RUNNING HEAD: EXPLORING PARTICIPANTS' EXPERIENCES OF THERAPY

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We Have a Voice:

Exploring Participants' Experiences of Stuttering Modification Therapy

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#### Abstract

**Purpose:** Qualitative data were obtained from eight people who stutter about their experiences and changes they perceived following attendance of an intensive group therapy intervention. Measures that related to reductions in stuttering, improved communicative confidence and impacts on stuttering and quality of life were used to complement the qualitative data.

Methods: Eight participants attended a group stuttering modification course for adults who stutter. They reported their experiences of therapy and perceived changes in a focus group immediately after therapy and at a semi-structured interview six months post-therapy. Participants completed five additional quantitative standardised outcome measures at three data collection points (before and directly after therapy and six months post-therapy). These measures provided information about stuttering severity and frequency, use of avoidance strategies, attitude change, communicative confidence, quality of life and locus of control. **Results**: Thematic analysis of the qualitative data identified four main areas: thoughts, feelings and behaviours before therapy and motivation for seeking therapy; direct experience of the course; learning outcomes and challenges and solutions for maintaining change; and ways in which attending therapy had made a difference. These reported changes were supported by the quantitative measures which demonstrated improved communicative confidence; reduction in stuttering frequency; increased self-awareness; affective, behavioural and cognitive changes, reduced use of avoidance strategies and lower impact of stuttering on quality of life.

**Conclusions**: The qualitative analyses confirmed positive speech and attitude changes consequent on participants' attendance at stuttering modification therapy. These changes, further corroborated by quantitative measures, were linked to reports of improved quality of

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life. Further research is required to investigate the effectiveness of this form of therapy empirically and from the client's perspective.

Three complications arise when considering how to provide effective therapy for adults who stutter<sup>1</sup>: (a) there is no therapeutic approach that is universally-applicable to individuals who stutter (Baxter et al., 2015); (b) stuttering is a heterogeneous condition necessitating diverse therapeutic approaches (Manning & DiLollo, 2017) and (c) there is no consensus concerning what constitutes effective therapy outcomes (Yaruss, 2010).

The type of therapeutic approach examined in this article is stuttering modification. This approach seeks to promote speech and affective changes. It is widely used but requires further empirical evaluation concerning its effectiveness (Blomgren, 2013). As background to the present study, evidence on the diverse nature of stuttering is reviewed, confirming the view that a range of therapeutic approaches is needed (stuttering modification and others). The section that follows describes stuttering modification therapy and contrasts it with other approaches. The available evidence on the efficacy of stuttering modification is briefly reviewed, highlighting the lack of qualitative research in this area. A consultation exercise with SLPs was carried out to determine the optimal way of measuring the effectiveness of stuttering modification therapy. This revealed that obtaining the views of clients was vital. Results from this consultation informed the qualitative study which focused on the direct experience and reported changes of participants who attended stuttering modification therapy.

## **The Diverse Nature of Stuttering**

Stuttering is a highly individual and complex condition which affects 5% of children and 1% of adults worldwide (Conture, 1996). The commonest type of stuttering, developmental, usually starts between the ages of 2 and 4 (Howell, 2011). It is a neurodevelopmental condition that involves the many different brain systems involved in producing speech (Chang, Zhu, Choo, & Angstadt, 2015; Walsh, Mettel, & Smith, 2015). There is growing evidence for a genetic component to stuttering (Kraft & Yairi, 2011) but the way genetics links to brain functioning and behaviour has not yet been established (Howell, 2011).

Stuttering has been perceived traditionally as difficulty in production of fluent speech (Bloodstein & Bernstein Ratner, 2008). Typical stuttered speech behaviours are prolongations, blocking of sounds and repetition of sounds and syllables. Although these behaviours are the most apparent aspects to a listener, often there are chronic psychological consequences of stuttering, revealed through client self-report (Blomgren, 2013; Plexico, Manning, & Levitt, 2009; Sheehan, 1970; Yaruss, 2010). For instance, Corcoran and Stewart (1998) interviewed eight people who stuttered and identified suffering from the effects of stuttering as the principal theme, with four major sub-elements (helplessness, shame, fear and avoidance). Tudor, Davis, Brewin and Howell (2013) reported intrusive memories in people who stutter and fluent controls, and also identified helplessness, shame, sadness and frustration as key experiences for this group. People who stutter frequently report a reduced quality of life and that attainment of their life ambitions has been limited (Boyle, 2015). Stuttering has a negative impact on the mental health of some people who stutter (Craig, Blumgart & Tran, 2009; Tudor et al., 2013), and they are at high risk of social anxiety (Iverach & Rapee, 2014). Stigma also plays a role in the development of affective, behavioural and cognitive consequences of stuttering. It is plausible that the public stigma people who stutter experience (St. Louis, 2015; Simon, 2011), and the resultant self-stigma (Boyle, 2013; Boyle, 2015), lead to avoidance of speaking that stops manifestation of stuttering ('avoidance' for short).

## **Stuttering Modification Therapy**

Given the diverse nature of stuttering, it is not surprising that there are many types of therapy for children, and adults, who stutter. Two common options for adults who stutter are speech restructuring and stuttering modification (Blomgren, 2010). Integrated models that

combine fluency shaping with desensitisation and modification are also available (Manning & DiLollo, 2017; Shapiro, 1999). Whereas speech restructuring focuses on using fluency techniques, stuttering modification is holistic, focusing initially on the psychological effects of stuttering by encouraging clients to reduce their fears by using desensitisation approaches. Clients are then taught to reduce struggle behaviours using modification techniques (Van Riper, 1973).

