The state of the art in non-pharmacological interventions for developmental stuttering. Part two: qualitative evidence synthesis of views and experiences.

Abstract

Background

A range of interventions have been developed to treat stuttering in recent years. The effectiveness of these interventions has largely been assessed in studies focusing on the impact of specific types of therapy on patient outcomes. Relatively little is known about the factors that influence how the delivery and impact of different types of intervention may be experienced from the perspective of both people who deliver as well as those who receive interventions.

Aims

The aim of the study was to synthesise available evidence in relation to factors that might enhance or mitigate against successful outcomes following interventions for stuttering. We aimed to do this by identifying and synthesising relevant qualitative research that explored the experiences of people delivering and receiving interventions that aim to improve fluency.

Methods

We carried out a systematic review including research that had used in-depth interviews and focus groups and conducted a substantive qualitative analysis of the data collected. Included study populations were either adults or children with a diagnosed stutter and/or providers of therapy for stuttering. An iterative approach was used to search for published qualitative evidence in relevant databases from 1990 to 2014. Retrieved citations were sifted for relevance and the data from articles that met the inclusion criteria were extracted. Each included paper was assessed for quality and a thematic analysis and synthesis of findings was carried out.

Main Contribution

Synthesised qualitative evidence highlights the changing experiences for people who stutter both historically and, for individuals, over the life course. Barriers and facilitators to implementation of interventions for stuttering are encountered at the individual, intervention, interpersonal and social levels. Interventions may be particularly pertinent at certain transition points in the life course. Attention to emotional as well as practical aspects of stuttering is valued by people receiving therapy. The client-therapist relationship and support from others are also key factors in achieving successful outcomes.

Conclusions

A synthesis of qualitative findings from published papers has added to the synthesis of effectiveness data in understanding how stuttering impacts on people across the life-course. Evidence suggests that a client-centred and individually tailored approach enhances the likelihood of successful intervention outcomes through attention to emotional, situational and practical needs.

Key words: stuttering; stammering; systematic review; qualitative evidence synthesis

Declaration of interests: The authors declare no competing interests.

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1. What is already known on this subject

- Reviews of effectiveness of interventions to treat stuttering show a tendency toward positive outcomes across all interventions.
- Qualitative research that explores the experiences of stuttering and therapy are necessary to understand in depth the therapeutic process.
- Assessing relevant and recent contributions to qualitative knowledge and synthesising the findings can create new insights into why interventions may or may not work for different people.

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2. What this study adds

- Synthesis of retrospective qualitative data highlights challenges at different stages of life for people who stutter.

- Stuttering and therapy experiences are contingent on historical and age related changes over time.
- Synthesised qualitative evidence highlights barriers to successful outcomes of therapeutic interventions for people who stutter are found at the individual, intervention, interpersonal and social levels as well as generating suggestions to overcome these barriers.

Introduction

A diverse range of interventions is available to treat stuttering across the lifespan, including pharmacological and non-pharmacological interventions. New therapies are periodically introduced and therapists have to make decisions on which interventions to use from an evidence base that has until now focused on reviews of the clinical effectiveness of specific intervention types.

A large body of research has been carried out to assess the effectiveness of non-pharmacological interventions for people who stutter. In a companion paper Baxter et al. (date) synthesise the available effectiveness evidence published between 1990 and 2014. The synthesis includes a typology of interventions and outcomes for all age groups. However, it is not clear from single effectiveness studies what aspect of the interventions lead to positive or negative outcomes or why people may or may not engage with therapy.

In order to identify why interventions might work and the obstacles that might hinder implementation, it is important to obtain the views of professionals who deliver interventions and people who stutter (PWS) who receive the interventions. Hayhow and Stewart. (2006) have made the case for the use of qualitative research methods to make sense of experiences of dysfluency and identify the meanings that the phenomenon has for the people affected.

Whilst individual qualitative studies are illuminating they tend to focus on a specific population or on a particular dimension of the subject area. In order to assess what is or is not feasible and why in terms of intervention provision requires extended research methods to that of the single study or the systematic review of randomised controlled trials (Pearson, 2004). Reviews of qualitative evidence that synthesise rich findings in relation to the research question can complement systematic reviews of effectiveness by addressing the 'how' and 'why' questions (Thomas & Harden, 2004).

