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## Parental beliefs about stammering and experiences of the therapy process: an on-line survey in conjunction with the British Stammering Association.

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### Abstract

This study investigated beliefs and perceptions parents have regarding their young child's stammering and their views and experiences of therapy. It is known that parents are often anxious about their child's stammering (e.g. Langevin, Packman and Onslow, 2010) and that it can have an impact on family life. Parents are often expected to have a role to play in therapy, yet there has been little in terms of large-scale research seeking more about parental experiences of having a child who stammers. An on-line survey was devised and sent out to parents via the British Stammering Association (BSA). Recruitment to the study was broad to encourage parents from a variety of backgrounds to the complete the survey, and to try to access parents who may not have had any professional advice or therapy. The questionnaire was developed from themes emerging from parent studies using qualitative methodology (e.g. Glogowska and Campbell, 2000; Goodhue, Onslow, Quine, O'Brian and Hearne, 2010; Hayhow, 2009; Plexico and Burrus, 2012;) with questions categorised into 6 main areas: beliefs about causes of stammering, level of concern, information seeking, strategies used to support their child, views of assessment and views of therapy. Quantitative and qualitative data from 69 parents of children who stammer (aged 10 years and under) are reported. The results revealed that parents had high levels of concern about the impact of stammering on their child; most did not know the causes of stammering or put it down to an environmental cause; and they employed a range of strategies to support their child. Most parents sought out speech and language therapy, but many experienced difficulties in accessing this support. Their experiences of therapy highlighted how important therapy was for the parent as much as for the child and that the support should come from a suitably trained and experienced specialist therapist.

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### 1. Introduction

Stammering usually begins in early childhood with the average age of onset at around 3 years (Mansson, 2000; Yairi & Ambrose, 2005). At this age children usually spend the majority of their time with their parents,

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with mothers often being the main caregivers. Although the chance of spontaneous recovery is high (Dworzynski, Remington, Rijdsdijk, Howell & Plomin, 2007; Mansson, 2000; Yairi and Ambrose, 2005) this can take several years and in the meantime stammering can impact on the child and the family. Existing literature on the impact of stammering on parents is limited, but two studies provide an interesting insight. Langevin, et al. (2010) devised a survey consisting of 19 open and closed questions providing quantitative and qualitative data about the impact of stammering on the child and on the parent. Results from 77 respondents showed that the majority of parents were emotionally affected by their child's stammering, including feelings of guilt and shame by some that they had caused their child's stammering. A smaller scale study by Plexico and Burrus (2012) used a phenomenological analysis of parent interviews to explore how parents cope with a child who stammers which revealed several themes: parents were uncertain about the nature and causes of stammering and how to react to it; parents used their own techniques to support their child; parents had mixed views of therapy and parents were concerned about their child living a restrictive lifestyle or experiencing negative emotions because of the stammer.

Although the onset of stammering potentially affects the whole family and environmental factors are thought to influence the development of the disorder, very few studies in the UK have explored parental views and experiences. The need for further research into this area is also important considering the drive for early intervention) when therapy is considered to be more effective (Fosnot, 1993; Jones et al., 2008; Manning, 2001; Millard, Nicholas and Cook, 2008). In quite a short space of time parents have to not only cope with the emotions of having a child who is stammering but they have to seek out support and information and begin what may be a lengthy therapy process with their child. There are two main approaches for therapy with young children – indirect e.g. the demands and capacities model (Franken & Putker-de-Bruijn, 2007; Starkweather & Givens-Ackerman, 1997) and Palin Parent Child Interaction therapy (Kelman & Nicholas, 2008); and direct e.g. the Lidcombe Program (Onslow, 2003) and in both cases parents are integral in the therapy process. Despite parents playing a critical part in therapy only a small number of studies have examined parents' experiences of stammering therapy. Hayhow (2009) carried out in-depth interviews with 21 parents taking part in the Lidcombe program and found that experiences were mixed. Some parents found the process positive and this was related to the child making good progress and enjoying the therapy. Others found it less positive, with some being surprised at the level of involvement they were expected to have in their child's therapy. A further study by Goodhue, Onslow, Quine, O'Brian & Hearne (2010) also used qualitative methodology to examine parent's views of the Lidcombe program and had similar findings: benefits of therapy included increase in quality time with their child, increase in knowledge and management of stammering and improved parenting skills. Difficulties included finding time and needing dedication to commit to the therapy.

