



Social and Emotional Needs of Parents of Children with Childhood Apraxia of Speech

Katelynn Carroll and Megan Overby, PhD
The College of Saint Rose, Albany, New York

Introduction

Counseling families of children with communication disorders is an important role of speech-language pathologists (SLPs) (Crowe, 1997). Counseling is a venue for clinical information while encouraging families to express emotions in a supportive environment (Roth & Worthington, 2005). It encourages clients and families to make positive changes in their behaviors and attitudes toward the diagnosis.

Several studies have examined the needs of parents of children with specific communication disorders, such as autism spectrum disorder (Altieri & Von Kluge, 2009; Lucyshyn et al., 2007). Feelings of grief and anxiety are common among parents of children with diagnosed communication disorders; however, no studies have examined the social and emotional needs of parents of children with childhood apraxia of speech (CAS). Understanding these needs could enable SLPs to provide improved services to clients and their families.

This study was designed to address the following questions:

1. What are the social and emotional needs of parents of children with CAS?
2. How do SLPs hinder the experiences of these parents?
3. How do SLPs facilitate the experiences of these parents?

Methods

To identify questions for a pilot survey, we posted the following question on the Facebook page of the Childhood Apraxia of Speech Association of North America: "What common issues are faced by parents of children with CAS?" After 3 days, responses (74) were collected and a phenomenological analysis (Creswell, 1998) conducted. Thirty themes fell into four categories of concern (school, parent, child, society). Inter-rater reliability was calculated with three speech-language pathology graduate students from a local college. Disagreements were discussed, data reanalyzed (categories, .90; themes, .90), and a pilot survey derived. The survey was piloted with three parents; no significant changes were necessary.

Survey.

Thirty-four administrators of web-based support groups for parents of children with CAS in 20 states were invited to post the survey (1 qualitative and 23 quantitative questions), available via Survey-Monkey (www.surveymonkey.com), on the group's website.

Participants were 60 parents (59 female, 1 male; X age = 31-40 years). All participants self-identified as White (Non-Hispanic). English was the most common primary language used at home (98.3%). Most (94.9%) participants were married. A large majority of respondents (36.7%) and their spouses (28.8%) had completed a graduate or professional school.

A majority (41.7%) of the parents' children (40 male; 20 female) were 3-5 years of age. They were most often first diagnosed by a speech-language pathologist (74.6%) and had been diagnosed for three or more years (40.0%). Thirty-eight respondents noted their child had one or more concomitant disorders; developmental delay was reported by 52.6% of parents.

Quantitative Results

Table 1
Selected Parental Perspectives on Adequacy of Diagnosis and Treatment of CAS by SLPs and Medical Professionals

Issue	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
It was easy to get a diagnosis of CAS	11.9%	22.0%	15.3%	23.7%	27.1%
My child receives enough hours of speech therapy per week	6.8%	18.6%	8.5%	35.6%	30.5%
My child receives appropriate therapy approaches for CAS	15.5%	29.3%	22.4%	22.4%	10.3%
School personnel are knowledgeable about CAS	0.0%	12.7%	29.1%	21.8%	36.4%
Medical professionals are knowledgeable about CAS	1.7%	15.5%	12.1%	43.1%	27.6%
SLPs provide adequate emotional and social support to caregivers	6.8%	27.1%	25.4%	22.0%	18.6%
SLPs provide sufficient information about CAS to caregivers	11.9%	30.5%	28.8%	13.6%	15.3%
SLPs provide useful and accurate information about CAS to caregivers	6.8%	27.1%	25.4%	22.0%	18.6%

Results indicated that both medical and school professionals were not perceived as knowledgeable about CAS, although parents appeared to have more negative feelings associated with school than medical personnel. SLPs, however, appeared to provide sufficient information to parents which was perceived as accurate and useful. More parents agreed than disagreed that therapy approaches were appropriate, even though most said SLPs did not provide enough hours of therapy. Only 1/3 of parents noted that SLPs provided sufficient emotional and social support.

