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What do children who stutter and their parents expect from therapy and are their hopes aligned?

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Abstract

Currently there are few published reports exploring what it is that children and their parents wish to see change or happen as part of therapy. A process of eliciting hopes or expectations for therapy using Solution Focused Brief Therapy (de Shazer, 1985) is routinely used at the Michael Palin Centre (MPC) with children who stutter and their parents. This qualitative study aimed to explore what children who stutter and their parents expect from therapy and whether their hopes are aligned.

Keywords: expectations; hopes; shared decision making, thematic networks.

1. Introduction

The importance of assessment in children who stutter (CWS) prior to the start of therapy is broadly accepted. This has two main purposes. The first is to understand the nature of the problem and to inform therapy, and the second is to provide a baseline against which change can be evaluated. There are a range of published assessments available to researchers and clinicians (e.g. Riley, 1994; Vanryckeghem et al., 2001; Yaruss&Quesal, 2006) that provide norms for comparison, as well as information about the need for therapy and the areas to target. In addition to published assessments, therapists may explore the client's hopes, expectations and priorities for outcome, in order to identify more refined and/or personalised goals. Core components of stuttering therapy have been described by many clinicians and researchers (Cook &Botterill, 2005; Conture, 2001; Guitar, 1998; Manning, 2005; Yairi& Ambrose, 2005).

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It appears that the aims of therapy for clients who stutter are usually established based on the assumptions, beliefs and clinical experience of professionals. However experts in the field argue that the most effective treatment results when goals are established in collaboration with the client. Sackett et al. (1996) define 'practice-based evidence' as 'the ability to use our clinical skills and past experience to rapidly identify each patient's unique health state and diagnosis, their individual risks and benefits of potential interventions, and their personal values and expectations'.

Elwyn et al. (1999) describe three broad models of doctor-patient interaction: 'paternalism', 'informed choice' and 'shared decision making'. Paternalism is described as a process where the practitioner takes responsibility for the decisions; informed choice involves giving the patient information and the practitioner then withdraws from the decision making process; and shared decision making is the 'middle ground'. Elwyn et al. (2000) conducted a small-scale study via group interviews to explore the process of decision making with General Practitioners (GPs). The GPs described shared decision making as a sequence of skills including exploring ideas, fears and expectations of the problem and possible treatments. Elwyn et al. (2000) found that the benefits of shared decision making include increased satisfaction and increased commitment to agreed management plans. As part of clinical assessment processes clinicians typically ask questions about what parents and children expect from therapy before it begins in order to develop a shared understanding of goals. Expectations are explored clinically, but there is no published research describing them.

Landau (2011, unpublished) conducted a small-scale retrospective study to explore the experiences and expectations of children who stutter (CWS) and their significant others. The research explored opinions of 10 dyads of CWS aged 13 to 19 years old and a significant other (SO) via retrospective interviews. Findings reported that CWS's priority for therapy was fluency (100%) whilst SO considered confidence building (50%), self-esteem raising (70%) and meeting other people who stutter (60%) as their priorities. All CWS expected a cure for their stutter, whilst SO reported that they did not expect a cure and were more focused on increased participation by the CWS. Landau highlighted that a patient's report of their expectations retrospectively is open to bias. Goals may be altered after the event (Ross et al., 1987). Landau (2011, unpublished) recommended prospective research to comprehensively explore expectations.

This qualitative study aimed to explore three questions: what are parents' expectations from therapy; what are children's expectations from therapy; and are their hopes aligned.

2. Method

2.1. Programme

A group of 10 to 14 year old children who stutter and their parents participated in a two-week intensive programme followed by four group follow-up days over one year. The intensive programme delivered at a specialist centre in London is an integrated therapy programme that aims to develop social communication skills, speech management strategies and the management of the cognitive-emotional aspects of stuttering (Millard, 2011). The theoretical framework (Cook &Botterill, 2005) was developed from clinical experience, or "practice-based evidence" (Sackett et al., 1996). Cook &Botterill's (2005) framework is set within a circle representing the 'real world environment' (Manning, 2001) which can be viewed both in terms of the support structures around the child as well as the opportunities for the child in terms of transfer and generalisation. Families understand that there is a two-week commitment, Monday to Friday, with a year's follow up including four group follow-up days. Pre-course information is given to each family that describes administrative procedures.