Similar themes have emerged from qualitative studies looking at parents' experiences of therapy for their child with other speech and language disorders. High levels of concern are again apparent especially around referral and discharge to therapy and also to when their child goes to school (Glogowska & Campbell, 2000) There is also a mismatch between what parents expect from therapy and what the child receives, with some parents expecting a more direct approach, or "cure" (Carroll, 2010; Glogowska & Campbell, 2000;). A study by Auert, Trembath, Arciuli and Thomas (2012) also revealed that parents were keen for therapists to use evidence based practice with their child, but also emphasised the importance of the therapist being skilled and experienced. Good communication and liaison between therapists, parents and teachers being paramount was also a theme apparent in the literature (Auert et al., 2012; Carroll, 2010; Glogowska & Campbell 2000).

The existing literature in this field has shown that parents are emotionally affected by their child's stammering, they are unsure about the nature of the condition, and they are concerned about the impact of stammering on their child. In terms of therapy, parents report mixed experiences and parental expectations are not in line with what they are being provided. Investigating what parents think and feel about their child's stammering and therapy they have received is important considering that environmental influences are thought to impact on the development of the disorder and parents also play a crucial role in therapy and are paramount in its success.

The purpose of the current study was to survey a large sample of parents of young children who stammer in the UK to help understand the beliefs they have about the causes of their child's stammer, the strategies they have employed to help their child, their level of concern and their views and experiences of the therapy process.

## **2. Method**

A questionnaire was devised drawing on the themes that had emerged from previous research. The questionnaire was initially discussed using a focus group of 9 parents who were taking part in a longitudinal study on childhood dysfluency at University Campus Suffolk. As a result of these discussions some amendments were made and the original 21 questions were reduced to 14 questions covering the following areas: beliefs about the causes of stammering, levels of concern, help and information seeking, views of

assessment and views of therapy. Questions were multiple choice, but with opportunities for participants to expand on their answers. There was also one final question which stated “we would like to hear any other views you have about how you have coped with your child’s stammer and what your experiences of therapy have been like” which gave participants the opportunity to freely express their views. The questionnaire yielded both quantitative and qualitative data. The survey was uploaded to the internet and the link was distributed to parents who had contact the British Stammering Association (BSA) and it was also advertised on the BSA website [www.stammering.org.uk](http://www.stammering.org.uk) and the BSA Facebook page. The survey can be found at [www.surveymonkey.com/s/MSS9TH2](http://www.surveymonkey.com/s/MSS9TH2). Data on age, gender and socio-economic status of parents was collected from the participants but the questionnaires remained anonymous. Quantitative data was gathered from responses to the closed questions and qualitative data was collected from written comments at the end of the survey. The qualitative data was analysed using a thematic analysis as outlined by Braun and Clarke (2006). This method was chosen as it accessible and flexible and is not embedded in any particular theoretical framework. Braun and Clarke (2006) also provide clear guidelines in carrying out a thematic analysis especially useful to those new to qualitative research.