The life course perspective has underpinned a sector of both psychological and sociological research since the 1960s. The premise of primary studies was and still is, to chart trends over time and behaviours over the life course. Proponents of this perspective (Elder, 1994; Mayer, 2003) are particularly interested in the intersections between historical and age related impacts upon society and individual / group psychology. Stuttering is a condition that typically begins in childhood and continues to require management to a greater or lesser extent (unless there has been spontaneous recovery) throughout the life-course.

As well as a review of effectiveness evidence that incorporated a broad spectrum of non-pharmacological interventions, we were commissioned to determine the applicability of this evidence, including the identification of staff and PWS perceptions about possible obstacles to successful outcomes of stuttering interventions. This paper reports on our assessment of qualitative evidence in this field firstly as it relates to different stages of the life-course of people who stutter, and secondly with a general focus on barriers and facilitators to implementing interventions for stuttering.

Methods

We aimed to carry out a synthesis of qualitative evidence in order to address the research question:

What are the factors that may enhance or mitigate against successful outcomes following intervention?

Identification of studies

An information specialist developed a search strategy to comprehensively address the research questions. The full search strategies are presented in an accompanying paper (Baxter et al., date). An iterative approach was used in that more than one search was carried out, each one building on retrievals and gaps from the previous search. An initial search of Ovid Medline was followed by a search of the Cochrane Library. Qualitative papers were also identified by sifting the initial searches and using keywords and author names to formulate a specific, filtered search. We scrutinised the reference lists of related reviews and of included papers to identify any citations that were not evident in the databases. Hand-searching of key journals was carried out, though this did not identify any new citations.

Inclusion and exclusion criteria

Retrieved citations were sifted at title and abstract level by three reviewers and coded in terms of relevance to the research question. Those that fulfilled the inclusion criteria were retrieved as a full paper and further assessed for relevance. The review of perceptions about stuttering interventions included studies that sampled people of any age who have a developmental stutter. Where interventions were discussed, any intervention that aims to benefit people with a stutter was included. We considered any qualitative method that provides rich data (for example interviews, focus groups, online forum). We did not include questionnaire data in this review since they do not provide rich data and they comprise responses to issues that have been identified a priori by researchers. We included only peer

reviewed publications from 1990 to present carried out in OECD countries and written in any language.

Quality appraisal strategy

Retrieved papers were quality assessed using a tool adapted from the Critical Appraisal Skills Programme (CASP 2013) tool for qualitative study designs (see Table 1).

Insert table 1 here.

Data extraction

'Data' included relevant issues in the findings and discussion sections of each paper. Only data relevant to the research question were extracted. We used a data extraction form adapted for use with qualitative findings. Both the quality assessment and data extraction tools were piloted with two papers to ensure that they captured the required information. No changes needed to be made to either form in order to obtain the data we needed. Quality assessment and data extraction were double checked by a second reviewer to identify missed data and to validate quality checks. Where differences were apparent between the judgements of two reviewers, we discussed these until there was agreement.

Initially we assessed qualitative data for information about experiences of specific interventions so that we could integrate the findings with those of the effectiveness review. Whilst we coded this data so that specific intervention experiences could be identified, it was not possible to integrate this data with the typology created from effectiveness studies due to the scant and disparate information available. Characteristics of included qualitative studies are presented in Table 2.

Extracted data was thematically analysed using techniques described by Thomas and Harden. (2008). It became clear that different issues were apparent for PWS at different life stages and across historical time, so we differentiated between these stages by presenting the findings in a chronological life course framework. We also analysed the data for specific barriers and facilitators to beneficial outcomes as well as perceptions about solutions to overcome these barriers. These are presented in Table 3 in the findings section of this paper.

Findings

Quantity and quality of available evidence

From the initial 4490 first search citations we identified 20 that were relevant to this research question. However on reading the full paper, six of these were rejected (n=14). The second search identified a further eight papers, one of which could not be obtained. Reference lists produced thirty eight potential citations that had not already been identified. On inspection of the abstracts, six of these were retrieved but one was rejected at full paper level (n=5). The total of included qualitative papers for the review was 25. One mixed method paper that was used for both the effectiveness and qualitative data was also included (n=26). The process is presented in the flow diagram (see Figure 1). Of the 26 included papers, three report findings with a different focus but from the same sample as another included study.

Insert Figure 1 here.

Using the adapted quality assessment tool, 18 of the 26 included papers were assessed as being at lower risk of bias and eight as higher risk of bias.

