Parent concerns and advice about raising a child who stutters

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Abstract. This paper presents data from an online survey of 131 parents of individuals who had been diagnosed with stuttering at some point in their lives (ranging in age from 3 to 42 years). Qualitative responses to open-ended questions asking about the nature of concerns, how those concerns might have changed since diagnosis, and what advice parents have for others raising children who stutter are presented according to dominant themes around the past, present, and future. Past concerns include worry about what the future might hold, stopping the stutter, and the use of techniques or tools. Present concerns address acceptance, the child’s emotional well-being, managing the stutter, and hope. Future concerns focus on coping with the stuttering, adjusting to adult life, emotional well-being, and life goals, such as career opportunities and marriage. Discussion centers on a developmental interpretation of the results and how such a view might inform clinical practice.

1. Background
There has been little empirical study of the effects of raising children who stutter (CWS) on parents. It is likely that the presence of a child who stutters introduces potential stress for all family members, yet how the nature of concerns change in families as children develop is still unknown (Yairi & Ambrose, 2005). Therefore, it would be beneficial to document changes in families as their children who stutter age, to have a better understanding of families’ needs. The identification of developmental trends relative to parental concerns and advice will assist clinicians in counseling families and in determining appropriate goals. For this reason, the following study was conducted to investigate concerns of parents of CWS in order to help professionals improve intervention and counseling with families over the child’s lifespan. Specific aims included:

a) Identifying the nature and priorities of parental concerns in raising a CWS;
b) Determining how concerns of parents raising CWS change over the course of child and family development;
c) Soliciting advice from parents for other families raising CWS.

2. Methods
Parents of CWS were recruited to participate in an online survey via email invitations to two U.S. consumer organizations for people who stutter: FRIENDS: The National Association of Young People Who Stutter (circulation of approximately 850) and the National Stuttering Association (NSA) (approximately 8300 subscribers). As well, the survey invitation was posted to Parent-W, an online group for parents of CWS and professionals working with these children. By using this method of distribution, it was hoped that a cross-section of parents of children at all points of development (from preschool/close to diagnosis to adulthood/years from diagnosis) would participate. A total of 144 participants started the survey, with 131 completing some portion of it.

The survey involved 20 questions requesting demographic information (e.g., the age of the CWS, how long the stutter had been present, who identified the stutter), and asked parents to rank concerns about their CWS. In addition, open-ended questions asking for a description of the concerns, whether or not they had changed since diagnosis, and if so, how, as well as a request for what advice they would offer another family raising a CWS were included.

Responses to the open-ended questions regarding concerns and advice were transcribed orthographically and subjected to thematic analysis. Thematic analysis is a qualitative research method that consists of identifying, examining and recording themes within data. Themes are patterns across data sets that are important to the description of the data in relation to specific research questions and represent some level of patterned response (Braun & Clarke, 2006). Three independent judges reviewed written comments to
questions regarding primary concerns, how those concerns had changed from the point at diagnosis, and what advice parents might have for other families raising CWS. Remarks were organized around past, present and future concerns, with several themes emerging. Past, present, and future themes identified consistently by all three judges were included in the analyses. Concerns and advice were also examined in a developmental fashion by grouping qualitative comments by the length of time the respondent’s child had been stuttering.

3. Results

a. Concerns (Past, Present, Future)
Qualitative themes pertaining to past parental concerns were worry about changes in talking (e.g., “I was worried primarily that he would stop talking altogether.”), how to stop the stuttering (e.g., “I used to want him cured.”), speech therapy techniques and tools (e.g., “I used to worry a lot about techniques and tools.”), and the future (e.g., “I wondered…if her life was going to be limited or a lot harder.”). Present themes expressed were those of acceptance and perspective (e.g., “I no longer look to get rid of it – I accept it as part of who he is.”), hope (e.g., “I am more hopeful he will grow out of it, or be able to manage it better.”), management but not cure (“Focus turns to equipping her with the skills to manage her stuttering.”), and concern about the child’s overall well-being, not just related to stuttering (e.g., “I am generally far more concerned about his emotional well-being.”). Concerns regarding the future clustered around themes of coping with the stuttering (e.g., “Now I worry about effects throughout his life.”), emotional well-being (e.g., “As he has got [sic] older, my concerns have changed – about his future socially and academically.”), and life opportunities (e.g., “I am more concerned about job finding, as he gets older.”).