2.2. Participants

- 7 children attended with a mean age at the start of the course of 13.02 years old, range 11.09 to14.02 years.
- There were 12 parents, 7 mothers and 5 fathers (2 children lived in homes with one parent, in both cases their mothers).
- There were 5 boys and 2 girls in the group.

- Children who stutter are referred to the MPC from across the UK for specialist assessment. There is also a local population for whom the centre is their local service. One client was local.
- Typically children have received some therapy previously and are referred to the MPC for more intensive or specialist input.
- Six of the seven children had attended therapy previously. Therapy was described as individual and included a combination of indirect and direct approaches.

2.3. Data collection methods

'Hopes' or 'expectations' from therapy (terms being used synonymously) were elicited using Solution Focused Brief Therapy (SFBT) scaling (de Shazer, 1985). As part of this counselling approach, a rating scale marked 0 to 10 was used, where 10 represented the child's or parent's 'Best Hopes', and 0 was the opposite of that. The child or parent was asked to describe what a rating of 10 will mean to him or her (i.e. what *will* be happening?), and what *will be* different when they reach that place. The therapist facilitated this discussion using an SFBT questioning style (i.e. using the language of change in the future tense, not conditional tense). The result was a list of individualisedbehavioural, emotional and cognitive medium- and long-term goals. Once the child's or parent's 'Best Hopes' had been explored, they were asked to imagine where on the ten-point scale they currently lay and what they *will be* doing more of when they make the next small step towards their best hopes. This provided the short-term goals and an understanding of their immediate priorities.

Standard questions included:
- What are your Best Hopes from therapy? (parents and children)
- What are your Best Hopes for yourself? (parents and children)
- What are your Best Hopes for your child? (parents only)

Questions were deliberately not fluency orientated in order that children and parents were helped to elaborate a broad picture of their Best Hopes. Typically if a child or parent was struggling to provide information and needed further prompt questions a few supplementary questions might be used:
- What will you be doing more of/ differently? (parents and children)
- How will you be feeling? (parents and children)
- What will others be noticing? (parents and children)
- What will your child be doing more of/ differently? (parents only)

2.4. Data collection points

Solution Focused Brief Scaling was completed pre- and post-course, day one and day ten respectively, and at each follow up.
- Day One
- Day Ten
- 1st follow-up day (6 weeks post course)
- 2nd follow-up day (4-5 months post course)
- 3rd follow-up day (8 months post course)
- 4th follow-up day (12 months post course)

The children's rating scales were completed during the morning of day one as part of initial assessment. Each child completed their rating scale individually with a specialist speech and language therapist (SLT) writing as they spoke. Parents completed the scaling activity as a group in the early part of the afternoon on day one and then wrote down their own individual expectations through the same guided process led by one specialist SLT.

2.5. Analysis method

The data that were provided in the form of Brief Scales were analyzed using thematic analysis

(Attride-Stirling, 2001). Thematic analysis is a form of data analysis that is used for qualitative research and is highly sensitive to categorizing and presenting qualitative information. Using this type of analysis allows the researcher to examine a text and identify main themes for a given global topic. Thematic networks are web-like illustrations that summarise the main themes constituting a piece of text. There are two stages in the process:

Analysis stage A: reduction or breakdown of text
- Code material
- Identify themes
- Construct thematic networks

Analysis stage B: exploration of text
- Describe and explore thematic networks
- Summarize thematic networks
- Interpret patterns

There are three levels of theme. Basic Themes are the lowest-level theme that is extracted from the written data. On their own, they do not provide a meaningful story about the general construct of interest because they are micro and are directly taken from the data. When several related Basic Themes are combined around a common trend, they form an Organizing Theme. Organizing Themes are middle-level themes that represent the main idea of several related Basic Themes. They are more abstract than basic themes, and begin to reveal patterns and trends in the data. When several related Organizing Themes are grouped, they form a Global Theme. Global Themes are high-level trends that express the general theme of the text. They offer a macro perspective of the overarching goal of the data. Figure 1. shows a thematic network with the Global theme at the centre, four Organising themes around that and Basic themes grouped around the Organising themes.

Figure 1. Structure of a Thematic Network (Attride-Stirling, 2001)

Analysis Stage A: reduction or breakdown of text

The data were analysed by researchers who were independent of the centre where the therapy was conducted (authors 2, 3 and 4 on this paper) to reduce the possibility of bias.