Characteristics of included studies

Of the 26 included papers, 25 used interviews to collect data, either alone or alongside another method. Interviews in 24 studies were carried out face-to-face (two studies used repeated interviews) with two of these studies also including telephone interviews. The remaining study used web-based technology to collect data. Interviews were also supplemented by questionnaires in one study, and focus groups in two studies. One study used only focus groups to obtain data.

Methods of data analysis were described as phenomenology (n=11), thematic analysis (n=7), grounded theory (n=2), content analysis (n=1) and framework analysis (n=1). Three papers did not report data analysis methods by name although in two studies the process described resembled thematic analysis.

Four studies were carried out in the UK, 11 in the US, six in Australia, three in Canada and two in South Africa. Included studies reported experiences of PWS at all ages from childhood through to late adulthood. However, none of the relevant studies included children as participants, rather, childhood experiences were reported by parents (n=2, one included only mothers) or retrospectively by adults. Only one study sampled adolescents, though some adolescent experiences were reported retrospectively by adults in other studies. One study focused on experiences during late adulthood and the remaining studies sample adults, with two studies exploring the experiences of spouses and partners of PWS. One study focused on ethnicity and the dual impact of being a stutterer. No study described participants as being clutterers. Finally, one study assessed the client-therapist relationship. None of the included studies assessed the perceptions of therapists.

Five included studies assessed participant perceptions of interventions for stuttering. The Lidcombe Programme (LP) was developed specifically for children, comprising parental training in timely and appropriate feedback to the child following stuttering instances. This approach reinforces non-stuttered speech through praise and reminders (Onslow et al., 2002). Two studies assessed parental perceptions of their own and the child's role whilst implementing the programme. Two studies assessed experiences of Prolonged Speech (PS) therapy for adults. One study assessed adolescent perceptions of a range of interventions including a week-long course in Smooth Speech and one in PS, the Camperdown Programme and regular PS. One study explored adult perceptions of late recovery from stuttering.

The following section is a synthesis of data from included studies presented across the life course. For children, stuttering could be described as "mysterious and uncontrollable" (Plexico et al., 2009b). By adolescence, PWS can be "sick of stuttering" (Hearne et al., 2008). Adults described their stutter as a "hindrance" (Plexico et al., 2009b) whilst older adults were more "accepting" of their stutter (Bricker-Katz et al., 2010).

Childhood Views

Whilst no paper included data directly obtained from children, eleven studies assessed experiences of children who stutter (CWS); nine of these reported retrospective data from adults (Anderson & Felsenfeld, 2003; Corcoran & Stewart, 1995; Crichton-Smith, 2002; Daniels et al., 2006; Daniels et al., 2012; Hughes et al., 2011; Kathard et al., 2004; Klompas & Ross, 2004; Plexico et al., 2005).

Stuttering as 'mysterious and uncontrollable'

For participants in included studies reflecting on the impact of stuttering on their childhood, the school years were perceived as challenging (Beilby et al., 2013). Teasing and bullying from peers at school (Bricker-Katz et al., 2010; Klompas & Ross, 2004; Plexico et al., 2009b) as well as limited understanding shown by teachers contributed to the perception that stuttering was a mystery, and was out of the child's own control (Plexico et al., 2009b).

Qualitative data from the included studies generally identified life events as impacting in positive or negative ways on stuttering, and one mother identified starting school as having a regressive effect on her child's progress with stuttering therapy (Hayhow, 2009). At school there was a desire to be accepted by peers which was impacted by stuttering. The feeling of not belonging, of being 'other' at school was reported by adults who experienced the double disadvantage of stuttering and having a minority ethnic background (Daniels et al., 2006).

Reading aloud was a particular source of distress that could distract from learning at school (Daniels et al., 2012; Hearne et al., 2008; Kathard et al., 2004). These themes translate to later life experiences when negotiating the work environment. Role models are an important factor in child development, and this was usually lacking at school, in the form of a figure that had negotiated life as a stutterer (Hughes et al., 2011). Where a role model, such as a teacher with a stutter, was accessible, support through shared experiential understanding and meaningful advice was reported to be beneficial (Hearne et al., 2008). There were mixed views about educating peers at school to try to prevent harassment as some preferred not to have others know about their stuttering. Also some participants did not feel that education would make a difference for children who have not experienced stuttering (Hearne et al., 2008).