Quantitative Results

Table 2
Selected Rankings of Concerns, Emotions, and Support System Availability by Parents of Children with CAS

Ranking	Concerns about parenting a child with CAS	Percentage
(1) Most Important	Concern about child's future	57.6%
(2)	Concern about child's future	15.3%
(3)	Self doubt about parent's ability to help child	19.3%
(4)	Getting insurance covering AND Finding professionals for child	16.7%
(5) Least important	Unwanted advise from others	15.2%

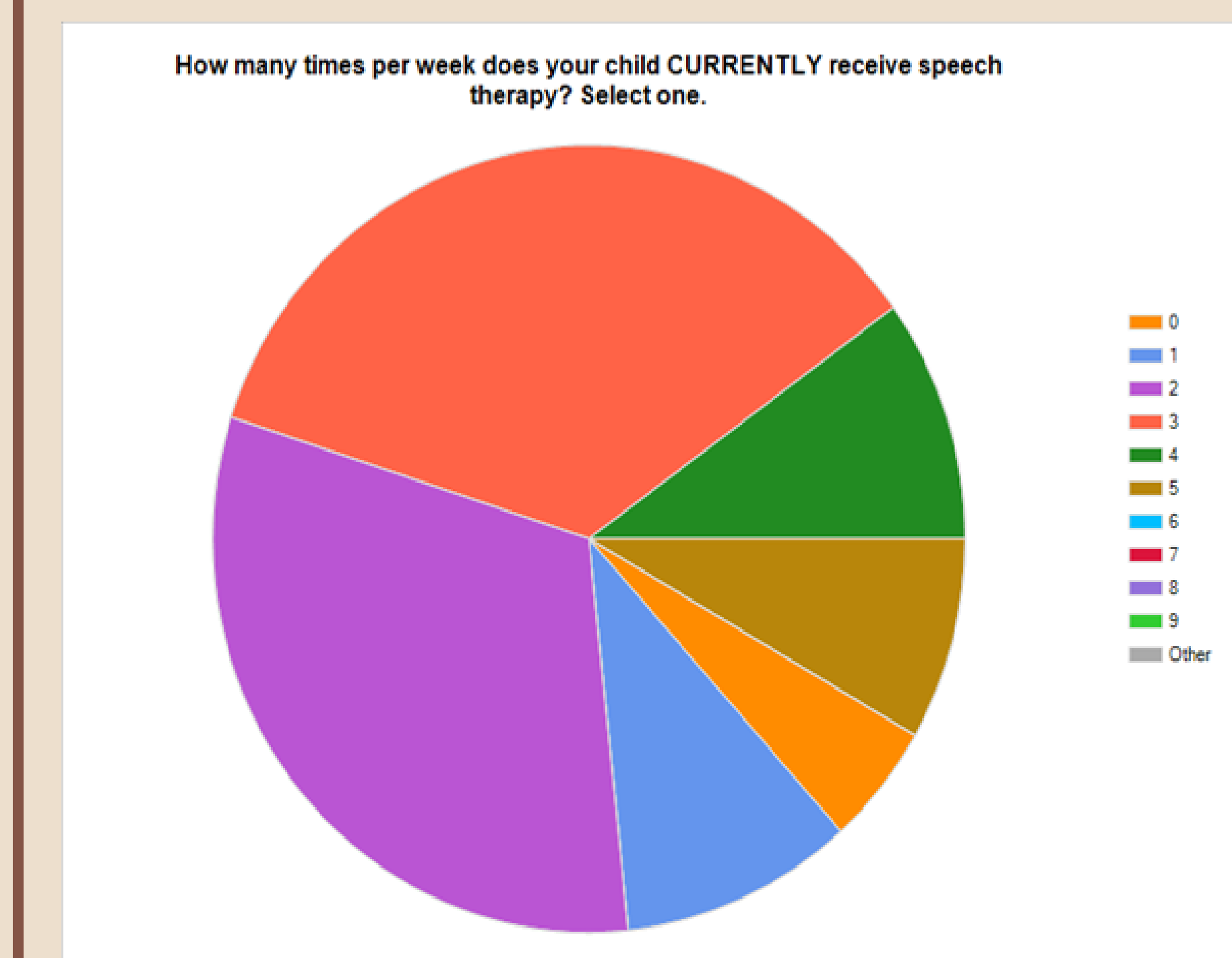
Ranking	Concerns for child's wellbeing	Percentage
(1) Most Important	Child's frustration	23.3%
(2)	Child's frustration	16.7%
(3)	Child's frustration	19.6%
(4)	Difficulty making friends	23.1%
(5) Least important	Child's inability to share inner thoughts/stories	18.4%

Ranking	Emotional and social supports available to parents	Percentage
(1) Most Important	Parents of other children with CAS	25.9%
(2)	Speech-language pathologists	27.3%
(3)	Parents of other children with CAS	21.6%
(4)	Friends	17.8%
(5) Least important	Friends	18.9%

For four survey questions, parents were given a list of emotions, concerns, and support systems derived from the pilot survey and asked to rank them from 1 (most) to 5 (least) important. Out of 16 possible emotions at the time of diagnosis, the emotion ranked most frequently (18.3%) as most important was fear. The emotion most commonly ranked as 2nd was grief (16.1%); 3rd was anxiety (18.5%), 4th was loss (15.7%), and 5th was guilt (16.3%). Out of 14 possible concerns about parenting a child with CAS, the greatest concern appeared to be concern over the child's future. It was notable that participants reported self-doubt about their abilities to help their child as a significant concern. Out of 12 concerns about their child's wellbeing, the most significant was their child's frustration. Although SLPs appeared to be a significant support system for participants, parents of other children with CAS were a more important resource.

Quantitative Results

Figure 1. Type and Frequency of Speech Therapy



A majority (35.0%) of parents related their child received speech therapy three times per week (Figure 1). However, some parents (7.0%) reported their child received therapy as much as five times a week, and 5.3% indicated their child received no therapy.

Parents noted most (40.7%) therapy sessions lasted 16-30 minutes and consisted of individual therapy (51.7% of the time) provided most often (66.1%) by a private SLP.

Qualitative Results

How do speech-language pathologists facilitate or hinder experiences of parents of children with CAS?

Forty-one responses yielded 110 core statements, 69 (62.7%) of which were negative and 41 (37.3%) positive. Negative statements were most often related to school or early intervention SLPs. Positive statements were most often related to private or clinic-based SLPs. Nine negative and five positive themes emerged. Inter-rater reliability with 3 speech-language pathologists (all female; 13.3 mean years of experience) revealed 100% agreement in the two categories (positive/negative); core theme agreement was 90.2%.

Appropriate therapy approaches appear to be the most valued aspect of speech-language services. For parents who have had adverse experiences, SLPs do not often seem to have sufficient experience with or knowledge about CAS nor understand the gravity of the diagnosis. For parents reporting positive experiences with SLPs, SLPs appear to be knowledgeable about CAS and provide a combination of specific tools for parents and emotional support.

Table 3
Perspectives of Parents of Children with CAS on Adequacy of Services by Speech-Language Pathologists

Negative Themes	Percent Reported	Positive Themes	Percent Reported
SLPs use inappropriate therapy techniques	23.2%	SLPs provide appropriate therapy	26.8%
SLPs have little exposure to CAS	17.4%	SLPs provide specific tools/techniques for parents	19.5%
SLPs do not provide parents enough information related to CAS	13.0%	SLPs are knowledgeable about CAS	19.5%
Insurance does not cover therapy	10.1%	SLPs provide adequate emotional support	19.5%
SLPs downplay the severity and significance of CAS	10.1%	SLPs facilitate parent understanding of CAS	14.6%
School policies limit success	8.7%		
SLPs overestimate parents' abilities (time, emotional, etc.)	7.2%		
Not enough therapy	5.8%		
Scheduling problems	4.3%		

Clinical Implications

Results from this investigation suggest that parents of children with CAS experience fear and grief upon the diagnosis of their child, and a majority of SLPs do not appear to provide parents adequate social and emotional support. Clinicians do not appear knowledgeable to parents about the characteristics of the disorder and although a majority of parents agree their child receives appropriate therapy, use of inappropriate therapy techniques seems to be a significant concern. Satisfaction with the amount of therapy provided may be low. SLPs need to be aware that parents of children with CAS appreciate specific tasks which can be performed at home as well as information about the disorder, that parents are concerned about their child's communication frustration, and they worry about their child's future.

References:
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