Code material

All the data from the children's and parents' Brief Scales from day one were entered into a spreadsheet and independently categorized.

Identify themes

Common basic themes were identified by reading through all the responses and color coding responses that were very similar *(e.g., "to control my stutter more"* and *"more strategies for my talking"*).

Construct thematic networks

The data points that were coded similarly comprised the Basic Themes. The labels for the Basic Themes contained subjective adjectives that often implied positive change (e.g., "increased use of techniques"). Basic Themes were grouped based on similarities e.g. the Basic themes of 'less isolation' or 'meeting other CWS' were grouped under the Organising Theme: "socialisation/social support'. These middle-level groups formed the Organising Themes and remained objective and were written without a positive/negative bias (i.e. 'socialisation/social support' instead of "improved socialisation/social support"). An Organising Theme was only created if there were at least two participants (n=2) who provided Basic Themes for that Organising Theme. For the parent scales, only the responses to the prompt regarding best hopes from the course, best hopes for themselves, and best hopes for their child were used. For the child scales, only the responses to the prompt regarding best hopes from therapy were used. When considered together, the Organising Themes collectively formed the Global Theme of "Parents' best hopes for themselves", "Parents' best hopes for their child", and "Child's best hopes from therapy". At each level, the 'n' refers to the number of participants who said this, not the number of different responses in the category. Basic themes were allowed to have an n=1, but for Organising Themes a minimum of n=2 (i.e. more than one respondent) was required. The nature of the organising theme is that it transcends multiple respondents, so that it is truly a "theme" across participants; therefore, the 'n' needed to be greater than one for the organising themes. If a participant reported more than one similar Basic Theme (e.g., Child 1 (C1) stated "talking out loud more in class" and "answer more questions in class and read out loud more", he would only be counted once for the n count). How the organising themes were expressed may have been more individualised, and therefore the basic themes reflect those nuances and capture the different aspects of the organising theme; therefore, a basic theme was allowed with only one respondent (n=1). Some of the data points were excluded from the finalized thematic networks if one data point (i.e. Basic Theme) was the only one that fitted into an Organising Theme.

2.6. Analysis Stage B: exploration of text

Describe and explore thematic networks

Thematic networks are a tool in analysis, not the analysis itself. The researcher needs to return to the original text and interpret it with the aid of the networks and read it through the Global, Organising and Basic themes. In a description of the text it is useful to present text segments from the original transcripts/data to support the analysis.

Summarize thematic networks

The researcher then presents the patterns emerging via illustration.

Interpret patterns

Finally, the researcher explores significant themes, concepts, patterns and structures that arise from the text. The researcher returns to the original research questions at this stage.

3. Results

Below is an illustration of the thematic levels:
CHILDREN'S BEST HOPES FROM THERAPY (GLOBAL THEME, n=7)
Participation (Organising Theme, n=6)

Increased Speaking in School (Basic Theme, n=4, which *means 4 children mentioned it with a total of 7 statements)*

C1 "talking out loud in class more"
C1 "answer more questions in class and read out loud"
C2 "taking part in speaking tasks at school"
C2 "reading out loud in class"
C2 "be able to ask for help from teachers"
C3 "they'll see me speaking more in class and groups"
C4 "talk out loud in class more"

