolitan areas. Perhaps the predominant messages for professionals from these findings are a) the need for understanding and empathy and the skills to convey these qualities to parents; b) the need to build up parents' feelings of self-efficacy and competence in undertaking the myriad tasks involved in parenting a child with a cochlear implant; c) the importance of flexibility in responding to families' changing needs; d) the importance of continuing efforts to provide prompt back-up services in case of equipment

breakdown; and e) the necessity for ongoing communication between the implant centre and children's schools and teachers.

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Table 1. Age-Related Characteristics of Children in Years

	n	M	Range	SD
Age	247	9.42	.67-25.0	4.63
Time since implant	247	6.21	.25-18.0	3.79
Age at implantation	247	3.27	.38-16.42	3.16
Age at bilateral implantation	65	5.16	.63-18.42	4.09

Rehabilitation stress in parents of children with cochlear implants

Table 2. Parents' Expectations and Experiences of Rehabilitation Efforts in Percentages

(*N* = 247)

Sub-scale item		Disagree	Neither agree nor disagree	Agree
My child would need/has needed intensive listening training	Expected	3.3	6.9	89.8
	Experienced	5.0	5.8	89.3
My child would need/has needed less speech training than children who use hearing aids	Expected	68.0	20.1	11.9
	Experienced	60.5	24.4	15.1
I would need/have needed to be heavily involved in communication teaching and practice activities with my child	Expected	2.9	6.1	91.0
	Experienced	4.2	3.8	92.1
I would have to/have had to work a lot (i.e., teach and practise) with my child	Expected	2.4	3.3	94.3
	Experienced	4.2	5.0	90.9
I would be/have been primarily responsible for my child's rehabilitation process	Expected	6.1	14.3	79.5
	Experienced	7.9	13.3	78.8
Professionals would be/have been primarily responsible for my child's rehabilitation process	Expected	50.8	29.1	20.1
	Experienced	45.5	30.7	23.7
My child would need/has needed a lot of family support	Expected	2.5	6.1	91.3
	Experienced	3.7	9.8	86.5

Rehabilitation stress in parents of children with cochlear implants

Table 3. Parents' Expectations and Experiences of Rehabilitation Stress in Percentages (*N* = 247)

		Disagree	Neither agree nor disagree	Agree
The decision to give my child a cochlear implant would be/was extremely stressful for me	Expected	33.6	23.0	43.4
	Experienced	38.9	13.1	48.0
The rehabilitation process would be/was extremely stressful for me	Expected	36.3	22.9	40.9
	Experienced	36.9	22.1	41.0
My level of stress would be/is no greater than that for any other child of the same age	Expected	38.4	22.7	38.8
	Experienced	50.0	14.2	35.9

Table 4. Significant Predictors of Rehabilitation Efforts

Variables	B	SE	Beta	t	Sig.
Child's age in years	-.02	.01	-.20	-3.20	**
Being resident in State of Victoria	-.26	.09	-.19	-3.05	**
Parent expected rehabilitation efforts	.57	.06	.53	9.65	***
Child being older when implanted	-.05	.01	-.29	-4.81	***
Child has additional disabilities	.18	.08	.13	2.17	*

*p<0.05, **p<0.01, ***p<0.001

Table 5. Significant Predictors of Rehabilitation Stress

Variables	B	SE	Beta	t	Sig.
Regional/remote location	.41	.20	.13	2.03	*
Parent expected positive social outcomes	-.16	.07	-.11	-2.36	*
Spoken language communication approaches	-.29	.13	-.14	-2.27	*
Parent expected rehabilitation stress	.74	0.05	.69	14.96	***

*p<0.05, **p<0.01, ***p<0.001