b. Advice
When asked to offer advice for other families raising CWS, several major themes emerged. These included acceptance, education, advocacy, techniques, action, and support. Examples of qualitative remarks regarding advice are provided in Table 1.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example Advice</th>
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<tbody>
<tr>
<td>Acceptance</td>
<td>“Accept your child for who he/she is – your child is a wonderful person who just happens to stutter.”</td>
</tr>
<tr>
<td>Education</td>
<td>“Get help as early as you can, so your child and others around him/her (e.g., school friends) can learn along with them on what stuttering is and how it affects the person who stutters.”</td>
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<tr>
<td>Advocacy</td>
<td>“Be an advocate for your child, check in with him/her regularly, empower him/her to continue to reach out to new activities/ experiences.”</td>
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<tr>
<td>Techniques</td>
<td>“Be patient, always look them in the eye and listen, no matter how long it takes them to speak, and don’t interrupt.”</td>
</tr>
<tr>
<td>Action</td>
<td>“Seek out a network of people for support and information.”</td>
</tr>
<tr>
<td>Support</td>
<td>“Always support your child, dont [sic] let him/her see your fears.”</td>
</tr>
</tbody>
</table>

c. Developmental Trends: Concerns
Twenty respondents identified their CWS as having stuttered for fewer than three years. Of these, nine provided qualitative comments. The majority of remarks involved the status of the child’s stuttering and what that might mean for the future (e.g., “He is doing better, so I am hopeful it will go away.”). Additional comments reflected concern about the effects of stuttering on future experiences. For children who had been stuttering three-to-five years, 20 participants responded, with seven qualitative remarks. These respondents identified concerns about how well the child understands therapy and expressed faith in the therapeutic process (e.g., “I now know that therapy can really help and make it manageable.”). For respondents whose children had been stuttering for greater than five years (total=93), 61 provided qualitative statements. The majority of comments indicated less concern and greater confidence in the child, but still concern around acceptance and the effect stuttering may have on life experiences (e.g., “I used to worry about stopping it, but now I worry about how to live with it.”).
d. Developmental Trends: Advice

For children who had been stuttering fewer than three years, 20 participants responded and all provided qualitative remarks. The two most frequently occurring advice themes were acceptance (e.g., “don’t avoid it and prepare others on how to deal with it.”), and use of techniques (e.g., “Slow your world down and take time to listen.”). Parents of children who had been stuttering between three and five years (19 respondents, 13 qualitative comments) reported advice around acceptance and action (e.g., “Look beyond the stuttering and love your child for the wonderful person he is.”), and support (e.g., “They need to get to at least one NSA conference.”). Seventy comments were obtained from respondents whose children had been stuttering for at least five years (93 total respondents). The primary themes of advice from these parents were support (e.g., “Love and support them unconditionally.”) and techniques (e.g., “Learn to be patient.”).

4. Discussion

Qualitative analysis of written responses provided by parents raising CWS indicate primary themes of concern about the effects of stuttering on the child’s life experiences, the need to provide love and support for the child, and making sure the child is getting appropriate therapy. When examined developmentally, concerns appear to change as time from diagnosis lengthens. Thus, within the first few years, parents report greater concern about the stuttering itself, wondering if it will go away or how to stop it. As the child grows and stuttering continues, parental concern regarding the child’s emotional well-being emerges as a stronger theme. At the same time, the idea of coping with the stuttering (rather than expecting it to go away) becomes more significant, and parents appear to place more emphasis on therapeutic techniques. Finally, for children whose stuttering has been evident for greater than five years, parents shift their concerns away from trying to manage the stuttering to focusing on skills that will aid the child in adulthood, and worries about the future (e.g. career, relationships) become more focused.

With respect to advice, four primary themes are evident. These include: acceptance, techniques (patience, listening), support and advocacy, and action and/or education. A developmental trend was not noted in the qualitative comments regarding advice.

The findings of this qualitative study suggest that parents raising children who stutter move through stages of concern as their children grow and develop. The more recently the family has received a diagnosis, the more likely parents report concerns directly related to the stuttering and how to change or eliminate it. As the length of time since diagnosis increases, parents shift their concerns to making the most of therapy, helping their youngsters develop coping strategies and supporting them emotionally. By the time their children reach adulthood, parents report more concerns regarding the impact of stuttering on the quality of the children’s lives, that is, employment opportunities, personal relationships, and life happiness emerge as themes, rather than particular concern about the stuttering behavior or therapy.

Caveats: These data should be interpreted with caution, as the sample from which they are gleaned is not likely representative of “typical” parents of CWS. Because the majority of respondents were recruited from national support or self-help organizations, the data are skewed toward those families who have taken steps to obtain information and help from the stuttering community. The vast majority of respondents (115/131, 88%) were mothers, and the “children” about whom they were reporting were older than preschool age (thus, representing families that had been living with stuttering for some time). Additionally, it is likely a not insignificant number of respondents were individuals who stutter themselves. Of those that did self-identify as people who stutter, a few (<5) indicated this as a factor in how they view their children’s stuttering.

Conclusions: It is clear that the needs and concerns of families of CWS change as their children grow and/or the stuttering advances. For clinicians, it is important to recognize that eliminating stuttering (by therapy and/or natural recovery) may be of greater import to parents of children who have recently received a stuttering diagnosis, than it is to parents whose children have been stuttering for some time. According to these data, parents of older (and grown up) children are more likely to report concerns regarding their children’s emotional well-being and life course, thus signalling to clinicians a shift in priorities toward
coping with stuttering. Overall, we have much to learn from parents and family members, and they have much to contribute as we work together to serve the needs of children who stutter.

References