Older participants reflected that they missed out on opportunities for therapy when they were at school (Bricker-Katz et al., 2010). Changes over time in access to therapy and engagement by schools in identifying and supporting children who stutter will have altered experiences for this age group. However, experiences within the family setting highlighted a tendency for some parents to 'silence' the issue so that children did not feel able to talk about their stuttering or express stuttering behaviour (Corcoran & Stewart 1995; Kathard et al., 2004; Plexico et al., 2005). Even well-meaning parents were reported to often behave in less than helpful ways (Butler, 2013; Corcoran & Stewart, 1995). Parents reported not having the knowledge to identify whether the stutter was serious enough to require therapy and hoped that the child would 'grow out of it'. Only when this was not apparent was therapy sought (Plexico & Burrus, 2012).

Experiences of interventions designed for children

Generally, adults reflected that as children they received practical advice and solutions for stuttering while their emotional needs went unaddressed (Corcoran & Stewart, 1995) and their individuality overlooked (Daniels et al., 2012). Children enrolled on the Lidcombe Programme were reported to find weekly visits to clinic burdensome; this could be overcome by a mix of face-to-face and distance therapy (Hayhow, 2009). Retrospective accounts of advice from therapists that included avoidance were now seen to have been unhelpful and led to some techniques having to be un-learned later. Family members could also pick up unhelpful advice and pass it to their child. Frustration that was felt about unhelpful techniques was reported to be counterproductive to children taking up interventions. Therapist characteristics were reported to be an important factor for all ages, including children. It was particularly important that the therapist was able to engage with the client and

their stutter (Corcoran & Stewart, 1995), and address the emotional aspects of stuttering (Hughes et al., 2011).

From a parental point of view, there were reported to be high expectations regarding 'fixing' the stutter quickly when facilitating the Lidcombe Programe (LP) with their child. Surprise was expressed by some parents regarding the extent to which parental effort and commitment is required. There were reports of difficulty remaining focused as well as feeling responsible for outcomes (Goodhue et al., 2010); some parents reported difficulty taking the lead with their child (Hayhow, 2009). However, generally parents perceived LP as effective (Goodhue et al., 2010), though enthusiasm for the Programme could vary over time for the same parent (Hayhow, 2009). For some parents there was a perceived lack of information about LP and its aims; suggested solutions to this situation included the provision of written information and support groups (Hayhow, 2009; Goodhue et al., 2010). In terms of practical issues, parents reported not having time to implement practice, particularly when caring for other children as well as the CWS. Parents also reported forgetting to implement practice; some children helped overcome this by reminding their parent (Corcoran & Stewart, 1995). Practicing during daily routine time together such as whilst walking to school or at story time, and having someone look after siblings for a short time were suggested ways of overcoming practical obstacles to implementation (Goodhue et al., 2010). Support from their own parents and friends helped mothers to cope with the emotional and practical aspects of assisting their child (Stewart & Richardson, 2004).

There was less clear evidence for views about the effectiveness and acceptability of other specific interventions for CWS (Stewart & Richardson, 2004). Irritations for children involved in other interventions included hearing the word 'smooth' and having constant

feedback on their speech. This was overcome by using different terms to describe speech that was deemed acceptable (Daniels et al., 2012). Reported benefits of LP included the increased quality time for parents and their child, specifically the exclusivity of time with one child. This could enhance the bond between parent and child and parents could improve their general parenting skills through engaging with the programme (Goodhue et al., 2010) whilst children became more aware of how to manage techniques at home (Goodhue et al., 2010; Hayhow, 2009) which increased confidence (Goodhue et al., 2010).

Adolescent views

Views about stuttering during adolescence included retrospective accounts in many of the studies with adult participants. Only one study (Hearne 2008) specifically focused on adolescent perceptions.

Getting "sick of stuttering"

Children who had grown up coping with a stutter described feeling isolated, different, and 'hollow inside' (Plexico et al., 2005) with stuttering being regarded as part of the self-concept. A particular situation that was a source of dread for this age group was communicating with more than one person, and especially more than two people (Plexico et al., 2009a). Expectations about fluency altered with changing life events such as leaving school, starting work or university and forming romantic relationships (Butler, 2013, Daniels et al., 2012). The desire to communicate more effectively in these new situations was often a trigger to seek out therapy (Plexico et al., 2009a). However this was not often regarded as the optimum time to start therapy, particularly if the drive to do so was coming from parents. Adolescence is a time when independence is developing, and it may be difficult to open up

emotionally to a therapist (Irani et al., 2012). An important factor at this age therefore was to make the decision oneself to seek intervention and to arrange appointments though some adolescents reported having had no knowledge about what stuttering was (Hearne et al., 2008),

Experiences of interventions designed for adolescents

In terms of intervention, some adolescent participants had received advice to avoid feared situations when they were younger and now had to unlearn these behaviours (Corcoran & Stewart, 1995). Some had practiced PS but reported that it felt unnatural to speak so slowly in real life situations (Corcoran & Stewart, 1995; Cream et al., 2003; Cream et al., 2004).