Systematic reviews that include these approaches have been conducted to guide clinical decisions and to evaluate evidence-bases (Baxter et al., 2015; Bothe, Davidow, Bramlett, Franic, & Ingham, 2006a; 2006b; Herder, Howard, Nye, & Vanryckeghem, 2006; Johnson et al., 2015; Neumann et al., 2017; Nye & Hahs-Vaughn, 2011). Apart from Neumann et al. (2017), who reported that speech restructuring was the most effective form of therapy, the findings from these reviews are inconclusive and indicate that most approaches benefit some people who stutter (Zebrowski & Arenas, 2011).

Speech restructuring considers reduction in severity of stuttering as the most important therapy outcome. Many of the reviews apply this measure when evaluating stuttering modification. However, outcome measures need to be broadened to reflect the wider experience of stuttering. This perspective is gaining ground amongst some researchers, as shown in the following quote: "While a sizeable body of studies included in this review reported effectiveness in terms of reduction in the overt frequency or severity of stuttering it is debateable how significant a reduction of, for example, two to three syllables per 100 syllables might be for the everyday functioning of a PWS, or indeed whether this reduction in overt stuttering level was the issue of most concern to a PWS." (Baxter et al., 2015, p. 689).

## **Evidence-base for Stuttering Modification Approaches**

Speech restructuring has a more extensive evidence-base than does stuttering modification because a reduction in syllables stuttered alone is commonly used as an outcome measure (Blomgren, 2013; Yaruss, 1998; Zebrowski & Arenas, 2011). However, focusing exclusively on speech change ignores the many ways in which a successful therapy outcome can be achieved. The desirability of alternative forms of therapy is supported by a survey of 216 people who stutter (Venkatagiri, 2009). Twenty percent of participants chose 'fluency' and 23% 'freedom from the need to be fluent' unequivocally as outcomes. These choices essentially reflect a preference for either speech restructuring or stuttering modification respectively. Venkatagiri concluded from the survey that a substantial proportion of people who stutter would choose stuttering modification if it were offered as a therapy.

A UK national centre for adult stuttering therapy favors stuttering modification: Equal weight is given to the overt (speech disfluencies) and covert (thoughts and feelings) aspects of stuttering, and the complex interplay between attitude and speech change is acknowledged. The approach primarily employs Van Riper's (1973) way of working and closely follows his stages of identification, desensitisation, modification and generalisation. Identification work aims to develop a client's awareness of their unique pattern of stuttering and their affective and cognitive responses. Building on this awareness, desensitisation is about the client becoming more open to, and less fearful of, the experience of stuttering, through the use of tools such as voluntary stuttering and self-advertising. The modification stage focuses on learning ways to modify moments of stuttering, either before, during or after it occurs, thereby helping the client to stutter with less tension and struggle. Generalisation seeks to stabilise and extend the progress made by the client and is achieved by taking the therapy out of the clinic and into the real world. In addition to Van Riper's stages, Sheehan's (1970) principles of avoidance reduction play a key role in the desensitisation phase of therapy. Cognitive behaviour therapy (Beck, 1995), mindfulness (Kabat-Zinn, 1994) and acceptance

and commitment therapy (Hayes, Strosahl & Wilson, 1999) are also incorporated, to support the four different stages of therapy.

Yaruss (1998) and Blomgren (2013) have highlighted the popularity of stuttering modification based on its frequent description in text books on stuttering (Manning & DiLollo, 2017; Peters & Guitar, 1991). Two surveys of people who stutter found that stuttering modification was considered to be either equally beneficial, or of more benefit, than speech restructuring. Thus, Yaruss et al. (2002) reported that a majority of their 71 participants reported that they benefitted from stuttering modification techniques. Euler, Lange, Schroeder and Neumann's (2014) retrospective study, involving 88 people who stutter, found that stuttering modification and fluency shaping had equally favourable effectiveness ratings.

Despite its popularity, there are fewer efficacy studies on stuttering modification than there are for fluency-based types of intervention. Mixed findings are reported in the studies that exist (Blomgren & Merrill, 2005; Eichstädt, Watt & Girson, 1998; Georgieva, 2015; Linklater, Murphy & Quigley, 2005; Natke, Alperman, Hell, Kuckenberg & Zuckner, 2010; Tsiamtsiouris & Krieger, 2010). None of these studies included a qualitative component. Indeed, there has been a relative lack of qualitative investigation into stuttering overall, as highlighted by Hayhow and Stewart (2006) and Tetnowski and Damico (2001). A systematic review, carried out by Johnson et al. (2015), synthesized qualitative evidence of nonpharmacological interventions for developmental stuttering. It identified 26 relevant papers in comparison to the 112 papers which were identified in a parallel review of quantitative evidence (Baxter et al., 2015). Out of the 26 papers, only five papers explored participants' experiences of therapy (Corcoran & Stewart, 1995; Cream, Onslow, Packman & Llewellyn, 2003; Irani, Gabel, Daniels & Hughes, 2012; Plexico, Manning & DiLollo, 2010; Stewart & Richardson, 2004). Three of these five papers explored client perceptions of a specific