3.1. Parents' Best Hopes for themselves

Eleven parents mentioned 'education' (which implies that the parent is taking information in to improve general understanding about stuttering but is not actively doing something) – basic themes included 'knowledge about child's stuttering' and 'understand child's needs'; six parents mentioned 'cognitive/affective skills' (which implies that the parent is actively doing something). Basic themes included 'improved coping skills' and 'how to help child when stuttering'; five parents mentioned 'family factors', such as 'working together', a 'more relaxed household', 'awareness of family influence', 'listening more carefully' and 'keeping work away from home'; and two parents mentioned 'resources/social support' which was mainly around 'social support'. Some of those respondents provided statements about both family factors and education, so there is some overlap in the respondents and subsequent "n" counts (see Figure 2.). For the parents, there were a total of 63 statements that were used and 0 were excluded as they all fitted into an Organising Theme.
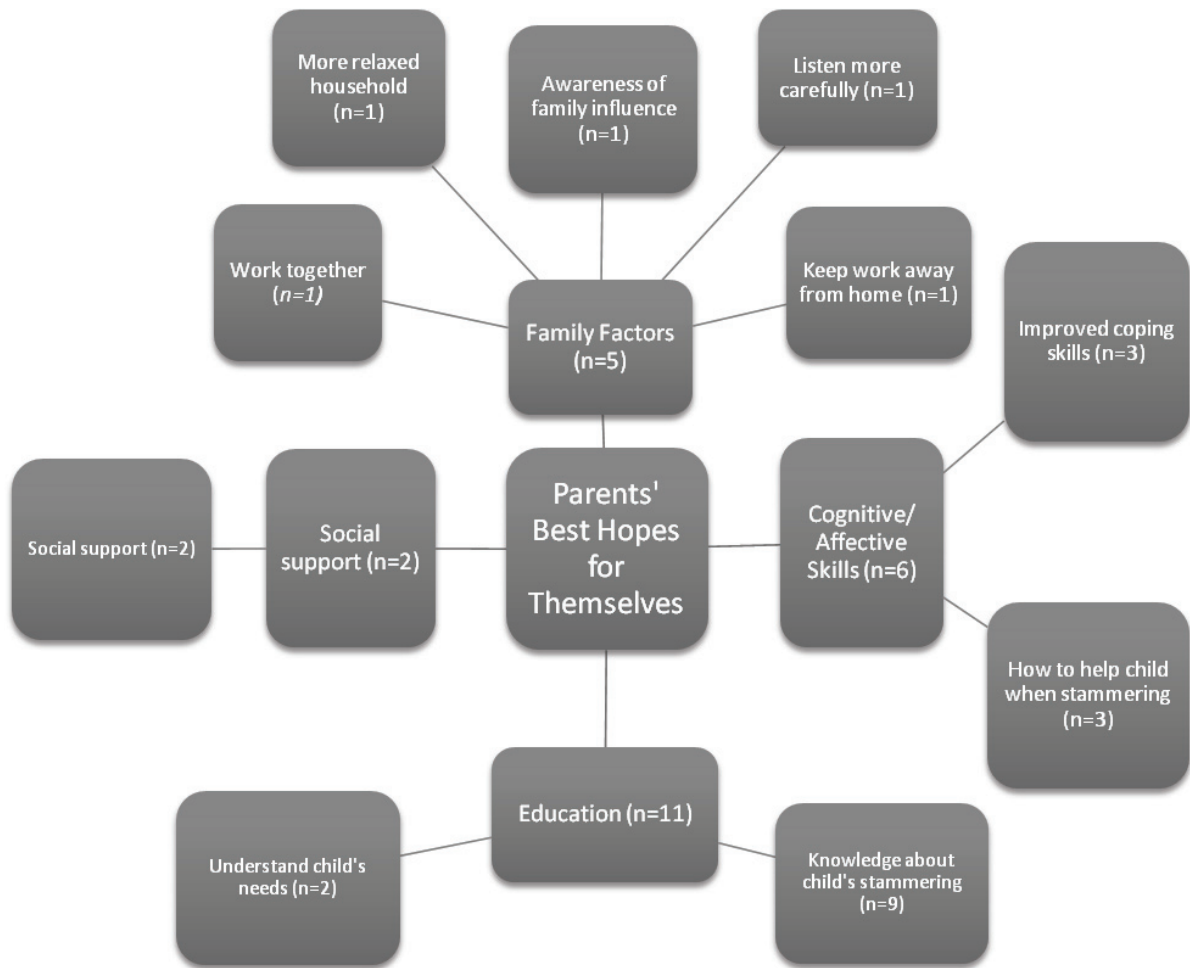
Figure 2. Parents' Best Hopes for themselves