### 3. Results

#### 3.1 Quantitative data

Data from 69 respondents has been analysed, although not all participants answered every question. The number answering each question is reported. Mothers comprised 91% (63) of respondents and 9% (6) were fathers. The age range of respondents was 25-45+ with the largest proportion (58%) in the 35-44 age category. Fifty-five out of 66 (83%) respondents were White British. Sixty-seven respondents answered the question on highest level of education completed: 15% completed compulsory schooling, 27% completed further education (A level/college), 33% completed undergraduate training (Bachelor degree) and 25% had completed postgraduate education. Sixty five participants stated their current employment and their occupations were classified according to the Standard Occupational Classification 2010 [accessed on-line [www.ons.gov.uk/ons/guide/classification/SOC2010/](http://www.ons.gov.uk/ons/guide/classification/SOC2010/)]. Forty-three per cent of the participants were in managerial, professional and technical occupations, 33% were in administrative, skilled trade, care and service occupations, 7% were in customer service, operatives and elementary occupations, and the remaining 17% were not in paid employment (either full-time parents or students).

These parents represented 61 children (as in four cases both parents completed the survey for their one child) 83% of which were male and 17% were female. The age range of the children was from 2 years 9 months to 10 years 9 months, with a mean age of 7 years 4 months and a median of 8 years 3 months. Eighty-seven per cent of respondents reported that their child had received a diagnosis of stammering from a health professional. All respondents answered the question about the age the child was at the onset of stammering and the mean figure was 3 years 7 months (range 1 year 8 months to 8 years). Some parents recalled this very specifically (e.g. “one week after her second birthday”) but the majority rounded it up to full or half years (e.g. 3, or 3 ½ years). Further results are outlined below according to the main question areas:

#### 3.11 Beliefs about the causes of stammering

Sixty-eight respondents answered the question of what they believe causes their child to stammer. There was the opportunity for parents to choose more than one response to this question – 35% cited one cause, 16% cited two causes, 12% cited 3 or more causes and 37% said they did not know the cause. In terms of types of causes 34% linked it to environmental causes (e.g. birthdays/Christmas, change in family circumstances, starting nursery etc.), 24% linked it to language development (such as being advanced in talking or learning two languages), 21% respondents believed it ran in the family, 13% cited other causes which included traumatic birth, family holiday, family stress and illness and 3% linked it to other aspects of development (such as toilet training).

#### 3.12 Level of concern

Parents were asked to rate their overall level of concern about their child’s stammer, of the 67 respondents, 45% reported being either extremely or very concerned, 37% moderately concerned and 16% mildly concerned or not concerned at all. The areas of concern are shown in figure 1, which reveals high levels of concern about most of these areas, with the highest level of concern (over 70% parents being very or extremely concerned) about their child being teased or bullied, the stammer affecting the child’s confidence, the child feeling different to other children and the stammer affecting their child’s future.

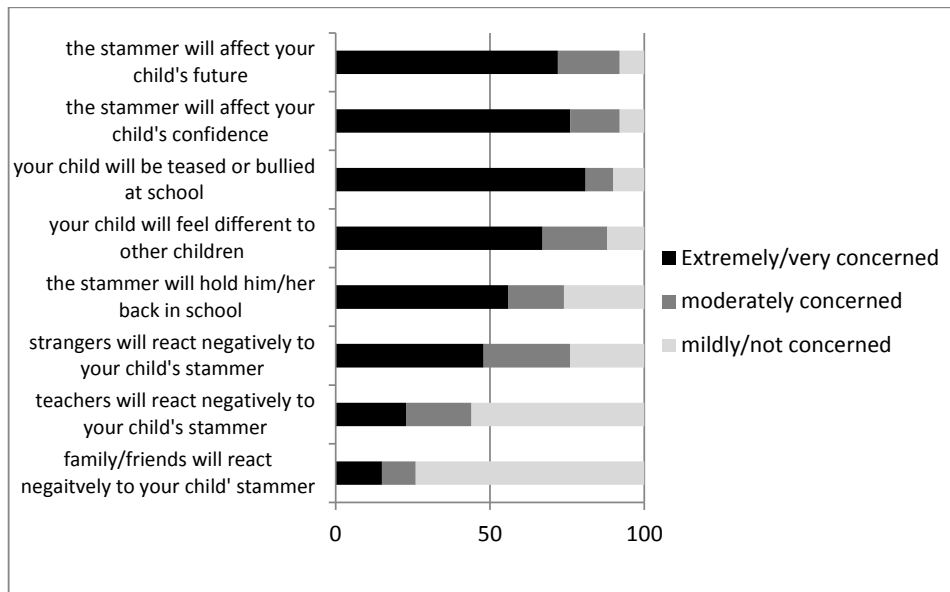


Figure 1. Parent's level of concern

### 3.13 Strategies used by parents to support their child

Parents report having used a variety of strategies to help their child, with many employing more than one strategy. A majority of 66 parents answering this question have: sought professional advice (84%), given their child more time to talk (90%), slowed down their own speech rate (69%) and created a calmer atmosphere (69%). Only a small number of parents have told their child off for stammering (4%) or moved their child to another school or nursery (3%).

### 3.14 Information seeking:

When asked what sources of information or advice they used, many parents (60 respondents) used the internet (78%), the British Stammering Association (71%) and Speech and Language Therapists (84%) with the overwhelming majority finding these sources helpful. Other sources of advice people used were family (33%), friends (27%), Health Visitor (33%), family doctor (10%), school or nursery (52%). (Percentages sum to more than 100 as a number of respondents had accessed more than one source). The reported helpfulness of these sources was not as high with, 47% of parents turning to these sources finding the family doctor unhelpful, 28% the health visitor unhelpful and 27% finding the school or nursery unhelpful.

### 3.15 SLT assessment:

The remaining questions concerned experiences of assessment and therapy. Sixty one parents reported that their child had seen a speech and language therapist regarding their stammer and eight had not. The reasons given by parents for their child not having seen a therapist included waiting for an appointment, not being too concerned, believing their child would grow out of it and not wanting to draw attention to their child's stammer. The mean age for the child's first appointment was 41 months. Parents were asked to rate their level of satisfaction with this first appointment. Figure 2 shows the responses parents made to the statements. On the whole a high level of satisfaction was expressed with over 50% of parents agreeing or strongly agreeing with statements such as "the appointment met my expectations" and "I was more knowledgeable about stammering following the appointment" compared to 15-20% of respondents who disagreed or strongly disagreed with the same statements.

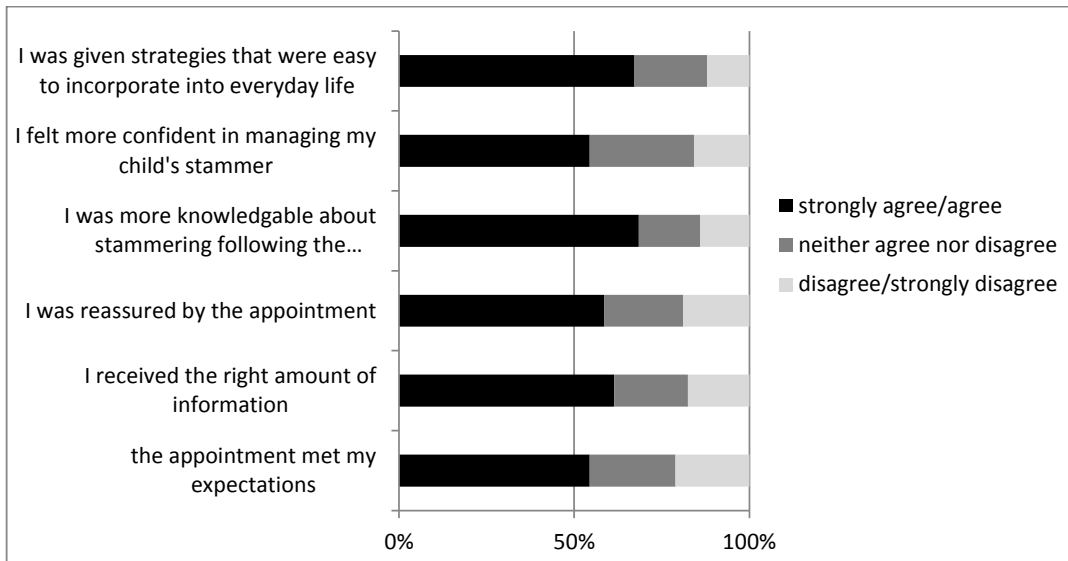


Figure 2. Parental reports of their child's first assessment with an SLT

3.16 Therapy:

Forty-two (67%) respondents had received regular therapy (i.e. a period of weekly sessions) for their child. Of the 19 (31%) who hadn't had therapy their children were either on a waiting list for therapy or the therapist was monitoring their child's speech. Two parents decided that they did not want therapy for their child. Parents were asked what type of therapy their child had received. 39% had received Lidcombe therapy, 34% had received Parent Child Interaction therapy, 14% had received group therapy, 54% had learnt specific speech techniques and 7% were not sure. (Percentages sum to more than 100 as a number of respondents had received more than one type of therapy). The mean age for children starting therapy was four years ten months.

Respondents were then asked to rate their satisfaction and evaluate the most recent type of therapy their child had received (see figure 3). Satisfaction levels were lower for therapy than for the assessment. Overall more than 50% parents agreed with being satisfied with the amount of therapy their child received; the amount of involvement they had in their child's therapy, and with the therapy overall. However only 45% parents reported that their child was more fluent following therapy, 46% felt therapy met their expectations, 40% reported being less concerned about the impact of stammering following therapy and 39% reported their child being more confident in speaking following therapy. The discrepancy between these outcomes and higher levels of parental satisfaction suggests that satisfaction from therapy comes more from being seen and supported than perhaps any discernible differences in the child.

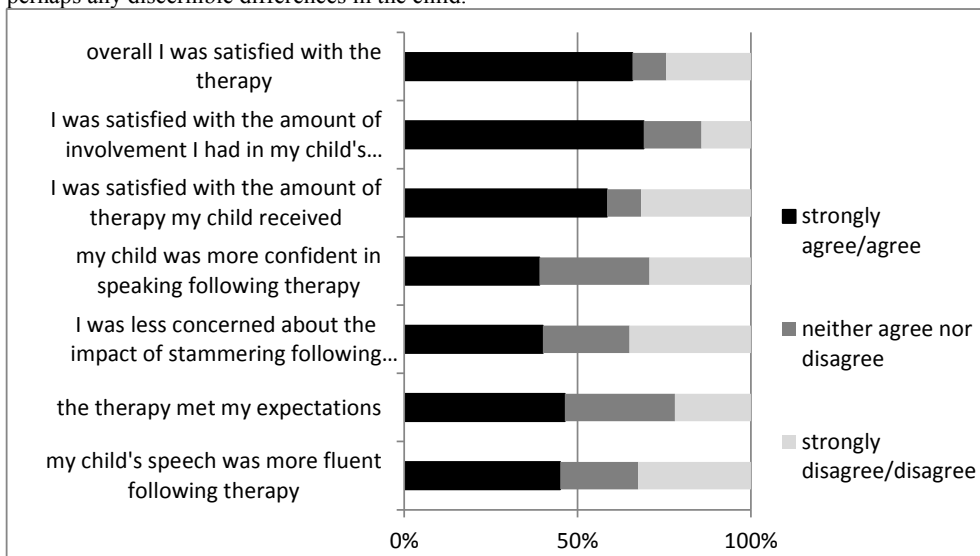


Figure 3. Parents' views of therapy their child received

### 3.2 Qualitative data:

Thirty-four parents wrote comments to the final question “we would like to hear any other views you have about how you have coped with your child’s stammer and what your experiences of therapy have been like”. Eight themes emerged from the qualitative data following the thematic analysis, which were: 1) experiences of therapy; 2) access to help; 3) description and aetiology of the stammer; 4) child in control; 5) concern; 6) impact on parents; 7) parents as supporters; 8) others perceptions of stammering.

#### 3.21 Theme one: Therapy

The most comments made by over half the parents were related to therapy. This was identified as one theme, with several sub-themes, which were “positive experiences”, “negative experiences” and “expectations”.

Positive experiences were cited by eight of the parents and were associated with the therapy being effective, enjoyable, tailored to the family and/or the therapist being regarded as knowledgeable and supportive. The positive comments about the therapist were related to the therapist being specialised or feeling supported by a specialist centre e.g. “we largely attended sessions with one particular SLT who came to the Michael Palin centre with us, she was fantastic” (parent 13), and another parent - “...we are really pleased with the progress and feel lucky to have our SLT as he is highly specialised in stammering” (parent 30). Parents also reflected feeling supported even when there wasn’t a change in the child e.g. “I feel that I learnt a lot from the group therapy meeting other children and parents but it didn’t make a difference to my daughter her stammer was the same” (parent 22).

Effectiveness was however important to other parents who viewed therapy positively, even if it did not necessarily last e.g. “The Lidcombe Program was brilliant and my son responded very well indeed. The stammer more or less disappeared completely but has since returned (parent 4).

The second sub-theme was around negative experiences of therapy. Many comments here were quite personal to the therapist – not knowledgeable, not helpful, and seeming not to care. For example, “Speech therapy was hopeless, she didn’t seem that knowledgeable about slightly older children having a stammer...I always felt as if she thought we were exaggerating the problem” (parent 12). There was also a potentially significant comment from a parent that therapy itself places a lot of demands on the parent “My son has been on the Lidcombe programme for nearly 3 years ...I have struggled myself and I think it’s quite a big pressure to put on the parent” (parent 7).

The final subtheme is around expectations of therapy, with a feeling from some parents that therapy has disappointed them. Their expectations had been more related to a cure, which hasn’t happened “the focus of therapy does not seem to be about techniques or helping the child overcome the stammer but helping them learn to live with it...I want to help him overcome it” (parent 6). Another parent also showed disappointment with the content of therapy “therapy has not provided us with many answers or suggestions on how to cope. It has pretty much consisted of our son being told to speak slowly” (parent 10).

#### 3.22 Theme Two: Access to help

A significant theme was identified around parents accessing support for their child. The main feeling that comes across through the comments is that of intense frustration at not being able to get the help they feel their child needs or resorting to paying for treatment even when they cannot afford it. Access issues were particularly related to waiting times for NHS treatment, such as “It took nearly a year to be referred for NHS therapy only to be told the waiting list is about a year!...so we have found a private speech and language therapist, even though we are a very low income family” (parent 32). Several other comments followed a similar vein e.g. “we had to pay for private therapy as the NHS were taking too long” (parent 1)

Even if parents reported having had some therapy, they sometimes felt that it wasn’t enough “I feel we certainly need more regular appointments as up until now they have been one session every three weeks” (parent 20). Another comment suggests that it is not just any help parents feel they need, but specialist help – “having a specialist available would be a help as most speech and language therapists are not always a great help” (parent 8).

Accessing help and support on-line however was generally viewed as a positive thing – “I get more support from the Facebook pages on the internet than anyone else” (parent 7) and “advice from the BSA website and from their helpline was outstanding and very much appreciated” (parent 31).

#### 3.23 Theme 3: Description and aetiology of the stammer

Eleven parents wrote comments relating directly to the child’s speech about how it has changed and what acts as a trigger “My son has quite a severe stammer which is especially bad when he is asking questions or talking about his day” (parent 17) and another parent – “stress does seem to make it worse”(parent 5). Some

parents describe the stammer in relation to a possible cause – *“I feel stammering was caused by the problem of learning to speak, i.e. trying to find the right words”*(parent 9) and another parent sees the fluctuations in stammering as confusing *“The stammer was always a bit baffling situation because there was largely no obvious cause or pattern. It could vary a great deal, and still does...”* (Parent 13).

#### 3.24 Theme 4: Child as central

This theme was identified as the child being the main person at the centre of the stammer. Several parents commented on how well the child copes with the stammer or how he/she isn't bothered by it. Parental comments here was very supportive – *“our son is great, he copes well so far and just gets on with it”*(parent 7), and *“my child copes well and at the moment it is not a major issue”* (parent 15). The child is also seen as being central in making a decision with regard to therapy *“the stammer has surfaced more noticeably but my child doesn't want any more treatment”* (parent 23) and *“...it has to be him that decides if he wants to resume therapy”* (parent 24).

#### 3.25 Theme 5: parents as supporters

This theme is parents seeing themselves as supporters for their child which includes seeing the stammer as something normal and not wanting their child to be excluded because of the stammer; For example one parent comments that *“we try to make sure that he takes part in everything”*(parent 29) and another *“my wife and I are determined that our son be as open as possible regarding the stammer...so he knows it is nothing to be worried about”* (parent 10). Reassurance and normalising the stammer occurs again with another parent- *“we encourage him to talk (and not to let the stammer hold him back) to reassure him that even people with “smooth speech” sometimes have bumpy speech patterns”* (parent 34).

Parents also comment on how they use techniques learnt in therapy to help their child. For example, *“I have continued with slow speech when possible, giving him lots of time and encouragement...”* (parent 24) and *“we have learnt some tools that we try to incorporate”* (parent 34).

#### 3.26 Theme 6: Concern

High levels of concern were found in the quantitative data and were expressed again by some parents. The concern parents reported feeling was always related to the child's future rather than on what might be happening at present. The areas of concern were to do with other people's reactions, the stammer affecting the child's confidence and the child's long-term future of high school and careers. These comments were *“I worry for my child's future”* (parent 14); *“we do get very concerned that in time he will be very affected by not being able to talk easily”* (parent 8) and *“as his mother I really worry how his stammer will affect his life especially teasing/relationships and job choices”*(parent 17)

#### 3.27 Theme 7: Impact on parents

Although feelings were mentioned by only four parents, the strong language they used highlights the significant emotional impact that stammering can have on parents. This is something that can affect both mothers and fathers, as one father commented *“we both found it devastating and depressing”* (parent 2) and a mother writes how the stress caused her to take time off work – *“When my child started to stammer I was devastated and really worried for him constantly, to the point where I had to take a number of weeks off work with stress and had trouble sleeping...”* (parent 11).

Another parent clearly finds the stammering frustrating and feels guilty that she cannot help; *“It's so hard to watch your child struggle and be unable to help. Also feel guilty that I haven't done enough...”* (parent 24).

Finally one parent sees the stammer as something to dislike and admits that listening to it can be hard *“I really hate him stammering. I hate the dysfluency as he is such an articulate child. I find it tiring to listen to him when he is in a dysfluent phase”* (parent 3).

#### 3.28 Theme 8: Others perception of stammering

The final theme was perceptions of stammering from others. Some parents were concerned about personal reactions to their own child's speech e.g. *“I find that when people i.e. other parents hear that your child has a stammer when they automatically think your child is stupid. They aren't. I wish people would not judge unless they know the true facts”* (parent 18). Other parents were also concerned about how stammering is viewed by the public, with some parents seeing it as a disability or a taboo subject. Frustration is also evident that it isn't given the attention it deserves; *“It seems like this remains a taboo subject and I feel it is minimised in speech therapy...I see it as a disability and I see very little research or public awareness about it. My god scientists can clone now yet there is no medical treatment at all to help children with stammers...”* (parent 6).

Another parent expresses amazement at general understanding about stammering “*I was quite amazed by the lack of general understanding and allowance by some people who should know better...I found that stammer was a condition affected by some people’s tendency to think of it as some sort of comical affliction...*” (parent 13).