There was a need at this age to identify with others in a similar situation though many participants did not know anyone else who stuttered. This need for identification possibly underpinned the findings by Hearne et al. (2008) that group therapy was overwhelmingly preferred. An added factor was that other adolescents in the group had similar interests, such as sport. One-to-one sessions were considered as suitable at the beginning of therapy, prior to group sessions. An intensive one week course was reported to be valued for its continuity which prevented techniques being forgotten between sessions. Also valued were activities that allowed practice in the 'real world' such as speaking during a shopping trip. It was also suggested that follow up sessions be organised to counteract slippage of practice following the end of a course (Hearne et al., 2008).

Social support was reported to vary, with some families more supportive than others. There was reported silencing about stuttering by some family members which created a barrier to receiving family support. However, for some, family members were reported to provide

assistance in the form of transport and/or paying fees for therapy, and some family members also provided emotional support (Hearne et al., 2008).

Adult views

Nineteen included papers reported views about stuttering and therapy from the adult perspective (Irani et al., 2012; Anderson & Felsenfeld, 2003; Beilby et al., 2013; Boberg & Boberg, 1990; Butler, 2013; Corcoran & Stewart, 1995; Corcoran & Stewart, 1998; Cream et al., 2003; Cream et al., 2004; Crichton-Smith, 2002; Daniels et al., 2006; Kathard et al., 2006; Klompas & Ross, 2004; Plexico et al., 2005; Plexico et al., 2009a; Plexico et al., 2009b; Plexico et al., 2010; Stewart & Richardson, 2004; Trichon & Tetnowski, 2011).

Evidence was mainly available regarding views of general therapy rather than focussing on a specific intervention. Exceptions to this were three papers (reporting two studies) that explored views about PS (Corcoran & Stewart, 1995; Cream et al., 2003; Cream et al., 2004), an evaluation of a 15-day residential programme (Irani et al., 2012), and one study that assessed the implications of group therapy (Stewart & Richardson, 2004).

In terms of study population, Trichon &Tetnowski. (2011) explored the views of adults who had recently attended a self-help conference and Crichton-Smith. (2002) compared views from therapy attendees with PWS who had not experienced therapy. Plexico et al. (2010) focussed on the client perspective of therapist characteristics, and Boberg & Boberg. (1990) interviewed wives of stutterers. Daniels et al. (2006) and Daniels et al. (2012) explored the impact of ethnicity on PWS.

Stuttering *as "a hindrance"*

From a lifespan perspective, adults were gaining a sense of who they are as they matured. For PWS this sense of self included being a person who stutters. Significant life events at this time such as marriage, new employment and having children could be the impetus to attend therapy where this had not already taken place (Cream et al., 2003; Plexico et al., 2009b). However, the unlikelihood of ever being completely rid of stuttering, and that instead, stuttering required lifelong management, was now recognised (Beilby et al., 2013; Plexico et al., 2005). There was evidence of increased understanding about stuttering and about the self; therapeutic techniques became less challenging as adults felt more comfortable within themselves.

Nevertheless, there remained pressures from having a stutter; in one paper stuttering was cited as a lesson in how to deal with adversity (Plexico et al., 2009b). Having a stutter in the workplace led to anxiety that colleagues and new acquaintances would judge the PWS as not knowledgeable (Kathard et al., 2006). The fear of public speaking continued and telephone conversations were particularly feared (Plexico et al., 2009a). PWS also reported that communication was more challenging where the audience comprised more than one person. This situation was characterised by less predictability and therefore PWS reported feeling less control over their ability to respond to interactions (Cream et al., 2004; Plexico et al., 2009b).

One reported way of compensating for this perceived lack of control was to achieve more highly than average, for example obtaining a good degree or driving an expensive car (Klompas & Ross, 2004; Daniels et al., 2012).