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therapeutic intervention. Cream et al. (2003) recognised the paucity of qualitative research when reviewing outcomes of a behavioural treatment such as prolonged speech, which has a high relapse rate (Onslow, Costa, Andrews, Harrison & Packman, 1996). Consequently, the Cream et al. (2003) study focused on client experiences of using prolonged speech following therapy. A major theme reported in this study was that the 10 participants continued to feel different from people who did not stutter after therapy. Both the Irani et al. (2012) and the Stewart and Richardson (2004) studies focused on client experiences of an integrated approach. The Irani et al. study involved seven participants who had attended the Intensive Stuttering Clinic for Adolescents and Adults at Bowling Green State University in Ohio, USA. The two main themes from this study were classified as direct effects and indirect effects. Direct effects of therapy were summarised as the positive or negative effects of the different components of the program. This included the duration and nature of the program; being with other people who stutter; speech techniques learned; attitude change and counselling, and desensitisation and transfer of skills. Indirect effects summarised subthemes not directly related to the program but which had a positive impact (for example, motivation and readiness for therapy and clinicians' attributes). Stewart and Richardson (2004) gave a number of reasons that showed the benefits in asking the client directly about their experience of therapy. Benefits included the richness of data generated in this way, allowing exploration of which aspects of therapy are responsible for change and the evaluation of long-term effects of therapy. Key themes identified by Stewart and Richardson were reduced isolation, importance of support, increased fluency, issues about transfer, change in attitude and change in lifestyle. The authors concluded: 'One might argue that the most important 'gold standard of effectiveness' is one where the client perceives the outcome as of value.' (p. 107).

#### Method

## **Participants**

Clients were invited to participate in the study following their recruitment to two group stuttering modification therapy courses in 2016. Eight clients (seven male, one female) out of a possible 17 took part. Age ranged from 20 to 48 years (M = 31.22 years; SD = 11.53 years). Three of the eight participants had received therapy in adulthood. All participants had English as their first language. Table 1 provides information about each participant (pseudonyms are used for confidentiality).

Table 1 about here

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With regards to severity of overt stuttering as measured by the SSI-4 (Riley, 2009), three participants had moderate stuttering, three participants had mild stuttering, one participant had very mild stuttering and one participant's stutter was so minimal that it did not appear on the scale. To include participants with anything less than moderate stuttering is unusual in research studies; the rationale for including these participants was a desire to reflect the range of clients presenting for therapy.

## **Intensive Stuttering Therapy**

Candidates had been assessed for their suitability for a day-time intensive stuttering therapy group course at a UK national centre. The assessment included an in-depth discussion of their hopes and expectations for therapy and an explanation of the therapy principles. All potential candidates had been accepted on the course based on the following criteria: chronological age (18 years of age and upwards); motivation and readiness for change; understanding of therapy approach and commitment required; ability and desire to participate in group therapy; mild to severe level of overt stuttering. (With regard to the latter point, if a client presented with a highly covert stutter, intensive therapy would be contra-indicated because the rapid pace of change could potentially be destabilising and distressing.)

The course followed a stuttering modification approach. It ran for seven days in total, from 9.30 am to 5.30 pm each day. The first five days covered the stages of identification, desensitisation and part of modification, followed by a four-to-six week break. The rationale for the break relates to transfer and generalisation of learning: clients used this time to work on aims in their everyday lives and were encouraged to keep in regular contact with each other as a means of support. The last two days of the course provided an opportunity for problem-solving, further practice and completion of the modification stage. At the end of the course, all attendees were encouraged to receive follow-up therapy. Three specialist SLPs delivered the programme for up to 10 clients per course. The group work was regarded as essential because it encouraged participants to learn from, and support, one another and gave opportunities to practise real-life scenarios such as group discussions, interviews and presentations.

## Design

Ethics approval for this study was granted by UCL Department of Experimental Psychology (EP/2016/002), and all participants gave informed consent. Each participant took part in a focus group directly after therapy and in a semi-structured interview six months after therapy (described below). In addition, participants completed four self-report assessments and one objective measure (described below) at three different collection points: (a) at the beginning of therapy; (b) immediately after therapy and (c) at the six months follow-up.

## Procedures

**Qualitative measures.** As mentioned in the introduction, no previous stuttering modification study was located which explored participants' experiences using qualitative methods. For this reason, each participant took part in a focus group and semi-structured

interview. The protocol for both focus group and semi-structured interview was developed via a survey of eight UK-based SLPs. Each SLP had a minimum of 10 years' specialist experience working with adults who stuttered. Topics of interest, identified in the survey, were:

- What motivated participants to attend therapy?
- What were they expecting? Were their expectations met?
- What did they gain from attending therapy?
- What was their opinion of therapy?
- What difference did attending therapy make to their everyday lives?
- How will they take their learning forward?

Questions related to these topics were generated by the first author and two additional specialist SLPS, piloted and revised following feedback from three SLPs and two adults who stutter. Detailed guides for both the focus group and semi-structured interviews were developed in this way (see appendix).

*Focus group.* The focus group gave participants the opportunity to reflect, whilst therapy was fresh in their minds, on the aspects of therapy that were most and least useful to them, and changes they made as a result of therapy.

Two face-to-face focus groups were held immediately after the end of each therapy programme; these were facilitated by a specialist SLP who was unfamiliar to the participants but was familiar with the therapy approach and qualitative interviewing procedures. In this way she was well positioned to probe where appropriate, to obtain a deeper understanding of each participant's experience of therapy and subsequent changes.

*Semi-structured interview.* The semi-structured interviews, which took place six months after the end of therapy, obtained participants' longer-term perspectives on the therapy experience, and any functional changes they had noticed, linked to attendance on the

course. Face-to-face interviews with individual participants lasted between 40 and 70 minutes and were facilitated by a specialist SLP not known to the participants, with an in depth knowledge of the therapy process.

*Analysis of focus groups and semi-structured interviews.* The two focus groups and eight semi-structured interviews were recorded using a Zoom H2 recorder. The interviews were transcribed orthographically and verbatim by the first author. The transcriptions were then added to the QDA Miner Lite software for detailed thematic analysis (Patton, 2002). Thematic analysis was used because of its flexibility and because it produced a detailed account of the data (Braun & Clarke, 2008).

Data from the focus groups and interviews were combined for analysis with the goal of identifying common themes relating to participants' experience of therapy and meaningful changes. The analysis followed the six stages described by Braun and Clarke (2013) and thematic networks were added (Attride-Stirling, 2001). The first stage involved detailed familiarisation with the data, achieved through transcription, repeated readings and notetaking, actively looking out for possible themes and patterns of themes. Every line of text was analysed for basic themes, defined by Attride-Stirling as 'lowest-order premises evident in the text' (p.388). During the second stage initial codes were allocated systematically to extracts of text for the entire data set. In this way the coding of the raw data was inclusive, thorough and systematic. The third stage focused on searching for themes that were allocated to codes identified in the second stage. This stage led to generation of organising themes, designed to capture categories of basic themes. The fourth stage involved two related processes: the first was to decide whether all the codes allocated to a particular theme fitted well under that theme, belonged to a different theme or the theme needed to be altered. The second process at the fourth stage required a re-reading of the entire data set with a view to ensuring codes related logically to themes. At this stage, thematic networks were created

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which illustrated how basic, organising and global themes related to one another. Global themes are 'super-ordinate themes encapsulating the principal metaphors in the text as a whole' (Attride-Stirling, p.388). The fifth stage involved defining and naming themes and possible sub-themes: each theme, with its related codes, was analysed and described. The final stage was to write a report that summarised the themes identified and select illustrative quotes from the data, with reference back to the research question and relevant literature.

To ensure reliability of the analysis, a coding framework was developed and refined at stage two, and shared with two experienced SLPs who analysed 20% of the data set. Where there was difference of opinion, consensus was achieved through discussion and changes made to the coding framework.

Researcher bias also needed to be taken into account as this could impact on the credibility of the study. In this case, the first author is a person who stutters and SLP employed at the UK centre, involved in developing and delivering the therapy intervention. To mitigate against bias with regard to the thematic analysis, the first author identified her beliefs and assumptions around clients' experience of therapy and subsequent changes. Examples of the first author's biases were:

- Seeking 100% fluency is unrealistic and unhelpful; working on reducing struggle and tension is more helpful in the long-term
- Clients' expectations of therapy may change over time
- Speech change is only effective if accompanied by attitude change
- Reducing avoidance behaviours is essential and needs to precede direct speech work

The resultant increased awareness enabled her to put to one side her personal standpoint and to analyse the data objectively.

## Quantitative measures.

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*Severity of stuttering.* Each participant was videoed reading a short passage and speaking spontaneously to an unfamiliar person at each data collection point. The reading and spontaneous speech samples were analysed subsequently using the Stuttering Severity Instrument – Fourth Edition, SSI-4 (Riley, 2009), which is norm-referenced and has been assessed for reliability and validity (Todd et al., 2014). SSI-4 provides an objective measure of three areas related to physical stuttering: frequency and length of stuttering events and physical concomitant behaviours. To assess inter-rater reliability, 20% of the speech samples were analysed by a second person. Cohen's Kappa (1960) was calculated, based on total scores for the SS1-4, to determine agreement between the two raters. Kappa was 0.71, indicating substantial agreement (Landis & Koch, 1977).

*S24-scale (Andrews & Cutler, 1974).* This 24-item dichotomous self-report questionnaire measures the communication attitudes of people who stutter. Users judge whether each of the 24 statements (e.g. 'I make a favourable impression when I talk') is true or false according to their personal experience. It has a test-retest reliability of .68 and good content validity (Franic & Bothe, 2008). Norm score for people who stutter is 19.22 and norm score for people who do not stutter is 9.14.

*Overall Assessment of the Speaker's Assessment of Stuttering, OASES (Yaruss & Quesal, 2010).* OASES is a 100-item self-report instrument and was used to obtain information on four areas: general knowledge and self-perceptions about stuttering; responses to stuttering (emotional, physical and cognitive), influence of stuttering on daily communication, and impact of stuttering on quality of life. Each item is rated on a 5-point scale, with high scores indicating greater impact of stuttering. It has an average reliability coefficient of .96 and a test-retest reliability of .95.

In addition, the Wright and Ayre Stuttering Self-Rating Profile, WASSP (Wright & Ayre, 2000) and the Locus of Control of Behaviour Scale (Craig, Franklin & Andrews, 1984)

were used but are not referred to in this study, the primary aim of which was to report on the qualitative analyses, supported by the quantitative measures.

#### Results

## **Qualitative Data**

The qualitative data are reported here according to the thematic analyses carried out, which identified themes both across and within participant's experiences of therapy. Each figure is a thematic network (Attride-Stirling, 2001), illustrating a global theme, together with its associated organizing and basic themes

## Theme 1: Before therapy: at a low ebb (Figure 1).

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Figure 1 about here

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Reflecting on their motivation for seeking therapy, all participants reported a range of negative feelings including shame, embarrassment, frustration, isolation, anger, desperation, fear and lack of confidence. These feelings were frequently accompanied by negative thoughts about their stuttering and the impact it was having on their lives (*'I just got into the feeling of feeling useless and just really really in a dark place', Jeff*). Over half of the participants commented on their readiness for therapy, using terms such as 'desperate for help' and describing therapy as their last resort.

Strongly connected to these negative thoughts and feelings were reports of avoidance:

'I felt really frustrated that I couldn't be me, I didn't feel able to stammer because I was scared of stammering at work and then I became very quiet so I would go to meetings and not say anything.' (Claire)

As illustrated in the quote above, workplace challenges featured strongly as a reason for attending therapy; examples of demanding speaking situations included meetings, interviews, presentations and communicating with clients and colleagues.

Most participants reported that at the beginning of therapy they wanted to reduce their stuttering (*'all I knew was my end goal was to not stammer as much', Fred*) with frequent references to learning or revising speech techniques. Over half of participants wanted to gain a deeper understanding of their stuttering. Some participants expressed the desire to change their perception of stuttering by becoming more open and accepting of it:

'I think my goals were to change the way I feel about my stammer cos I think that was a big part of why I avoided so much.' (Peter)

## .Theme 2: Direct experience of the course (see Figure 2).

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Figure 2 about here

All participants commented that the course had met or surpassed their expectations, with several reporting that the course content was different from what they had expected: they had believed the content would focus primarily on learning speech techniques.

The majority of participants experienced unexpected learning as a result of increased awareness about their stuttering, their feelings towards it and their communication in general. Areas where they became more aware included extensive use of avoidance strategies, lack of eye-contact, rapid rate of speech and reduced volume:

'And I thought I was in control of the stammering but I was realizing, I realised that I was using filler words so in fact I wasn't actually in control of anything and I thought I was quite open about it but after coming here I realised that I wasn't open at all.' (Andy)

When talking about their likes and dislikes, many commented on the value of identification as a means of increased awareness ('*I've always had that belief that once you know what the problem was, it's easier to solve', Fred*) and in particular watching themselves on video. Likewise, working on becoming more open about stuttering was described as a useful element of the course and in this respect practising speaking exercises outside, involving members of the general public, was frequently mentioned as an uncomfortable but beneficial task:

'A part of the therapy when we had to go out and speak to 5 people, that helped me be more confident speaking to people. I find it's something that's not really scary to do.' (Terry)

The third stage of therapy, modification, was frequently cited as a key element of therapy with some frustration expressed by many that this part was not allocated sufficient time during the intervention.

All participants commented on the value of being part of a group, citing various reasons for this: sharing experiences openly and honestly, being understood, reassurance ('I think some of it felt like I wasn't doing that badly', Sam), reduced sense of isolation, healthy competition' ('if they can do it, I can do it', it's no big deal', Fred), providing motivating feedback, and the opportunity to practise speech techniques in a safe space.

Theme 3: Key learning and challenges/solutions (see Figure 3).

Figure 3 about here

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Key attitudinal changes included increased openness, confidence and acceptance. All participants described talking to friends, family and colleagues about their stuttering, stuttering more openly, and use of self-advertising and voluntary stuttering. (Self-advertising refers to disclosing to others about stuttering and voluntary stuttering refers to stuttering on purpose; both are used as a means to reduce the fear of stuttering.) The benefits of being open about stuttering included feeling more comfortable about stuttering, being themselves (*'it's changed everything for me because it's allowed me to be me', Michael*), developing new or existing relationships and feeling more confident.

All participants reported increased confidence, either in relation to using speech techniques or to being able to express themselves freely, without the fear of being judged. Some participants described feeling empowered, with the skills and knowledge to manage their stuttering on a daily basis and/or the right to stutter if they so wish.

Closely linked to openness and confidence was a greater acceptance of stuttering, reported by all participants. Participants either identified increased acceptance as a way of supporting speech change (*'I'm more accepting and I now see it as an opportunity to practise and refresh my memory on the techniques I have learnt', Fred*) or as developing the belief that stuttering is acceptable (*'it has given me the confidence to stammer more openly and to consider that as an okay form of communication', Sam*).

All participants reported a change in their feelings and thoughts around stuttering. In terms of feelings, participants described feeling less anxious, worried, angry, frustrated and embarrassed and more positive, laid-back and relaxed. In terms of thoughts, some participants reported spending less time thinking about stuttering and more time thinking about what they wanted to say. Others reported having the skills to modify or be with their thoughts.

'And even if you just write down your negative thoughts and then start challenging yourself, generally you can drive a bus through most of them.' (Michael)

As a result of the changes above, all participants reported a shift in their attitude towards stuttering whereby whether they stuttered or not became less important than getting their message across as well as being able to drawn upon speech techniques: 'I've got a stammer and it doesn't matter because I'm still getting my point across to you.' (Sarah)

Changes in behaviour included direct speech change and reduced avoidance. All participants reported making speech changes, whether it be improved fluency (*'my goal was to reduce my stammering by at least 75% which I managed to do', Terry*), ability to use strategies (*'I use the techniques every day', Peter*) or to modify another aspect of their communication.

A major area of behavioural change reported by all participants was reduced avoidance of stuttering. This included reduction of word substitution ('I don't think 'Oh, I should avoid saying that because I might stammer'', Terry), participating in previously avoided situations and speaking to more people.