#### 4 Discussion

The majority of parents either did not know what causes their child to stammer or cited only one cause, with diverse reasons being given, such as a family holiday being the trigger or the child’s traumatic birth. Parents’ tendencies to put stammering down to a single cause or not having an idea about the cause goes against the research that views stammering as multifactorial in nature being triggered by a combination of physical, environmental and linguistic factors (e.g. Smith and Kelly,1995). It highlights a potential need for further education and information to parents. If they do not have an understanding about the causes of stammering or have a belief that it is down to a one off event such as a holiday then parents may believe they caused the stammering leading to distress and feelings of guilt. Such feelings could impact on the effectiveness of therapy. There is therefore a role for both therapists and support networks such as the BSA to keep parents informed about current research on the causes of stammering.

On the whole parents were at least moderately and many were extremely concerned about their child’s stammering, which was reflected in both the quantitative and qualitative data and backs up previous research (Langevin et al. 2000). The highest area of concern was around their child being teased or bullied because of the stammer. Although no parents reported current issues of teasing and bullying it was something they anticipated in the future. Past research has shown that children who stammer are more at risk of being teased or bullied because of their stammering (Davis, Howell & Cook, 2002; Lau, Beilby, Byrnes & Hennessey, 2012) so the concerns parents have are very real. There is scope here for more education in schools around the issue of teasing and bullying.

Parents in this survey used mainly useful strategies to support their child such as talking slowly with their child and creating a calm atmosphere. As most of the families had seen a speech and language therapist these strategies may have been given to them by a therapist. The qualitative data has suggested this might be the case with some parents reporting using strategies they had learnt in therapy. Parents’ acting as a support to their child was a theme that emerged from the qualitative data and backs up existing literature (Plexico and Burrus, 2012)

On the whole parents were satisfied with the speech and language assessment. However the qualitative data revealed that many parents had difficulties in accessing support, reporting having to fight for NHS treatment or resorting to paying for private therapy. Information was not collected on where participants lived so there may be geographical variations on provision of services that requires further investigation in the future.

Despite access issues, the majority of parents reported that their child had received some therapy (classed as a period of weekly appointments). The average age for starting therapy was 4 years 10 months. In such a young age range it was perhaps surprising that over half of these children had been given specific speech techniques in therapy where the evidence base for young children in stammering treatment is for Lidcombe and Palin Parent Child Interaction (Palin PCI) therapy (Millard et al 2008; Millard, Edwards and Cook, 2009; Jones et al 2005; Jones et al 2008). Several children had received more than one type of therapy so it is possible that the speech techniques were being introduced as a top up to Lidcombe or Palin PCI therapy. It could also indicate training deficits – both techniques require post-graduate training in the UK and it maybe that there is a lack of suitably trained therapists.

One interesting finding was that most parents rated themselves as being satisfied with therapy yet less than half noticed changes in their child such as being more confident in talking or more fluent following therapy. This was backed up by the qualitative research with one parent commenting “*I feel that I learnt a lot from the group therapy meeting other children and parents but it didn’t make a difference to my daughter, her stammer was the same*”. This gives the impression that parents are benefitting from therapy even if their children are not. Therapy is therefore as much about supporting the parents as the child. From the qualitative data it seemed that parents were positive about therapy when it was successful and the therapist was competent. Negative views of therapy were associated with the skill of the therapist or the demands placed upon them as parents. Finally there was a mismatch between parental expectations and what they received, backing up findings from other studies examining therapy for other speech and language disorders (Carroll, 2010; Glogowska and Campbell, 2000;). There was evidence to show that parents found on-line support and phone lines helpful, especially from the BSA. Providing more information and support to parents via the internet or telephone is a potential area for further development and could provide a more cost effective alternative to face to face contact.



This study has revealed the pervasive impact of having a child who stammers within the family, particularly on the parent. Support is as important to the parents as therapy is for the child. However the study points to the importance of the support and therapy coming from a highly specialized speech and language therapist who has a focused interest and clinical experience of stammering. This has implications for postgraduate training of speech and language therapists and the management of clinical services

### Acknowledgements

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