3.2. Parents' Best Hopes for their child

All twelve parents mentioned 'child cognitive affective skills' under the Basic Themes of 'increased confidence', 'increased happiness', 'less anxious', and 'improved coping skills'; eight parents mentioned 'speech related' hopes including Basic Themes of 'increased fluency', 'use of speech strategies', 'manage speech' and 'more conversational turn-taking'; and three parents mentioned 'social support' with Basic Themes of 'less isolation', 'deal with teasing', 'meet other CWS' and 'socialising to be easier' (see Figure 3.).
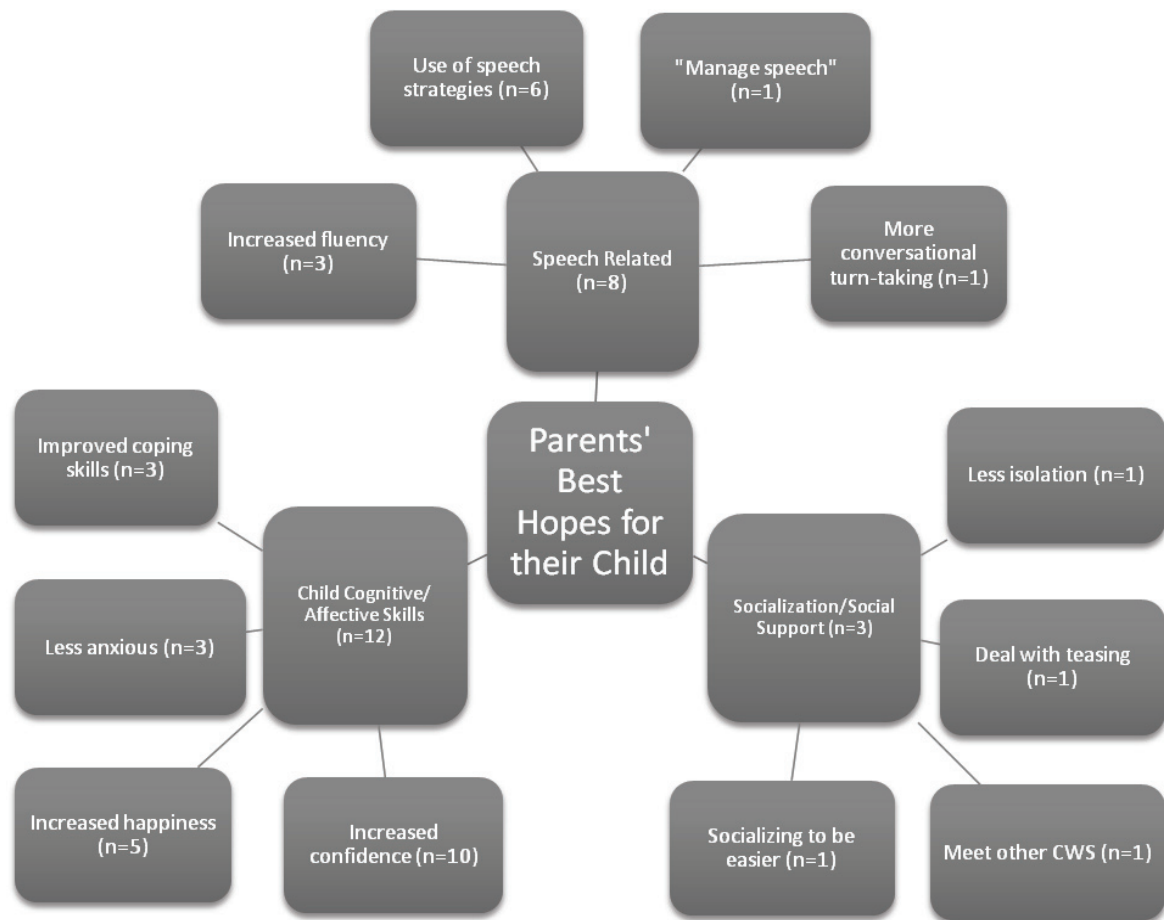
Figure 3. Parents' Best Hopes for their child

3.3. Children's Best Hopes from therapy

All seven children mentioned 'speech related' with Basic Themes of 'increased fluency' and 'increased use of techniques'; six children mentioned 'cognitive/affective skills' under the Basic Theme of 'increased confidence', 'increased happiness', and 'feel calmer'; six children mentioned 'participation', (with the Basic Theme of 'increased speaking in class' and 'increased speaking in community') and six children mentioned 'socialisation/social support' with the Basic Theme of 'meeting other CWS', 'more friends' and 'others awareness of child's improvement' (see Figure 4.). For the children, there were a total of 83 statements that were used in the analysis and four that were excluded. Whilst Basic Themes were allowed an n=1, Organising Themes required a minimum of n=2 (i.e. more than one respondent). Excluded statements were: less bodily tension C5, understanding/education C8 x 2, self disclosure C8.
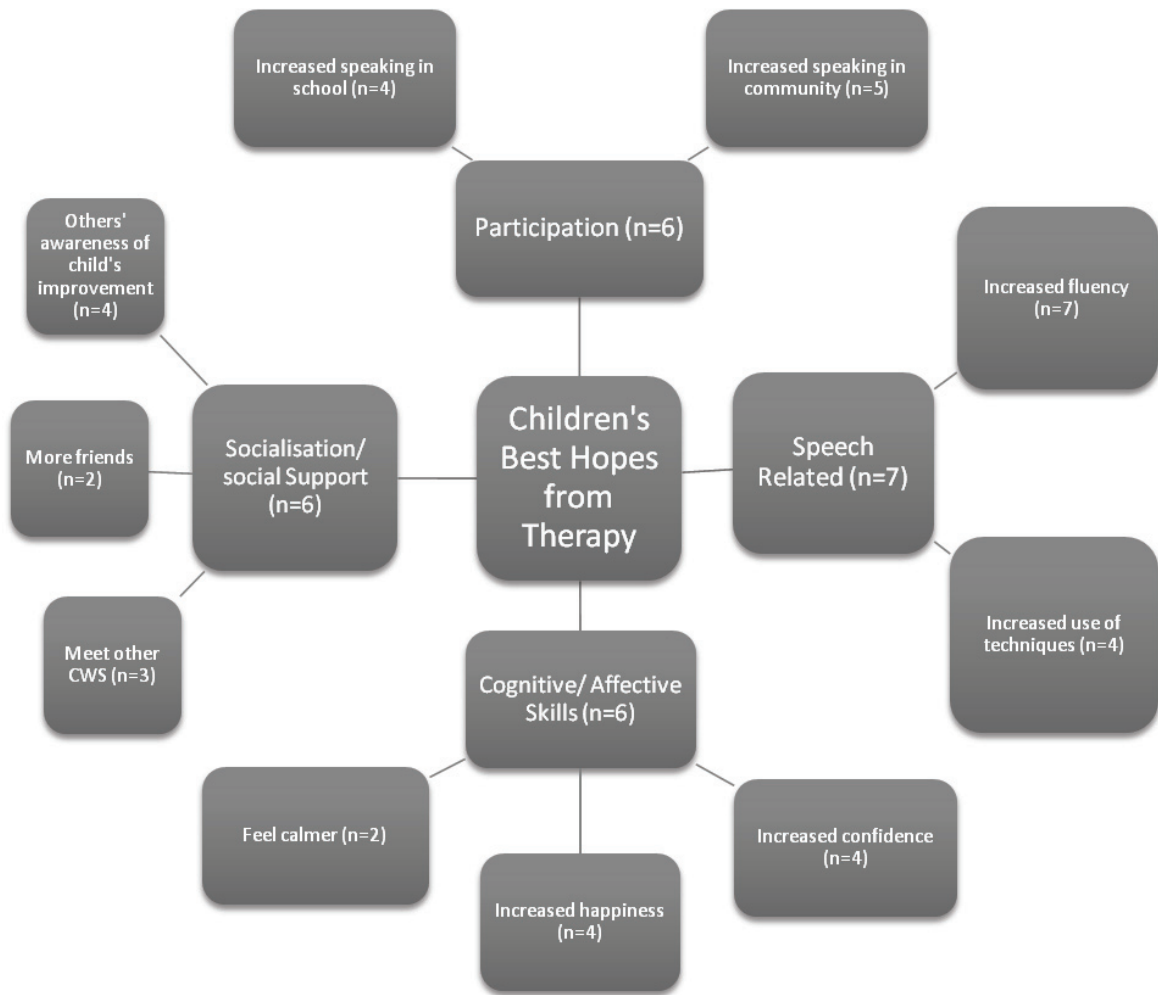
Figure 4. Children's Best Hopes from therapy

3.4. Alignment

A comparison of the Organising Themes across groups indicates some alignment between groups:
Cognitive/Affective skills (Organising Theme)
- Increased confidence (parents for child n=10, 83%; children n=4, 57%)
- Increased happiness (parents for child n=5, 42%; children n=4, 57%)
- Improved coping skills (parents for themselves n=3, 25%; parents for child n=3, 25%)
Speech Related (Organising Theme)
- Increased fluency (parents for child n=3, 25%; children n=7, 100%)
- Use of techniques/speech strategies (parents for child n=6, 50%; children n=4, 57%)
Socialisation/Social Support (Organising Theme)
Meet other CWS or parents of CWS (parents for themselves n=2, 17%; parents for child n=1, 8.3%; children n=3, 43%)

At the Basic Theme level there is also some alignment between groups in terms of:

- Increased confidence (parents for child n=10, 83%; children n=4, 57%)
- Increased happiness (parents for child n=5, 42%; children n=4, 57%)
- Improved coping skills (parents for themselves n=3, 25%; parents for child n=3, 25%)
- Increased fluency (parents for child n=3, 25%; children n=7, 100%)
- Use of techniques/speech strategies (parents for child n=6, 50%; children n=4, 57%)
- Meet other CWS or parents of CWS (parents for themselves n=2, 17%; parent for child n=1, 8.3%; children n=3, 43%)

Table 1 (below) summarises the Organising Themes for the parents (for themselves and for their child) and for the children demonstrating what the groups hoped for and the areas of alignment.

Table 1. Expectations from therapy – Organising Themes

Parent hopes (self) n=12	Parent hopes (child) n=12	Child hopes (self) n=7
Cognitive/affective skills (n=6)	Cognitive/affective skills (n=12)	Cognitive/affective skills (n=6)
Social support (n=2)	Socialisation/ social support (n=3)	Socialisation/ social support (n=6)
Family factors (n=5)	Speech related (n=8)	Speech related (n=7)
Education (n=11)		Participation (n=6)

4. Discussion

This is a qualitative study that aimed to explore what children who stutter and their parents expect from therapy and whether their hopes are aligned. In terms of expectations there were a number of common themes and differences that emerged across groups. At the Organising Theme level the groups have some commonality: 'cognitive/affective skills' is mentioned by parents for themselves and for their child and by children for themselves; 'speech' is mentioned by parents for their child and by children for themselves; 'social support' is mentioned three times and 'socialisation' is mentioned twice: (socialisation: parents for child, children) (see table 1). It seems that parents and their children know what they want from therapy and that their hopes have some alignment.

Interestingly Landau's retrospective study (2011, unpublished) found that significant others (SO) considered confidence building (50%), self-esteem raising (70%) and meeting other people who stutter (60%) as key priorities for the child who stutters. However the retrospective study found that children's hopes were centredaround fluency (100%). The findings of the present study indicate that children's hopes from therapy include fluency however there are other expectations too. It could be that the nature of the SFBT questioning style helps the child to broaden his/her perspective when considering expectations prior to the start of therapy so that their hopes are not solely fluency focused and are also about what difference it will make to be more fluent. This is a process that continues throughout the year-long programme.

There are also areas of difference. Parents identified hopes that the children did not mention in terms of:

- Education (n=11) which meant knowing more about their child's stuttering and understanding what their child needs; and
- Family Factors such as working together and a more relaxed household (n=5).

Children also identified hopes about 'participation'. The children's group were the only group to mention participation specifically, however parents best hopes for their children included basic themes of 'more conversational turn-taking' and 'socialising to be easier'. Parents did not specifically mention increased speaking in

certain contexts, such as school and the wider community, whilst their children did. It might be hypothesised that the children identify earlier in the process the need for increased communication in specific situations – whilst this probably becomes evident to parents during the process of the intensive programme but not initially. It is also possible that parents make the assumption that increased fluency and confidence will lead to increased participation and therefore they don't mention it specifically.

We can recognise that expectations and hopes are more diverse than just increased fluency – this supports an integrated therapy programme. Parents' and children's hopes identified through this qualitative research have some commonality particularly around 'speech', 'cognitive/affective skills' and 'socialisation/social support'. These findings underlie the importance of joint goal setting, developing a therapeutic alliance and having shared outcomes that can be evaluated. The results of this study, in terms of what parents and children hope for from therapy, supports the theoretical framework used for the intensive group programme (Cook &Botterill, 2005) that aims to:

1. develop social communication skills – helping CWS to be the best communicators they can be whether they stutter or not;
2. develop their cognitive-emotional skills - (i.e. increasing confidence, handling negative thoughts (Beck, 1976) and building resilience); and
3. develop speech management strategies.

Cook &Botterill's model (2005) is set within a circle representing the 'real world environment' (Manning, 2001) which can be viewed both in terms of the support structures around the child (parents expectations for themselves e.g. Education, Family factors, Cognitive/Affective skills, Social support) as well as the opportunities for the child themselves in terms of transfer, generalisation and increased participation.

One important question is to discuss how much priming parents and children receive prior to the day one SFBT scaling task where their Best Hopes are explored. Any prior contact may influence their expectations. As with any therapeutic intervention there is a process of 'socialisation' into the way of working. When the intensive programme is recommended discussion takes place about the broad aims and objectives and a rationale for why it may be a useful context for the child's therapy. It could be argued that parents' and children's expectations are influenced from first contact in their local clinic, a referral to the Michael Palin Centre (a specialist centre for stuttering) may also bring with it certain expectations, as might the in-depth assessment process at the MPC. In addition the parents' group had a visit from a parent on a previous course during the morning of day 1. This is a 45-minute session that enables them to hear from a parent who has completed the process they are embarking on. This cohort of parents and children decided to attend a two-week intensive therapy programme which requires a high level of commitment. Therefore the expectations explored through this qualitative research are from a particular cohort.

Secondly the nature of qualitative research includes the risk of bias during coding and data analayis. The advantage of researchers who were independent of the therapy and the centre where the therapy took place categorising the data is their objectivity.

In the future it may be useful to explore whether expectations change over time, whether expectations between groups become more closely aligned and whether expectations are met. This study did not include a systematic exploration of 'what children expect or would like for their parents'. This additional question could help us to promote understanding between parent-child dyads and address any mismatch. This question is now asked during the intensive programme.

References

Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research.* SAGE Publications, London, Thousand Oaks, CA and New Delhi) 1 (3), 385-405.

Beck, A.T. (1976) *Cognitive Therapy and the Emotional Disorders*. London, Penguin.

Cook, F., & Botterill, W. (2005) Family-based approach to therapy with primary school children: 'throwing the ball back'. In R. Lees and C. Stark (Eds.). *The Treatment of Stuttering in the Young School-aged Child.* London: Whurr.

Conture, E. (2001). *Stuttering: Its Nature, Diagnosis and Treatment*. Needham Heights: Allyn and Bacon.

De Shazer, S. (1985) *Keys to solution in Brief Therapy*. New York: Norton.

Elwyn, G., Edwards, & Grol, R. (1999) Towards a feasible model for shared decision making: focus group study with general practice registrars. *British Medical Journal, 319, 753-756.*

Elwyn, G., Edwards, A., Kinnersley, P. & Grol, R. (2000) Shared decision making and the concept of equipoise: the competencies of involving patients in healthcare choices. *British Journal of General Practice, 50, 892-897.*

Guitar, B. (1998). *Stuttering: An integrated approach to its nature and treatment*. Baltimore: Williams & Wilkins.

Landau, A.R. (2011) *Experiences and Expectations of Children who Stutter and their Significant Others: A small scale retrospective study*. (Unpublished MSc Dissertation), University College London.

Manning, W.H. (2001) *Clinical Decision Making in Fluency Disorders* (2nd Ed.)

Millard, S.K., (2011).Intensive group therapy for children who stutter: Early Evidence. *Perspectives on Fluency and Fluency Disorders,* 21, 22-32.

Riley. G. (1994). *Stuttering Severity Instrument for Children and Adults (3rd ed.).* Texas: Pro-ed Inc.

Ross, C.K., Frommelt, G., Hazelwood, L. & Chang, R.W. (1987) The Role of Expectations in Patient Satisfaction with Medical Care. *Journal of Health Care Management*, 7: 16-26.

Sackett, D.L., Rosenberg, M.C., Gray, J.A., Haynes, R.B., Richardson, W.S. (1996) Evidence based medicine: what it is and what it isn't. British Medical Journal; 312: 71-72.

Vanryckeghem, M., Hylebos, C., Brutten, G.J., &Peleman, M. (2001). The relationship between communication attitude and emotion of children who stutter. *Journal of Fluency Disorders, 26, 1-15.*

Yairi, E. and Ambrose, N.G.(2005) *For Clinicians by clinicians. Early Childhood Stuttering.* Pro-ed. Austin Texas.

Yaruss, S. & Quesal, R.W. (2006). Overall Assessment of the Speaker's Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment. *Journal of Fluency Disorders, 31,* 90-115.