Some participants described stuttering more as a result of avoiding less and recognised the benefits of reduced avoidance such as speaking to more people and expressing themselves freely.

With regards to challenges and solutions, several participants described how it was easier to use speech techniques in some situations than others and the frustration they experienced when they were not able to use the technique in the moment.

Several spoke of the difficulties they faced being more open about stuttering (*'it was very tough to just tell people that I do have a stammer', Peter*) and reducing avoidance (*'I try not to avoid although word avoidance has slipped in again', Sam*). Several participants talked about their fear of relapse, recognising the need for regular practice. What prevented some participants from relapsing was a strong desire not to return to their original starting-point or not wanting the time and money they had invested in the course to go to waste.

When faced with these challenges, participants described solutions such as seeking support from other members of the group, their family and friends, and/or organisations.

With regard to group support, frequent reference was made to the 'buddy system' set up at the end of the first week of the course, where each person linked up with another person, for mutual support.

To maintain the progress made on the course, several participants referred to the skills and knowledge they had acquired during the course to become their own therapist.

Theme 4: Impact of the learning: making a difference to everyday life (see Figure 4).

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Figure 4 about here

All participants commented that attending the course had made a difference to them and the way they led their lives. Common themes, already reported above, included increased confidence, more openness, greater awareness, communicating with more people,

feeling less negatively about stuttering and being more assertive.

With regard to their professional lives, most participants reported changes in the way they are perceived, either at work or at study, and the benefits of being open about their stuttering in the workplace, such as developing friendships with colleagues and feeling more accepted at work. Others described how using speech techniques in work situations such as presentations, phone-calls and interviews had made communication easier.

With regards to their personal lives, most participants reported speaking more openly and honestly to friends and family ('*I suppose it's allowed more intimate relationships into fruition'*, *Sam*), speaking more to their peers ('*I've been speaking more to my classmates*, *Terry*), socialising more and seeking new relationships.

## **Quantitative Data**

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For ease of reference, the three data collection points are referred to as follows:

- T1: Time 1, start of course;
- T2: Time 2, end of course;

T3: Time 3, six months after the end of therapy.

**Inclusion of quantitative data:** Data from the three norm-referenced assessments are included as a means to complement the qualitative data provided thus far.

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Table 2 about here

Improved ease of speech. Severity of stuttering was measured using the Stuttering Severity Instrument – Fourth Edition (Riley, 2009). As illustrated in Table 2, severity equivalent descriptions (Riley, 2009) changed from 'moderate' at T1 to 'mild' or 'very mild' at T3, for three participants (Peter, Terry and Sarah). All other participants remained at very mild or mild severity ratings. When the data for all eight participants were analysed statistically, using a repeated measures ANOVA, no significant difference was found. Mauchly's test was significant ( $\chi^2(2)=15.046$ , p<0.001), so sphericity was therefore violated. Correction of degrees of freedom was attempted, using the Greenhouse-Geisser estimates ( $\epsilon$ = 0.521), but significant levels were still not obtained (p = .306).

**Increased communicative confidence.** Referring to the results from the self-rating profile, the S24 scale (Andrews & Cutler, 1974) in Table 2, all participants' scores reduced from Time 1 to Time 3 and were within or approaching the norm for people who do not stutter (9.14), apart from one participant, Peter, whose S24 score increased. A repeated measures ANOVA identified that the group mean scores differed significantly between time points (*F*2, 14 = 6.273, *p* = .011). Post-hoc tests including the Bonferroni correction revealed a significant difference between T1 and T2 (*p* = .031) and a difference approaching

significance between T1 and T3 (p = .051). Therefore, it can be concluded that participants' attitude towards their communication improved between T1 and T3.

**Overall impact of stuttering.** The OASES (Yaruss & Quesal, 2010) was used to measure participants' perceptions of the impact of stuttering on their quality of life. Table 2 shows that for three participants (Jeff, Andy and Michael), their impact score stayed the same, whereas for the other five participants (Peter, Sam, Terry, Fred and Sarah), it reduced. A repeated measures ANOVA identified that the mean scores differed statistically between time points (F2, 14 = 14.86, p = .000). Post-hoc tests including the Bonferroni correction identified a significant difference between T1 and T2 (p = .038) and a significant difference between T1 and T3 (p = .005). Further analysis identified that two sub-tests were responsible for these differences: section 1 - general information (F2, 14 = 15.819, p = .000) and section 2 - speaker's reactions (F2, 14 = 10.546, p = .002). For both sections post-hoc tests including the Bonferroni correction showed a significant difference between T1 and T2 (section 1 p = .034; section 2 p = .021) and a significant difference between T1 and T3 (section 1 p = .001; section 2 p = .020).

These results from the OASES indicated improvement in the following areas: ability to manage stuttering, knowledge about stuttering, overall impression of speaking ability and affective, behavioural and cognitive reactions to stuttering.

## Discussion

This qualitative study provided a perspective on participants' perceptions of therapy and changes to participants' everyday lives. Participants sought therapy when they were at a low ebb in relation to their work, social life or education. Expectations from therapy were for speech change initially. Despite their expectations being somewhat different from the course goals, all participants reported that their expectations were met or exceeded and that therapy had made a difference to their lives.

Unexpected benefits for many participants were increased awareness of their avoidance strategies and insight into their overall communication skills. Participants valued working in groups and identified the group environment as a safe space in which to practise strategies, similar to the theme of 'being with other people who stutter' reported by Irani et al. (2012) and the themes 'reduced isolation' and 'improvements made in the group' reported by Stewart and Richardson (2004). Exercises conducted outside of the clinic space were considered vital for developing confidence. Specific changes associated with the course content were in outlook and in behaviour, reflecting the equal importance placed on attitude and speech change in therapy, with changes in attitude supporting the speech work, as reported by Irani et al. (2012).

Self-acceptance and reduced avoidance were commonly reported, mirroring the finding by Plexico, Manning and DiLollo (2005) that one of the five key themes for successful stuttering management is self-acceptance and fear reduction. In addition, participants reported positive impact on their work, study and personal lives, including improved status at work and development of new and existing friendships. These findings are tangible evidence of ways in which individual participants improved their lives, subsequent to attending therapy.

Participants described the challenges in integrating the learning into their everyday lives. These challenges included difficulty in using speech techniques or being open about stuttering in certain situations and the possibility of relapse. The difficulty in generalising and transferring speech techniques to every situation is a common theme as reported by both Cream et al. (2003) and Stewart and Richardson (2004). Participants suggested solutions including support from others (group members, family and friends) and organisations/groups, as well as developing the skills to become their own therapist.

All participants commented on how their speech had changed. This included increased fluency and easier speech. Of particular note were comments from three participants that indicated that they noticed more stuttering because they spoke more and avoided less. Objectively, this increase could be seen as a negative outcome when reduction in stuttering is targeted (Bloodstein & Bernstein Ratner, 2008). However, a key aspect of stuttering modification therapy is avoidance reduction and, clinically, a positive outcome is more speaking (and possibly more stuttering).

These findings from the qualitative analyses are supported by the quantitative data. Communicative confidence, as measured by the S24 scale (Andrews & Cutler, 1974), improved over the time period for all participants, except one With respect to improvements in speech (as assayed by SSI-4), stuttering severity declined for three participants. The remaining five participants had a mild stutter at the beginning of therapy. Therefore, there was little scope for severity to reduce further. This could have been avoided by excluding participants whose severity fell below a certain percentage (Carey et al., 2010). However, this was not done in the present study because the intention here was to document the therapy experience of participants with diverse forms of stuttering (including variations in severity). OASES scores (Yaruss & Quesal, 2010) showed a reduced impact of stuttering for the majority of participants, in line with participants' recognition that they were thinking, feeling and behaving differently after therapy.

## **Clinical Implications**

When considering changes to the stuttering modification course delivered at the UK national centre, more time needs to be allowed for practising speech techniques in and out of the clinic room. In addition, the way cognitive behaviour therapy is woven into the content of the course needs to be re-appraised as most participants had poor recall of this particular component. This may have been because this element was considered less helpful and therefore perhaps unnecessary. Alternatively, this may have arisen because the questions related to cognitive behaviour therapy used terminology that was confusing and unfamiliar.

Broader clinical implications relate to the value participants placed on the group aspect of the therapy and the safe space provided for working together on different aspects of stuttering. Although the value of group therapy is well documented (Hayhow & Levy, 1989; Manning & DiLollo, 2017), group stuttering therapy is provided relatively rarely in other parts of the UK, mainly because it is difficult to recruit the requisite number of clients. The UK national centre is addressing this issue by seeking funding and partnerships to deliver group therapy in different parts of the UK.

#### Limitations

The research was conducted by an SLP involved in delivering the therapy, and could lead to researcher bias (Malterud, 2001). This limitation was mitigated to some extent: the focus groups and semi-structured interviews were facilitated by another SLP; all videorecordings were made by a person unfamiliar to the participants; a reanalysis of 20% of the video-recordings was conducted by someone with no connection to the therapy and the coding framework developed for the thematic analysis was double-checked for consistency by two specialist SLPs.

The scale of the qualitative study was small and therefore the findings cannot be generalised to the larger population of adults who stutter. However, as illustrated above, many of the themes identified in this study mirror those in similar qualitative studies exploring client's experiences of therapy and as a result suggest that the current findings carry weight.

## Conclusion

Whilst acknowledging the above limitations, this study achieved its objective in deepening our understanding of participants' experience of stuttering modification therapy and subsequent changes. The next step would be to carry out a larger study, involving more participants and a control group, to explore the overall effectiveness of this type of approach, using both quantitative and qualitative approaches.

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#### Footnote

<sup>1</sup>The terms stammering, stuttering and dysfluency are used interchangeably in the literature. The preference here is to use the term 'stutter' or 'stuttering'. Likewise, the therapeutic approach commonly known as 'stuttering management' or 'stuttering modification' will be referred to as 'stuttering modification' for brevity

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| Name    | Age | Gender | Previous<br>therapy | OASES overall<br>impact score<br>pre-therapy | SS1-4 severity<br>rating pre-<br>therapy<br>Not on scale<br>(2) |  |
|---------|-----|--------|---------------------|--|---|--|
| Jeff    | 46  | М      | As adult            | Moderate (2.82)                              |   |  |
| Andy    | 22  | Μ      | None                | Moderate (2.72)                              | Very mild (9)   |  |
| Peter   | 23  | Μ      | None                | Moderate/severe (3.53)                       | Moderate (25)   |  |
| Sam     | 27  | Μ      | As child            | Moderate/severe (3.01)                       | Mild (20)   |  |
| Terry   | 20  | Μ      | None                | Moderate (2.64)                              | Moderate (29)   |  |
| Fred    | 28  | Μ      | None                | Moderate/severe (3.05)                       | Mild (19)   |  |
| Michael | 48  | Μ      | As adult            | Mild/moderate (1.96)                         | Mild (20)   |  |
| Sarah   | 44  | F      | As adult            | Moderate/severe (3.12)                       | Moderate (26)   |  |

## Table 1

Demographic information for each participant with OASES impact score and measure of overt stuttering (SS1-4 severity rating)

Pseudonyms have been used for reasons of confidentiality

# Table 2

Summary of norm-referenced assessments for each participant at three different times points. (Time 1 = before therapy; time 2 = after therapy; time 3 = six months post-therapy)

| Name    | OASES overall<br>impact score<br>Time 1 | OASES<br>overall<br>impact score<br>Time 2 | OASES<br>overall<br>impact score<br>Time 3 | S24<br>score<br>Time 1 | S24<br>score<br>Time 2 | S24<br>score<br>Time 3 | SS1-4<br>severity<br>rating pre-<br>therapy<br>Time 1 | SS1-4<br>severity<br>rating<br>pre-<br>therapy<br>Time 2 | SS1-4<br>severity<br>rating<br>pre-<br>therapy<br>Time 3 |
|---------|---|--|--|------------------------|------------------------|------------------------|---|--|--|
| Jeff    | Moderate (2.82)                         | Moderate (2.55)                            | Moderate (2.55)                            | 9                      | 8                      | 4                      | Not on scale (2)                                      | Very mild<br>(12)  | Not on scale (8)   |
| Andy    | Moderate (2.72)                         | Moderate (2.39)                            | Moderate (2.33)                            | 13                     | 13                     | 10                     | Very mild (9)   | Very mild (12)   | Very mild (13)   |
| Peter   | Moderate/severe (3.53)                  | Moderate (2.43)                            | Moderate (2.4)                             | 17                     | 13                     | 17                     | Moderate (25)   | Mild (18)  | Mild (18)  |
| Sam     | Moderate/severe (3.01)                  | Mild/moderate (2.04)                       | Mild/moderate (2.17)                       | 15                     | 9                      | 12                     | Mild (20)   | Mild (22)  | Mild (21)  |
| Terry   | Moderate (2.64)                         | Mild/moderate (1.68)                       | Mild (1.38)                                | 12                     | 10                     | 9                      | Moderate (29)   | Not on scale (7)   | Very mild (11)   |
| Fred    | Moderate/severe (3.05)                  | Mild/moderate (2.21)                       | Moderate (2.26)                            | 13                     | 11                     | 11                     | Mild (19)   | Very mild (15)   | Very mild (13)   |
| Michael | Mild/moderate (1.96)                    | Mild/moderate (2.24)                       | Mild/moderate (1.73)                       | 11                     | 10                     | 9                      | Mild (20)   | Very mild (17)   | Very mild<br>(16)  |
| Sarah   | Moderate/severe (3.12)                  | Moderate (2.73)                            | Moderate (2.45)                            | 21                     | 16                     | 10                     | Moderate (26)   | Mild (21)  | Mild (21)  |

# List of Figure Captions

Figure 1. Theme 1: Before therapy: at a low ebb

Figure 2. Theme 2: Direct experience of the course

Figure 3. Theme 3: Key learning and challenges/solutions

Figure 4. Theme 4: Impact of the learning: making a difference to everyday life

## Focus group questions (administered directly after therapy)

## Prior to the course

- 1. How were you thinking and feeling about stammering before the course?
- 2. What were you hoping for from the course?
- 3. What did you think the course would focus on?

During the course (includes the first week and the final two days)

4. What stands out for you during the course?

## During the break...

- 5. During the break, between the first week of the course and the final two days, what aspects of the course did you continue to work on?
- 6. Did you experience any particular challenges during the break? If so, how did you manage them?

## Directly after the course

- 7. What for you have been the main changes you've experienced as a result of coming on the course?
- 8. How are you thinking and feeling about stammering, now the course has finished?
- 9. Are there things that you are doing now (in everyday life, work, socially) which you weren't doing before the therapy? If yes, what are they?
- 10. Looking back on your experience of the course, what parts do you feel were most helpful to you?
- 11. And what parts do you feel were not helpful to you?
- 12. What do you think could be done to improve the course?
- 13. How has coming on the course made a difference to your everyday life?
- 14. Is there anything else you'd like to say?

## Guide for semi-structured interview (administered six months after therapy)

#### Looking back at the course

What were your expectations for attending the course? To what extent were your initial expectations of the course met or not met? What do you remember from the course? Can you remember any of the stages of the course? What were the key parts of the course for you? What were the most helpful aspects of the course? What were the least helpful aspects of the course? Can you suggest anything that could have been done differently? Looking back how did you find having therapy in a group with other people who stammered? *Making a difference* Has attending the course made a difference to you? If so, in what way? Has it changed what you do or how you feel about your communication? Has it changed the way you live your

life?

#### Support over the last six months

Have you had any therapy since you finished? Have you attended any self-help groups?

Have you kept in touch with other members of the group?

If you've not had any therapy over the last six months, can you say why?

*Where are you now?* 

How is your speech currently? To what extent are you able to manage a moment of stammering nowadays? How are you thinking and feeling about stammering? How do you manage challenging speaking situations? Eg presentations, interviews, speaking in a group of people

Closing question: is there anything else you'd like to add? Any final thoughts?