Self- Identity and stuttering

Corcoran and Stewart (1998) report that avoidance strategies are protective mechanisms that are learned in order to cope with the negative consequences of stuttering and their effect on self-identity. Removal of fear was reported in included studies as an important factor in attaining therapeutic progress (Plexico et al., 2009a). Removal of fear was enhanced and facilitated by a deeper understanding of their stuttering through for example, speaking to other PWS. Epiphany moments were reported where PWS quite suddenly came to a better understanding and started to come to terms with rather than hide their dysfluency (Corcoran and Stewart, 1995; Klompas & Ross, 2004; Stewart & Richardson, 2004).

Experiences of interventions designed for adults

A motivating factor for adults initiating therapy was awareness that something could be done about their stuttering (Plexico et al., 2009b). Prolonged Speech techniques were the only specific intervention discussed by adults in included papers. Whilst this technique was reported to improve fluency by slowing speech down and reducing the frequency of stuttering, stuttering did not cease (Corcoran & Stewart, 1998). PWS reported that they felt fraudulent when using PS because they were passing themselves off as fluent. This in turn created anxiety in case their stuttering was found out (Cream et al., 2003). However when stuttering was controlled using PS, a rise in confidence and self-esteem was reported (Cream et al., 2003; Cream et al., 2004).

PWS also discussed taught or learned strategies for dealing with feared situations such as speaking on the telephone. These strategies included desensitisation, or repeated exposure to the feared situation (Irani et al., 2012), and disclosing stuttering to the listener at the beginning of a conversation (Klompas & Ross, 2004) to eliminate the element of surprise (Plexico et al., 2005) and potential discrediting by the audience (Butler, 2013; Cream et al.,

2003). Using these approaches allowed PWS to become less fearful and therefore less likely to use avoidance tactics. This in turn facilitated learning about the self and accepting the stutter (Plexico et al., 2005), encouraging risk taking and problem solving rather than risk aversion. The focus on stuttering and its consequences was thus decreased, lowering anxiety levels (Plexico et al., 2009b; Irani et al., 2012).

Therapist-client relationship

Therapy acceptability was reported to be influenced by the way that therapists interacted with the client as well as their general attitude to stuttering (Corcoran and Stewart, 1995; Crichton-Smith, 2002; Klompas & Ross, 2004; Plexico et al., 2010). Client-centred practice was reported to be the most helpful approach as it encouraged the development of an individually tailored programme. Other important characteristics included being professional, passionate, confident and committed, with a firm belief that therapy can work and that the PWS can achieve change. PWS valued a caring therapist who was willing to listen without judgement. In one paper it was reported that a positive aspect was for therapists to take the client's socio-cultural situation into account (Daniels et al., 2012) and to acknowledge the importance of translating taught techniques in the 'real world'(Plexico et al., 2010).

Conversely, ineffective therapists were reported to lack understanding and patience, not take individual requirements and preferences into account and to give the impression that their main purpose was related to their pay-cheque. Therapists could be judgemental, giving PWS the feeling that they were 'under the microscope'. PWS reported feeling embarrassed, blamed and angry in these circumstances as well as demotivated from continuing with therapy (Plexico et al., 2010).

Support from others

Included studies reported the significance of support from other people when coming to terms with stuttering and carrying out interventions. Indeed, there were reports that significant others had been instrumental in encouraging the PWS to attend therapy sessions (Anderson & Felsenfeld, 2003; Beilby et al., 2013). Where appropriate and feasible, it was also reported to be helpful for partners to accompany PWS at therapy sessions. Partners could not fulfil this role where therapists did not encourage partner involvement, or where partners had difficulty attending due to other (e.g. family) commitments or where partner involvement was distracting to the PWS and detrimental to progress (Boberg & Boberg, 1990).

There was a general view that openness and the ability to communicate about experiences relating to stuttering was beneficial and therapeutic. A particular bonus for PWS who attended group therapy (Stewart & Richardson, 2004) or a self-help conference (Trichon &Tetnowski, 2011) was the opportunity to share knowledge and experiences with other PWS and their partners, to not feel 'alone'. Partners of PWS also benefited from meeting other PWS and their partners as they could better understand stuttering and its impact on the PWS as well as share their own experiences (Boberg & Boberg, 1990).

Stuttering in the "real world"

Across a number of studies there was a reported need for strategies and interventions to reduce stuttering and improve fluency to be feasible outside the therapeutic environment (Cream et al., 2003; Irani et al., 2012; Stewart & Richardson, 2004). This might include practice in a shopping centre as part of a residential course (Irani et al., 2012), or ensuring that strategies do not affect speech to the extent that PWS feel even more "different" when they are engaging in day-to-day situations (Cream et al., 2003).

In respect of maintaining practice following therapy sessions, study participants mentioned the potential benefit of booster sessions to help reinforce the techniques learned (Irani et al., 2012; Stewart & Richardson, 2004). This was also important because PWS reported the extent to which continual effort and awareness was necessary to avoid "falling off the wagon" (Anderson & Felsenfeld, 2003 p249; Cream et al., 2003) and feeling responsible for reverting to habitual practices (Crichton-Smith, 2002).

Older adult views

One included study (Bricker-Katz et al., 2010) focused specifically on the stuttering experiences of the older adult and two studies included views of some older adults (Cream et al., 2003; Crichton-Smith, 2002). There was no included evidence relating to specific interventions aimed at this stage of life.

A "certain degree of acceptance"

In narratives of older adults there was a notable theme of acceptance related to attitudes later in life. There was a reported lessening of the anxiety created by the perceived negative evaluations from other people and a lowering of self-consciousness. This was partly due to a change in the way that older people are viewed in society as ageing is commonly associated with a greater likelihood of exhibiting communication challenges caused by long term conditions or the effects of a stroke (Bricker-Katz et al., 2010).

The impact of work related fears such as carrying out dreaded activities and projecting a professional and knowledgeable image was reduced following retirement (Cream et al., 2003; Crichton-Smith, 2002). For those who were still working outside the home, these fears

remained. For some, there was less emotional energy available to deal with stressful situations. In terms of therapies, expectations were low though for some there remained hope that new insights might be unlocked through speech therapy (Bricker-Katz et al., 2010).

Older adult experiences of interventions

Typically, participants at this stage of life had tried a range of therapies including self-directed strategies, over the years, often without success. They felt let down as therapies did not offer the "magic bullet" they had hoped for. There was a reported need for therapists to understand the specific requirements at this life stage. Participants reported that use of interventions to improve fluency in the real world interfered with spontaneity of communication. There was the additional challenge of implementing strategies at a time where physical and emotional energy were waning. Support from other people was reported to be as important at this stage as it had been when younger (Bricker-Katz et al., 2010).

Insert Table 3 here.

Summary: Barriers and facilitators to the implementation and maintenance of stuttering therapy practices

Included studies have been presented according to the life course perspective. We found that as well as being able to make distinctions between life stages, analysis of the literature identified commonalities in terms of the barriers and facilitators to achieving positive outcomes across age groups. These enhancing or mitigating factors operate at the individual domain, the intervention domain and interpersonal and social domains.

In the individual domain, for example the child, parent or adult, barriers and potential facilitators to implementation were reported at emotional, information and practical levels. Emotionally, negative experiences could lead to fear and anxiety relating to situations where certain types of verbal communication or words were required. This was temporarily mitigated by avoidance of situations and denial of stuttering as a part of the self. It was therefore important to address emotional aspects of stuttering before practical strategies are introduced to facilitate effective therapy.

Lack of information and skills to deal with stuttering were reported barriers that could be overcome by greater public, parental and individual awareness. This would also reduce the feelings of isolation for the PWS. Effective therapists were also instrumental in improving the knowledge and skills of their clients and family. Frequent interaction with other PWS increased experiential knowledge through the sharing of stories.

At the practical level, continued effort required to practice was hampered by a reported lack of time and forgetting to practice. There were suggested strategies in the literature to limit these barriers, mainly centred on integrating practice into everyday routines, recruiting the help of other people, for example to share child care, and developing a self-reminder system.

In the intervention domain reported barriers included a tendency to ignore the emotional, psychological and practical needs of the client in favour of single techniques to improve fluency. There was evidence from the literature that individually tailored intervention were more acceptable because PWS beginning therapy arrive with a range of experiences and skills in respect of their stuttering that is unique to each person.

There were also reports across the papers of interventions being difficult to implement in the 'real world' when compared to the therapeutic environment. Efforts to incorporate real world scenarios into intervention implementation were therefore reported to be valued by PWS. Another valued approach was to reinforce learned skills by arranging intensive courses followed up by booster sessions. These helped PWS to remember their practice and maintain practices over time.

Reported interpersonal/social barriers included perceived unhelpful therapeutic relationships, for example where a therapist lacks knowledge and/or empathy with the emotional life of the PWS. It was reported that unhelpful interactions were a de-motivator for attending or continuing therapy. From the data a client-centred approach addresses these issues, creating an environment where mutual learning can take place.

Support from the family, peers, friends and figures of authority at school and at work was also an important factor in maintaining feelings of competence in social, educational and professional situations. The literature suggested that silencing or blaming for stuttering had been a common experience for PWS that resulted in feelings of isolation as well as enhancing feelings of difference and stigma. This could be due to lack of awareness among potential supporting figures. Increasing exposure to PWS and their partner/family stories was reported to help reduce these feelings. Similarly, raised public awareness and knowledge about stuttering could render stuttering as less mysterious and encourage people to understand stuttering and therapeutic approaches as well as provide support for those receiving therapeutic intervention.

Discussion

The purpose of this study was to synthesise qualitative findings to provide insight into experiences of parents of children who stutter, adolescents, adults and their partners and older adults who stutter. We have identified a limited body of work incorporating 26 papers reporting 23 separate studies that meet the inclusion criteria. Much of the included data is retrospective, sometimes recalling childhood experiences as an adult. We did not identify any studies that met the inclusion criteria reporting the views of children who stutter or health professionals delivering interventions for stuttering. We found variation in quality according to our chosen assessment tool, with around two thirds of the papers achieving a higher standard. The most common weakness was a failure to fully report on items such as data analysis and ethical considerations.

The literature is presented according to a life stage perspective given that the experiences of stuttering and interventions for stuttering alter over the life course. Each stage of life presents a set of challenges for people who stutter, mainly concerned with verbal interactions and the perceived reception of stuttering by others. In childhood, stuttering behaviour and the child's response to it are influenced by experiences at home. For some this means having to repress, hide or avoid stuttering in the presence of family members. In the early to middle years there are feared situations that most likely become fearful due to early negative experiences. These include speaking in public, speaking on the telephone and situations where a number of people are interacting. Therefore, school, college, university and the workplace are reported to be stressful compared to communicating at home or with friends. Ageing brings a degree of respite as PWS feel more at ease with themselves and their stutter, are less likely to encounter feared situations and perceive less judgemental behaviour from others.

Experiencing life stage transitions often alters attitudes and behaviours due to the increased pressure for fluency. This can present as a temporary lapse in fluency but can also provide a valid reason for taking up interventions to address stuttering. These transitions include starting a university or college course, entering the workplace, beginning new relationships, getting married and having children. From a historic standpoint (Elder, 1994), family dynamics, school assessment and provision of support for children who stutter, as well as research and its translation into intervention techniques generally have developed over time. This has an impact on the perceptions of younger participant samples and those recruited into later research studies as they will likely feel the benefit of new attitudes and technologies that were missed by their predecessors. Mayer (2003) proposes that life course research needs to integrate social and psychological perspectives because social institutions such as school and the workforce eventually have a bearing on the experiences of individuals. Likewise, psychological impacts are in evidence such as emotional responses to stuttering and cognitive changes that can be prescribed once emotional responses have been explored. This synthesis of evidence supports Mayer (2003) in that attention to the psychological and sociological domains at all stages of the life course, taking into account personal history, would allow a better understand of how stuttering can be best addressed.

Data for obstacles that might impede intervention across age groups were synthesised at the individual, intervention and interpersonal/social levels and are presented alongside facilitators described or suggested in the literature to improve intervention access, acceptability, practice and maintenance. Across the included literature there is a consensus that emotional factors are best addressed prior to teaching techniques to improve fluency. Once techniques for improving fluency are established they are better understood when backed up with informational support and better implemented when practice is integrated into daily life with

support from others at hand. Interventions are useful when they are tailored to individual requirements relating to historical experiences and stage of life. Interventions that incorporate practice in real world situations are valued. Practice is better maintained where follow up sessions reinforce learned behaviours and practices. Finally, individuals are better motivated to attend and continue therapy where there is a perceived positive relationship with a knowledgeable client-centred therapist.

Hayhow et al. (2006) identify the complexity of trying to change learned sets of behaviours over time and also the necessity for individual assessments and corresponding individualised therapy. The authors also cite the therapist – client relationship as having an impact on the effectiveness of particular therapies. They conclude that more qualitative work is needed to understand the requirements of people who stutter in relation to intervention. This review synthesises more recent studies that provide rich data about experiences of stuttering and therapy and in so doing presents the main challenges that arise over time, producing a narrative that 'goes beyond' the original studies (Thomas & