

Children Diagnosed with Auditory Processing Disorder and Their Parents: A Qualitative Study about Perceptions of Living with APD

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Abstract

Background: Negative psychosocial consequences have been reported for children with auditory processing disorder (APD). The current literature surrounding APD does not sufficiently address the emotional and psychological consequences of living with the disorder. It is recommended that data be collected from multiple sources, including the child living with APD. Subjective reports of the perceptions of children with APD and their families have real-life validity and can inform clinical decisions and guide future research.

Purpose: The aims of this study were to explore the psychosocial consequences of APD as perceived by children with the disorder and their parents.

Research Design: Qualitative cross-sectional study.

Study Sample: Thirteen participants were interviewed: six children with APD, aged 10–12 yr, and one parent for each child (in one case, two parents participated in the interview).

Data Collection and Analysis: Semistructured interviews were used to examine the social, emotional, and educational well-being of children with APD. Inductive thematic analysis was conducted to develop themes that illustrated the experiences of living with APD.

Results: Three themes were identified forming a causal network conceptual framework that is reciprocal in nature: (1) external factors, (2) internal problems, and (3) coping. The themes revealed how APD impacted negatively on children's psychosocial well-being (internal problems: covert thoughts, overt behaviors) and described the basis for these outcomes (external factors: environmentally based problems, dissatisfaction with support) and the ability of children and their parent(s) to manage the impact of APD (coping: positive, negative).

Conclusions: The three themes identified in this research provide a novel understanding of the experience of APD. The themes reflect the psychosocial consequences of external factors that are created internally through "thought" and expressed externally through "behavior." Pathways to support positive coping strategies while discouraging negative coping strategies will enable children to overcome problems and improve their psychosocial well-being.

Key Words: auditory processing disorder, child, interview, parent, qualitative research, quality of life

Abbreviations: ADHD = attention-deficit hyperactivity disorder; APD = auditory processing disorder; ASHA = American Speech-Language-Hearing Association; CHQ-PF = Child Health Questionnaire Parent Form; HRQoL = health-related quality of life; SLP = speech-language pathologist

INTRODUCTION

Auditory processing disorder (APD) is a deficit in the perception or processing of auditory input that can result from a number of different etiolo-

gies in the central auditory nervous system (AAA, 2010). APD is associated with a heterogeneous range of difficulties that includes learning, speech, language (including written language, reading, and spelling), social, and related functions that are associated with listening

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problems (ASHA, 2005). Test batteries involve a number of difficult listening tasks that mainly require children to be school age for a definitive diagnosis (Chermak, 2001; AAA, 2010; British Society of Audiology, 2011). Hence diagnosis can be delayed, and children may have developed a number of problems before the need for treatment is identified. In formal testing, children with APD show deficits in a range of areas such as dichotic listening, auditory discrimination, selective attention, auditory memory, and phonological (speech sound) awareness (Chermak and Musiek, 1997; Moore and Hunter, 2013; Glydenkærne et al, 2014). Functionally, these deficits are associated with difficulty hearing in background noise, difficulty following instructions given orally, asking for things to be repeated, distractibility, and reduced rate of information processing compared to peers (Chermak et al, 2002; Barry et al, 2015). Anecdotally, these functional effects have been reported to have psychosocial consequences for the child, but this has not been widely explored in the literature. The American Speech-Language-Hearing Association (ASHA) recommends that professionals should refer to the appropriate specialist if they observe social and emotional difficulties in a child with APD, although these difficulties are not used to diagnose APD (ASHA, 2005). Kreisman and colleagues (Kreisman, 2007; Kreisman et al, 2012) contend that the paucity of research in this area means that audiologists, speech-language pathologists (SLPs), and other professionals do not have complete understanding of the psychosocial well-being of their clients and hence it could be difficult for professionals to know when to refer. Zoppo et al (2015) interviewed young adults (18–30 yr) who were assessed for APD in childhood (between 7 and 16 yr) and reported persisting listening and communication difficulties. They identified four major themes: listening and communication difficulties, participants' sense of self, change, and participation. Zoppo et al (2015) concluded that young adults with a prior referral for or a diagnosis of APD as a child continue to experience auditory processing difficulties across a range of daily situations and that this had a lasting impact on their sense of self. Although the AAA guidelines (2010) recommend the inclusion of a psychologist in the multidisciplinary team, the focus is on assessment of cognitive abilities rather than psychosocial difficulties. Therefore, this study will use thematic analysis to explore the psychosocial consequences of the disorder, including perceptions of children with the disorder as well as their parents.

Psychosocial Outcomes in Attention-Deficit Hyperactivity Disorder and Hearing Loss Quality of Life Studies

Psychosocial is a term used to describe the relationship between the internal (psychological) and external

(social) environments of a person (Macintyre, 2008). Emphasis has shifted away from the medical model of health that is intended to identify the cause of the disorder, toward a biopsychosocial model that describes, assesses, and measures the relationship between the objective health state and the subjective well-being of the patient (Bamiou et al, 2001). Although people with APD can detect auditory information, they struggle to use it effectively, and hence functional and psychosocial outcomes may be similar to those of children with peripheral hearing loss, attention-deficit hyperactivity disorder (ADHD), and/or speech-language disorder (Chermak et al, 2002). Studies have shown that hearing loss is associated with reduced psychosocial well-being and decreased quality of life (Wake et al, 2004; Kreisman, 2007; Umansky et al, 2011). For example, Wake et al (2004) found reduced health-related quality of life (HRQoL) in a study of 86 children (aged 7–8 yr) with mild-to-profound hearing loss. HRQoL was not correlated to degree of hearing loss. This suggests that there can be effects on well-being even when hearing loss is mild. This was further explored by Wake and colleagues in 2006 in a study of that included 55 children with slight-mild bilateral sensorineural hearing loss (Wake et al, 2006). Wake et al (2006) also found the correlation between pure-tone average and overall HRQoL was not significant; however, there was a positive correlation between children's self-reported levels of hearing-related problems on the emotional scale and pure-tone average.

Quality of life can be seen as a struggle between internal factors versus external factors. In a study by Kaidar et al (2003), in which they interviewed children both with and without ADHD, the children without ADHD reported their problematic behaviors to be less within their control than did those without ADHD.

Furthermore, a child or adolescent's sense of self can be affected directly from the disorder itself and also from environmental factors associated with the difficulties parenting a child with a disorder. In a study of adolescents with ADHD using qualitative exploratory design, results suggested that the adolescent's sense of self was distorted and disrupted by external factors, including parental struggle and social role expectations (Krueger and Kendall, 2001).

Parental Report versus Child's Perceptions

Parent reports are often taken into account when diagnosing and making decisions about a child's socio-emotional health. It is important to include in the research whether child and parent reports are congruent. An unpublished study by Sanchez (2005) assessed HRQoL using the 50-item Child Health Questionnaire Parent Form (CHQ PF-50) in 105 Australian children with a diagnosis of APD. The children with APD rated their socio-emotional health as lower than the norm and

their general health as higher than the norm. Parents rated their children with APD as lower than the norm (and worse than the children's ratings) on all subscales except physical function. This is consistent with evidence from other health conditions that parents perceive an illness to have a more negative impact than do the children themselves. For example, Ennett et al (1991) found that parents rated their child's juvenile arthritis to have more effect on competence and self-esteem than did the children themselves. A systematic review by Eiser and Morse (2001) showed similar discrepancies in other studies when parents' and children's perceptions of HRQoL were compared. A possible implication of this discordance between child and parental views is that there could be lower motivation from children participating in intervention for APD than from their parents.

A young child or a child with APD and comorbid language difficulties may have insufficient linguistic skills to understand and respond to questions. Parents often act as a proxy to either substitute or complement their child's answers (Eiser and Morse, 2001; Sanchez, 2005). In both research and clinical settings, it is assumed that the parent/caregiver can give correct answers in relation to their child. Different informants (including children) can differ in their perceptions (Achenbach et al, 1987; Eiser and Morse, 2001), however, suggesting a need for multiple informants rather than simply relying on parental views. Accuracy of parental reports may depend on the domain that is being examined. Achenbach et al (1987) found higher correlations between parent judgments of undercontrolled (external) problems than between overcontrolled problems (internalizing). They concluded that parents are more able to judge external symptoms such as behavior and physical well-being and less able to judge internal symptoms such as anxiety or sadness. This demonstrates the difficulty for researchers who use rating scales on a questionnaire to ensure they are collecting accurate information from participants. The accuracy of the information relies on the participant's ability to recognize internalized problems. Therefore, using qualitative research methods, which uncover latent themes, enables the researcher to gain a more informative and accurate picture of a child's psychosocial well-being.

Qualitative Research

Qualitative methods are becoming more popular for capturing the intricacies of psychosocial health (Markham and Dean, 2006; McCormack et al, 2010). Thematic analysis identifies patterns in text data and provides flexibility, richer descriptive results, accessibility of results for a wide audience, and the generation of unanticipated themes (Braun and Clarke, 2006) that could lead to further research into psychosocial consequences of APD.

McCormack et al (2010) conducted interviews with 13 preschool children with speech impairment (mild to se-

vere) and 21 significant others (family members and teachers) using a phenomenological framework, a method aimed at gaining an understanding of the child and his or her communication partner's experiences. They constructed three global themes encompassing "problems" experienced by participants (i.e., the child's inability to speak properly, the communication partner's failure to listen properly, and frustration caused by the speaking and listening problems) and "solutions" used by participants to overcome the problems (i.e., strategies to improve child's speech accuracy and listener's understanding). This study suggested that success in communication is dependent on the skills of listeners and speakers. Thus, intervention should go beyond the focus on the child and extend into the communication environment.

Elkayam and English (2003) adapted the Self-Assessment of Communication and significant other questionnaires to investigate the attitudes and perceptions of children with hearing loss (12- to 18-yr-olds). Communication difficulties were assessed in a variety of situations on a five-point continuum (Schow and Nerbonne, 1982), and thematic analysis was conducted on counseling transcripts. The five themes identified from interviews with the children were (a) inherent isolation of hearing loss, (b) identity and self-concept, (c) cosmetics and other hearing aid issues, (d) problem-solving, and (e) self-acceptance. These themes may also be relevant to a child with APD because, as occurs for children with hearing loss, children with APD may have situations where their inability to listen and interpret instructions and conversations makes them feel isolated and different. Children with APD may also have concerns about the cosmetics of remote microphone hearing aid devices, the third theme identified by Schow and Nerbonne.

Markham and Dean's (2006) study investigated the quality of life of children with speech and language difficulties and uncovered ten descriptive themes that included environmental factors, outside the child, of specific difficulties experienced each day. The theme "inclusion" identified by Markham and Dean (2006) was based on children's isolation attributed to being different from their peers. This theme is consistent with a theme identified by Elkayam and English (2003) in their study of adolescents with hearing loss; these participants also discussed their isolation in terms of not being understood by their peers (referring to the experience of being hard of hearing and not feeling connected with their peers who did not have hearing difficulties). Markham and Dean (2006) concluded that SLPs should ensure that assessments and interventions reflect both the disorder and the quality of life and well-being of a child affected by the communication disorder. Findings such as these indicate that children and adolescents with communication difficulties are not only experiencing negative feelings but also attributing "reasons" to them and thereby building potentially

unhealthy constructs about themselves around these feelings.

The Current Study

The current literature surrounding APD does not sufficiently address the emotional and psychological consequences of living with the disorder. There is a dearth of information regarding the psychosocial effects of APD. The current study explored the psychosocial consequences of APD as perceived by children with the disorder and their parents. Using semistructured interviews, children and their parents answered questions about the effects of APD on their social, emotional, and educational well-being. An inductive qualitative analysis approach was adopted to identify possible key areas for intervention and identification of functional consequences of APD. Parental interview responses are used to complement and compare the interview data obtained from children with APD about their experiences. Differences were anticipated and are discussed in terms of conflict, diverse experiences, and differences in understanding.

METHOD

Ethics

The study received ethics approval from the University of Auckland Human Participants Ethics Research Committee (Reference 2010/075).

Participants

Thirteen participants were interviewed: six children aged 10–12 yr and one of each of their parents (except for a single case in which two parents participated in the interview). Each participant was interviewed alone. In a bid to protect the identities of the research participants, the children were assigned pseudonyms in alphabetical order with only gender matches: Ava, Brianna, Christine, Daniel, Eddie, and Fletcher. The genders of the participants were evenly distributed, with three females and three males in each informant group (children and parent). The six children had a diagnosis of APD (AAA, 2010) and were sourced through the University of Auckland Clinic. Some were previous participants in a study investigating remote microphone hearing aid systems in children with APD (Smart et al, 2010). The test battery used was as follows: parent interview, dichotic digits test (Musiek, 1983), frequency pattern test (Musiek and Pinheiro, 1987), random gap detection test (Keith, 2000), compressed and reverberated words (65% compression, 0.3-sec reverberation; Kelly, 2007), digit span test from Clinical Evaluation of Language Fundamentals-5 (CELF-5) (Wiig et al, 2013) and masking level difference test (Lynn et al, 1981). Although the chil-

dren all had a diagnosis of APD (performance on at least two of the diagnostic APD tests two or more standard deviations below the norm; AAA, 2010), their individual test results were not available. The children were diagnosed in a clinic that routinely makes management recommendations (e.g., remote microphone hearing aids, preferential seating in the classroom), but these would be implemented via the school and education services and not followed up by the clinic. Potential participants were sent a letter/e-mail with the information and consent forms.

Procedure

The first author carried out all 12 interviews. The children and parents were interviewed separately. Interview times ranged from 36.5 to 48.1 min for children and from 47.4 min to 1 hr 18.2 min for parents. The parent who responded to the request for participation in the study was interviewed, with one exception (Eddie) for whom both parents contributed to the interview. Children were interviewed alone, with a parent nearby but not in the room. As noted by Gardner and Randall (2012), the influence of parents is complex when interviewing children due to the change in power relationships when the parent is present. The presence of parents may hinder or help children to express their ideas. In the current study, the children were separately interviewed in an effort to better capture their experiences and perceptions as distinct from those of their parents. Children needed warm-up questions at the beginning of the interview to establish rapport (e.g., “What school do you go to?”), resulting in more closed-end questions and short answers, whereas adults needed little rapport building and produced long answers with little prompting. Interviews were digitally audio recorded, and the interviewer took notes of any nonverbal gestures that were relevant to the data. Participants were briefly told the aims of the interview and reminded that they could stop the recording at any time. The interviews were conducted in the child’s home, face-to-face, with the order of adult and child interview determined by the child. The home environment was chosen over a neutral environment based on recommendations that best practice for conducting interviews with young people is to ensure the child feels safe and relaxed in the interview environment (Wilson and Powell, 2012). All interviews were semistructured and followed the same question order (although some answers led to additional questions for clarification and extension), with probe questions developed based on the areas addressed in Landgraf et al’s (1999) CHQ-50 (see Appendix). Interviews were transcribed and analyzed using NVivo 8 software (QSR International, 2008).

Data Analysis

The data were subjected to six phases of inductive thematic analysis (Braun and Clarke, 2006). On the

first reading, the researcher identified codes primarily at the surface level and continued to examine underlying ideas at each new reading to create latent themes. A latent theme goes beyond description and produces deeper, more conceptualized ideas (Braun and Clarke, 2006). Codes and themes were compared within and across interview transcripts to maintain an accurate portrayal of the data set as a whole, using the process of constant comparative analysis (Patton, 2002). For instance, the theme of “control” was initially considered, but comparative analysis revealed that it could be incorporated into “internally based problems” because it was identified as stemming from the same codes and causation. During the creation of themes, diagrams were created and redefined as the reviewing process moved from the level of codes to themes.

RESULTS

References, Codes, and Themes

This research used thematic analysis to determine the psychosocial consequences of APD for a child, as perceived by the child and his or her parent(s). The analysis created 1,132 references in the data. Each reference is a unit of meaning that has been coded from the

data. These references made up 29 codes that were collapsed into six subthemes and three themes: (a) external factors, (b) internal problems, and (c) coping (Figure 1). Each theme was made up of two subthemes, and each subtheme had a reciprocal relationship to the other subtheme (as shown by the rotating arrows in Figure 1). For example, in the theme “internal problems,” there are the subthemes “thought” and “behavior.” The indexing codes for behavior, such as “emotional responses,” directly impacted children’s behavior, as shown by the code “losing control.” Thus the codes were condensed to make up one theme. The themes formed a reciprocal conceptual framework with balancing codes (Figure 2). Balancing codes are also known as negative cases and are defined as coded units that contradict the subcodes (Markham and Dean, 2006). For example, one code was labeled “misunderstood by others,” with numerous references relating to misinterpretation; however, seven references demonstrated instances where parents understood their children (balancing code: “parent understanding”), providing a pathway for balancing the data.

Theme One: External Factors

This theme reflects the thoughts and behaviors of others that caused concern or were barriers to a child’s

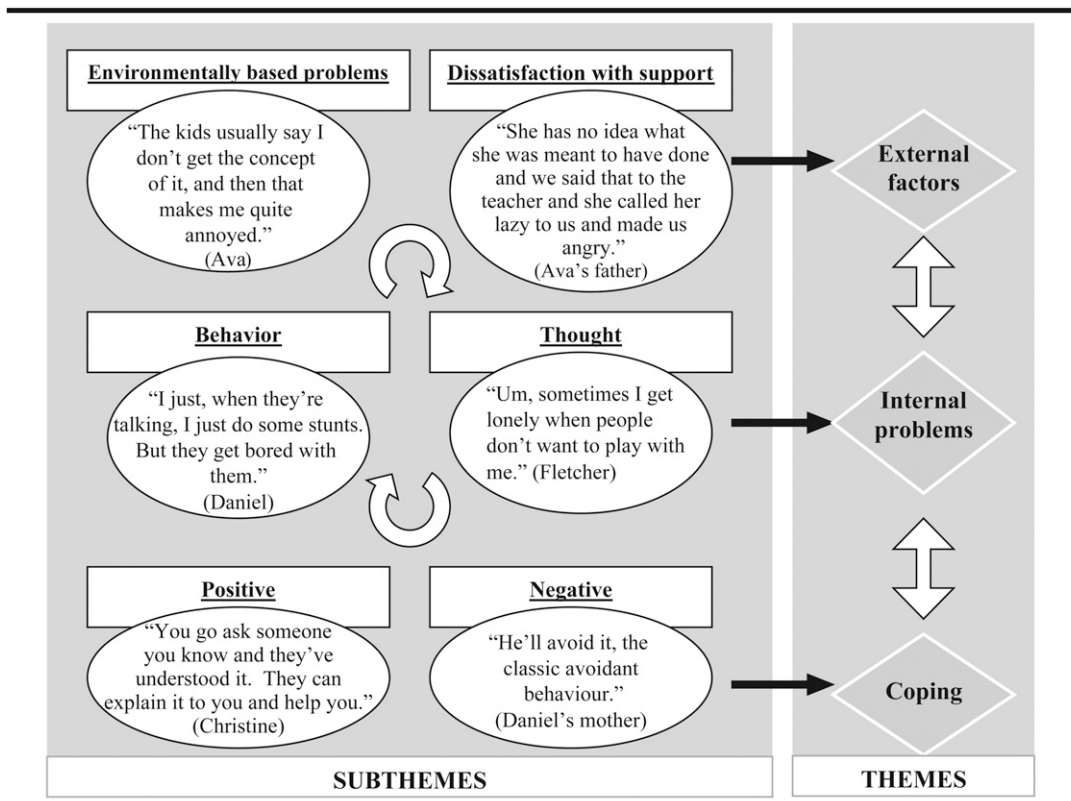


Figure 1. A model showing the causal network and conceptual framework of the three main themes. Each theme was further illuminated by subthemes that consisted of codes and balancing codes. The core themes and subthemes are illustrated by excerpts from the interviews.

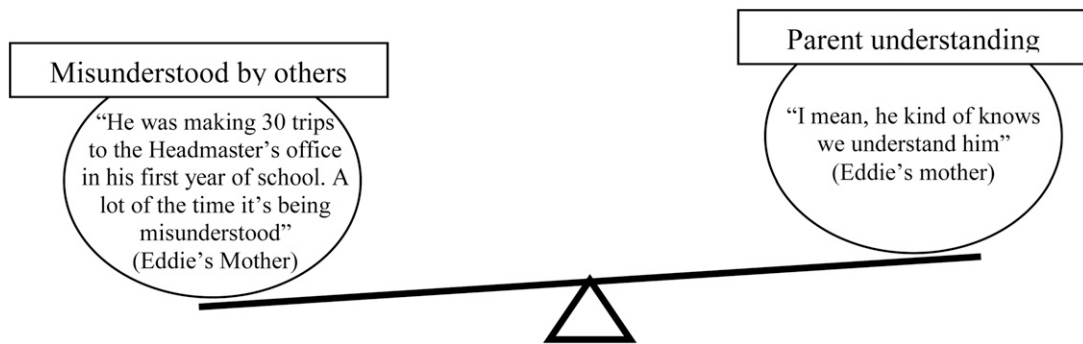


Figure 2. Example of the code “parent understanding” balancing the code “misunderstood by others.”

emotional, educational, or social progression. “Environmentally based problems” and “dissatisfaction with support” were distinguished as two subthemes.

Environmentally Based Problems

These were problems outside of the child’s control. The majority of adults and children identified three factors that compounded the effects of APD: noise, new situations, and length of instruction. These difficulties were exacerbated by the behaviors of others and the perceived rigidity of the school system. Lamenting the lack of flexibility that the school system has to accommodate her child with APD, Brianna’s father stated,

She often doesn’t take in what you’re saying and the natural thing to do is to repeat, to repeat, to repeat, to repeat and it’s not getting through and she didn’t cope with the general system of learning because the school system . . . has to work that way, as one system and one system only. (Brianna’s father)

Adult/peer exclusion from friendship groups and educational opportunities was described as an effect of APD. Parents noted that the struggle to hear and keep track of conversations meant that the children had difficulty forming friendships and following class instructions. This was corroborated by the child’s experiences in the playground; for instance, “This boy—he shouts really loud but I can hardly hear him. Cause like it goes ‘whoosh’ right past me that I can’t hear it properly” (Daniel).

Parents reported hopes of whom they would want their child to socialize with, which in some cases differed from the realities of whom the child was actually socializing with:

The funny thing is that when I look at [Ava] with her friends at school there’s three of them, a little gang of three and I haven’t told her this but I call them the outcasts because really when you look at it, [Ava] gets on with a lot of kids at school there and she could pretty much play with anyone but she plays with [name] who is a [ethnicity] girl, really nice girl, but doesn’t get on with anyone else in the class. So she’s an outcast

and then the other one, again a very nice girl, but she was held back for a year and she’s got [condition]. So that’s their little gang of three and it’s quite an oddball little mix but, hey, if it works, it works. (Ava’s father)

Parents admitted that their thoughts might not be as concealed as they would like them to be and that this could lead to negative emotional consequences for the child, such as anxiety and frustration. “He was frustrated that people were not understanding him and hearing his case and he could see that Mummy and Daddy were pretty upset and it was gutting” (Eddie’s mother).

Children and parents reported a moderate amount of bullying; there were 23 references in the data to bullying. For example, Eddie reported a high amount of misunderstanding and teasing by other children, particularly surrounding his specific interests and negative behaviors. All children demonstrated awareness of negative adult and peer interpretations of themselves, even if it was not through bullying. For instance, Eddie disclosed his awareness in words, and his emotion through body language (looking down) and verbal behaviors (using fillers and speaking softly) when commenting that “everyone called me the, um, the naughtiest person in the school.”

Dissatisfaction with Support

Participants observed the dichotomy between “too little” and “too much” support given to their children and discussed the consequences for each. The frustration of “too little” support primarily revolved around education. The children perceived certain teachers to be disinterested in them, and they felt ignored. Parents reported that the school and professionals should provide extra support and had experienced situations where a dearth of support created anxiety and barriers to their child’s success. Children recognized the difference between a “bad” teacher and “good” teacher as how much support and time the teacher gave them. “The teacher would not help me. She would go off and help the people who are already started and going well” (Christine). Several parents attributed the paucity of

support to the school system, citing teacher load and an increase in diagnosed children. They expressed their disappointment but also accepted that this was the way the system often worked, saying that “things get done the way they get done” (Fletcher’s mother). Some parents reported that it was certain teachers in particular who were barriers to their child’s progress. One teacher was compared to “racists” who divided the class into the “elite” and the “difficult.” Parents talked about laziness of some teachers and how their rigidity contributed to their child’s negative emotional well-being:

I mean it’s like, for yourself, in the sense of if you’ve, you know, you haven’t heard something correctly—“Oh, you silly child, you’re stupid, you’re dumb” and all the rest of it because she has got no consideration for children with different learning. (Brianna’s father)

Some parents had a more relaxed attitude about support, however, and made fewer comments concerning their child’s emotional well-being at school. Other parents were more concerned about their child’s participation in school educational and social activities. Children expressed an appreciation for teachers that did not single them out or become angry with them. They considered strict teachers to be satisfactory as long as they were consistent with the class. Parent reports corroborated this perception: parents noted that their child would shut down if the teacher did not explain why the child was in trouble:

Through the new teacher we’re not getting constructive teaching and so she (Brianna) is getting told off and that telling off is damaging her confidence and shutting her down. She doesn’t like the teacher so she doesn’t—she’s not learning as well as she has. With the teacher we have got currently, it’s “not completed, not done, see me!” Well, that’s hopeless because there is no direction. What do you mean it’s not completed? I don’t understand. Whereas, the previous teacher would say, “Come here. This is what you’ve got to do. You haven’t finished this and you need to do this, this and this.” She understood exactly and so that sort of trouble is different and it was constructive trouble. (Brianna’s father)

Participants did acknowledge good teaching where it was deserved, which created the balancing code “support of professionals.” Parents expressed many theories about why a teacher was satisfactory, including structure of discipline, gender of teacher, and coordination with parents. When asked why they liked a certain teacher, the children’s answers were simple, yet revealing, indicating that patience and understanding were appreciated. For example, Eddie answers, “Well he doesn’t get really angry with me.” All parents actively involved their children in activities outside school specifically to combat the consequences of APD. These ranged from audiologist-recommended programs based at the listening and language clinic to certain sports, for example, karate (two parents were recommended this for hand–eye coordination).

A majority of parents had entered their children in more than two activities targeted at treating APD. For the children, the amount of work imposed upon them caused fatigue and sense of restriction:

Oh, well I kind of didn’t want to do it because we had to do it in the morning and the night so we had to do two things each morning before school so I had to wake up early and do all of that and have my breakfast and get ready. (Ava)

In contrast, parents also expressed concern that “too much” support given to the child meant that the child was not learning for him- or herself. Parents were very aware of their own need to let the child be independent but acknowledged that at times this was overcome by a need to get things done or reduce child anxiety. Children picked up on the fact that they had access to support, and some revealed that they knew how to work the system to achieve results easier and reduce workload:

Sometimes with my maths. My mother emailed the maths teacher and she said that if she gives me a sheet and I say, “Oh this is too hard I can’t do it,” but then when I’m at my maths class I can do it. (Ava)

Theme Two: Internal Problems

This theme encompasses the thoughts and behaviors experienced by the children with APD in their communication environment. Internally based problems were expressed as covert “thoughts” and overt “behaviors.”

Thoughts

This subtheme concerned the process of internally constructing problematic perceptions of themselves through comparison to others, increasing awareness of their problem, and responding emotionally to peer and adult attitudes toward themselves. A high state of anxiety was expressed by the children and described by the parents:

Um, worried about how he’s going to deal with a situation. Worried about what someone’s going to think. Worried about whether he’s going to get in trouble, maybe. Worried about, um, you know, how he’s going to cope with people looking at him. (Eddie’s mother)

Anger and frustration were other emotions that were commonly described. Frustration often resulted due to the consequences of APD. For example, two children (sisters) had difficulty with listening to tapes of time-tables that they had to memorize, and they expressed frustration at having to repeat the tape over and over at the same spot. At times the children could not express these thoughts verbally, and so they did so through “behavior.”

Behavior

The two common ways in which children lost control of their emotional responses were through tantrums

(for one child occurring four to five times a week) and aggression, for instance, “She has a meltdown, cause it’s the frustration more than anything so we know now not to interfere and she calms down and we just go back to scratch and do it again” (Christine’s mother).

The practice of “self-imposed exclusion” was a common topic. This was caused by the children’s need to “get away” and protect themselves from rejection. Despite this, children often expressed their enjoyment of “belonging.” This indicates a balancing act between avoiding emotional pain and the pleasure of social engagement.

The balancing code of “belonging” is further expressed by the children’s awareness and distress of being excluded by their peers; they conveyed a keen sense of wanting to belong:

If someone asks me to go [to a sleepover] I would say yes but sometimes . . . if I ask them to go they sometimes say, um, no. *Interviewer: They can’t come. Why do you think that is?* Well, no they can come but they don’t really want to. (Eddie)

The functional consequences of having APD produced problematic learning attitudes and behaviors. The most significantly mentioned behaviors were “zoning out,” forgetting instructions, fatigue, and taking longer to achieve results than other children:

Um, just you’re constantly reminding them and when you have friend’s kids or family’s kids, you know, they can do 3 or 4 tasks. You ask them to go brush your teeth, go do your hair, make your bed and they will go and do it. Whereas he gets half way up the stairs and he’s like, “What am I doing?” (Daniel’s mother)

The older children were more aware of their emotions and the consequences of APD. While maturity meant that aggression and negative emotional responses were less observable, the emotions were still present and expressed in increasingly covert behaviors: for instance, Brianna’s attempt to control emotions was recognized by her father: “Oh yeah. You can see how intense it really is when she’s holding the pen. It’ll almost break.”

Theme Three: Coping

This category concerns the process of coping with the external factors and their subsequent psychosocial outcomes. The subcodes in this theme have been categorized into positive and negative strategies. A number of codes have been acknowledged that are negative mechanisms (e.g., defensiveness and avoidance). Lazarus and Folkman (1984) argued the existence of negative coping strategies and defined them as “negative” because of their contribution to internally based problems and participation.

An example of a negative code denoting poor coping mechanisms was labeled “releasing hostile feelings.” Adults referred to this code more than children.

We had a bit of unhealthy behavior in touch rugby . . . this girl was intimidating a couple of the other girls and so [Christine] dealt with her. She intimidated her. She gave her a thump in the chest and, like, don’t you push me around. . . . (Christine’s father)

Positive coping behaviors deal with the problem through adaptation by the child and their communication partners, seeking support, creation of accommodating relationships, and management of hostile feelings. There are many examples of children, parents, and their teachers creating strategies to enhance learning and positive self-image. For instance, Brianna’s father played a large role in his child’s education. When discussing the child’s difficulties with handwriting assignments, he stated, “Well, we, the school changes the rules sometimes and I said to the teacher, ‘Well, just let her type, just let her type.’”

The children created friendships that complemented their social abilities and also gave them a sense of control. Parents acknowledged that children were drawn to others who had diagnosed disorders, such as autism spectrum disorder or apraxia, and at times awarded negative perceptions to this. Children described how friendships created positive emotions and appreciation by saying things like, “He understands me” (Eddie) and “She helps me” (Christine). Therefore the negative perceptions of this coping strategy have been coded under the “negative” theme, whereas the positive perceptions have been coded under the “positive” theme.

Children’s recognition of their own self-worth meant that they could focus on their strengths rather than weaknesses. Interestingly, mathematics was established as a favorite subject of five out of six children, who attributed their success and the subject’s structured learning style. Parents also adopted the approach of focusing on the success of their child, and the adaptation of their goals and values became apparent as the interviews progressed. This exemplified the human ability to adjust to situations by constructing their subjective view of their own, and their child’s, world based on previous experience:

Just, all in all, all we had ever hoped for was an average child and we’ve got that. The APD was a little bit of a setback, I suppose, um, but then, as I said I remember when I was a kid I didn’t really do much until I hit Standard 4 [the final year of elementary school, usually age 11 years in New Zealand]. (Ava’s father)

Parent versus Child Answers

Results from the analysis of parent report compared to child report showed that parents’ answers contained more depth and length. There were 32 codes that showed the parent and child’s answers directly disagreeing (see Table 1 for example of a code that disagrees). The codes that directly disagreed were almost all about the positive

Table 1. The Length, Depth of Coding, and Example Quote Statements That Demonstrated Agreement vs Disagreement, and Number of Codes That Agreed and Disagreed

Variables	Child	Adult
Length: <i>Longest answer (words)</i>	244	640
Depth: % of references coded within the themes	34%	66%
Agreement: (example) <i>Fletcher and Fletcher's mother</i>	"I think I've got fine hearing but I don't."	"No, no he knows he has auditory processing and it's not his hearing it's that information in between where he hears it and how it's interpreted, but I think he really perceives it now as not an issue."
Disagreement: (example) <i>Fletcher and Fletcher's mother</i>	"I know what it means but it doesn't make, I mean all my other friends, well one of them does have dyspraxia, like, and I don't see what the difference is."	"I think if he doesn't quite get the marks . . . that his friends get. I think that makes him, not anxious, but just kind of concerned why he can't do it."
Number of codes that directly agreed		17
Number of codes that directly disagreed		32

perception a child had for his or her friendship with another child with a disorder versus the negative perception the parent had toward the same friendship. There were only 17 codes that directly agreed (see Table 1 for an example of a code that agrees). Therefore, there are more codes that disagree than agree.

DISCUSSION

The main objective of the current study was to investigate the psychosocial status of children living with APD by interviewing children and their parents. An important outcome of identifying psychosocial consequences of APD was to establish possible key areas for intervention. Previous literature reported that living with a communication disorder has negative effects on HRQoL (Elkayam and English, 2003; McCormack et al, 2010). This is consistent with the current findings. The themes revealed how APD impacted negatively on children’s psychosocial well-being (internal problems) and described the basis for these outcomes (external factors) and the ability of the children and their parents to manage the impact of APD (coping).

The relationship between themes was reciprocal (Figure 1). Participants described internal problems caused by external factors (e.g., length of instruction → zoning out) and internal problems contributing to external factors (zoning out → difficulty forming friendships). They also described the approach used to resolve and cope with these problems, if negative, to actually contribute to internal problems (avoidance → isolation). Thus, a negative spiral was created. A factor that broke this cycle was identified as “positive” coping mechanism. For example, children created friendships that complemented their social abilities and gave them a sense of control. Children described how these friendships cre-

ated positive emotions and described them as “he understands me” (Eddie) and “she helps me” (Christine).

Comparing Parent and Child Answers

Previous research found that children with APD had lower perceptions in certain psychosocial dimensions than other populations of children (Kreisman et al, 2004; Sanchez, 2005; Kreisman, 2007); however, these quantitative studies did not describe specific difficulties leading to psychosocial problems. To our knowledge, no previous APD research has interviewed children to gain their subjective perspective on social and emotional consequences. Parent answers were used to complement the child’s responses in line with research that showed evidence of comparative differences between child and adult perceptions of the child’s HRQoL (Achenbach et al, 1987; Ennett et al, 1991; Eiser and Morse, 2001). The data contained examples of parent/child agreement and disagreement that supplemented the evidence toward creating certain codes (Eiser and Morse, 2001). For example, Fletcher demonstrated a number of instances where he made it clear that he did not perceive having a problem, yet admitted to difficulties caused by APD at other points in the interview, suggesting denial and defensiveness. His mother noted that APD clearly caused problems, but that he would not consider it a problem. The results from the agreement versus the disagreement of parent and children’s codes lends qualitative support to previously published data that see parent report to be different than children’s report in the CHQ-50.

Psychosocial Consequences

The current study’s findings translate well into Macintyre’s (2008) definition of “psychosocial” as the relationship between a person’s internal and external

environments. A review of related literature, in the absence of any published or thematic psychosocial studies in the field of APD, exposes a number of similarities with the current study.

Internal Problems: Thoughts and Behaviors

A common theme of “isolation” in Elkayam and English’s (2003) and Markham and Dean’s (2006) studies relates to the current study’s findings. Elkayam and English (2003) reported the theme “inherent isolation of hearing loss,” which expressed the impact of hearing loss on participation. Two parents interviewed in the current study commented that their main concern was their child’s lack of participation; one parent noted that her child was a loner but was not overly concerned about it, and another parent expressed curiosity as to why his child chose to mix with “outcasts” (Ava’s father).

The most apparent reason children chose to isolate themselves from situations and peers was to escape immediately painful or difficult situations, for instance, a child who played by himself at birthday parties to escape the noise. Another possible reason was preventative self-protection. This is one way for a child to take control and avert any possible instances of exclusion by others, for example, by choosing activities that are not team based. Peers of the child/adolescent may fail to understand and relate to his or her experiences and the emotional responses that are provoked, such as frustration (Elkayam and English, 2003; Markham and Dean, 2006). In the current study, comments around anger and frustration were made regarding the formation of friendships and comparison to peers. Children demonstrated insight into their difficulties when comparing themselves to their peers. Parents discussed the elusive “cleverness” that peers possess (Fletcher’s mother) and the concern and frustrations of the children with APD who feel that they put in more effort than others and achieve poorer results even though they “work, work, work” (Daniel’s mother).

Eddie’s comments revealed feelings of loneliness and frustration due to difficulties forming friendships. His parent’s corroborated his comments by explaining how he used to have them ring up child after child until someone would play with him, or until the list ran out. Interestingly in this case, both parent and child revealed that this was in the past and that he now appreciates having a small group of friends. However, age-related social sensitivity has been reported in nonverbal behavioral studies, which suggests that at the age of 12 yr, children’s awareness of others’ perceptions of themselves may alter their behaviors rather than change their values (Overton and Gallagher, 1977).

Expression of covert thoughts and emotions were noted. Behaviors that revealed these controlled attitudes were sleeplessness, crying, tantrums, physical tension, avoidance, and shyness. Elkayam and English’s “identity and self-concept” theme addressed children’s own

perception of themselves and how they believe others perceive them. Behavioral expressions such as shyness and avoidance were rationalized by parents in the current study, for instance, “She doesn’t want to appear the stupid kid” (Ava’s father).

All children were aware that they had a “listening” or “hearing” problem but did not specifically identify it as APD. For example, “It’s loud and everything and I just don’t like it” (Brianna), “My eyes get fuzzy and my ears get really fuzzy and I can’t really hear and see when she’s writing on the board” (Christine), “I don’t really like writing ’cause I know I spell most of it wrong” (Ava), “. . . constantly have to look in the dictionary . . . they all look the same and they all sound the same” (Ava). Similar level of awareness has been reported in previous studies investigating communication experiences of children. For instance, the McCormack et al (2010) study revealed that only one in 13 children were aware of their speech disorder. In the current study, all acknowledged that they had it. Reasons for this distinction may be the age difference between McCormack’s participants (4 yr 1 mo to 5 yr 9 mo) and the current study’s participants (10 yr 4 mo to 12 yr 3 mo).

These results encourage audiologists, SLPs, and other health professionals to be more aware of hidden psychosocial consequences when assessing a child, refer appropriately when psychosocial problems are identified, and provide more information on this topic early in the diagnosis to parents and children, as is required by client-centered practice (Stewart, 2001).

External Factors

A novel but not surprising discovery in terms of APD research was the perception of unsatisfactory support. This encompassed “too much” as well as too “little support.” References to “too much” support reflected two key ideas. First, children and parents were fatigued by extramural activities that created pressure and extra work. Second, parents criticized themselves when admitting their part in their child’s learned helplessness. Children admitted using the extra support to make their life easier. References toward “too little” support were based on individual teachers’ rigidity and the educational systems that were perceived as unyielding. The three major environmental factors—noise, new situations, and length of instructions—identified as contributing to functional consequences of APD correspond with functional difficulties reported by Musiek and Chermak (1995). The numerous substantiating comments from children and their parents demonstrated the pervasiveness of these factors and their contribution to psychosocial consequences.

Coping

In response to external factors and the resulting problems that they caused, both children and their

parents had developed strategies to cope with APD. The solutions that the children had were not always productive. For example, defensiveness and avoidance can lead to greater problems in the future. The evidence from this theme is useful for professionals when considering interventions. Adults identified positive strategies that adapted the environment in their home, for instance, doing homework in front of the parent. They also introduced solutions at school such as having meetings with the teacher to discuss specific needs of the child. Furthermore, parents enrolled their children into after-school activities and classes that would support their children's social, educational, and emotional well-being and adapted their parenting style in order to best support their children. These reports corroborate McCormack et al's (2010) strategies used to improve the listening and speaking environment for children with speech and language disorders. Similar to McCormack et al's (2010) findings, children and adults in the current study noted that speakers often had to repeat themselves in order for an instruction to be acted upon. However, many times repetition did not produce the desired response, and communication partners became frustrated. Reports from nearly all participants indicated that breaking up sentences into manageable pieces (chunking) and writing them down were successful techniques for following instructions, as recommended by Chermak and Musiek (1997) as a compensatory strategy for poor auditory memory. Chermak and Musiek also recommended specific techniques for other functional deficits, such as using remote microphone systems for children who are distractible. Two children in the current study reported use of a remote microphone system. One child discussed the "ear things" (Eddie) to be a turning point with his behavior and attributed their implementation to why he was not naughty anymore. The second child used them as a trial for a study and did not mention their benefits within the interview. The results for this theme encourage the promotion of positive coping techniques and discouragement of redundant techniques, such as teachers repeating the same information, even when a child does not respond. Acknowledging the basis for negative coping techniques, such as avoidance due to discomfort and self-protection, can help professionals work with families toward developing better techniques.

Limitations

The following issues are thought to have limited this study. First, it is important to acknowledge that there is contention among professionals as to what the test batteries are really measuring (auditory, memory, language, executive functions) when testing children for APD (Dawes and Bishop, 2009). However, children in the current study who performed poorly on these tests

are having a common group of difficulties that impact their psychosocial well-being. Second, due to a small sample size it is not possible to determine if all reflections of participants can be generalized to the population of children with APD, so caution is required when interpreting these results. Third, more complete access to files and a larger potential participant pool would mean that children with reported comorbidities could be identified and excluded in the future. This would result in a clear distinction that the participants' reflections were not characteristic of other disorders. Fourth, only one method of data collection was used in this study, so we could not triangulate our findings with other methods of data collection such as direct observation and questionnaire. This is a preliminary investigation, and future research that includes additional qualitative research methods would be illuminating.

CONCLUSION

This research provides a novel understanding of the experience of APD and identified three interrelated themes: (a) external factors, (b) internal problems, and (c) coping. External factors such as "environmentally based problems" and "dissatisfaction with support" contributed to negative psychosocial well-being. The psychosocial consequences of APD as perceived by children and their parents are constructed as internal thoughts and expressed by the children as explicit behaviors. Therefore the coping strategies discussed by children and their parents are critical in the facilitation of a harmonious socio-emotional relationship. Negative coping strategies need to be recognized and positive strategies should be promoted early in the intervention process. Teachers and parents need education and support to ensure that children's well-being is monitored, particularly as the children enter adolescence.

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APPENDIX
Interview Probe Questions

Adult

1. Can you tell us about your experiences with having a child with APD?
2. Can you tell me about your child's hearing and listening?
3. How did the diagnosis happen? (When did it happen?)
4. What do you understand about the results of the testing?
5. Has your child had treatment for APD—can you tell me about this?
6. Has your child seen other specialists or had other diagnoses?
7. What sort of activities is your child in—has your child been limited in what they do by their hearing/listening/APD?
8. Has your child shown difficulty/avoidance with any activities because of behavioral/emotional difficulties?
9. What things make it more difficult for your child in social situations?
10. What sort of personality does your child have?
11. How is your child in social interactions?
12. How do they feel about their self-image?
13. How much of the time do you think your child: felt lonely, acted nervous, bothered or upset?
14. Can you tell me about your child's attention, behavior, school experience, friends, compared to other children the same age?
15. What are their relationships like: friends/family/teachers?
16. What are the things you have noticed mostly about how APD affects them?
17. How APD affects education?
18. Has your child shown difficulty/avoidance with schoolwork because of emotional difficulties?
19. What things help/make more difficult in school situation?
20. How is your child at the beginning of the day?
21. How is your child at the end of the day?
22. How does your child react to change/new things?
23. Is there anything else you want to tell me about your child with APD?

Child

1. Have they had their hearing tested?
2. What happened?
3. What do you understand about your diagnosis?
4. In general, how would you rate your hearing/listening/attention compared to your classmates and friends?
5. What is school like for you?
6. What helps you to listen/learn/get along with people?
7. What makes it difficult?
8. Is there anything you avoid or have problems with because of your hearing?
9. Has it been difficult to do certain kinds of activities with friends because of problems like feeling sad or worried? Can you tell me about these activities?
10. What do you do with your friends or family?
11. What do you like and what is difficult about social times?
12. Is it difficult to spend the usual amount activities with friends; or do activities with friends?
13. What things help in social situations, in school, at home?
14. Do you use anything to escape from social situations (e.g., reading/TV/playing alone/computer)
15. How much of the time do you felt lonely, nervous, bothered or upset?
16. How often do you argue with parents/friends/siblings?
17. Do you get told off a lot at home/school? Why do you think that is?
18. What are their relationships like: friends/family/teachers?
19. How has your hearing/listening affected school for you? (What's good about school/what's not good about school)?
20. Has it been difficult to do certain kinds of schoolwork because of problems like feeling sad or worried?
21. Does it take longer to do schoolwork than your friends, or get schoolwork done at all?
22. What things help/make more difficult in school situation?
23. How do they feel at the beginning of the day?
24. How do they feel at the end of the day?
25. How do they react to change/new things? (What it's like to change class at the beginning of a new year, exciting/anxious)?
26. Is there anything else you would like to tell me?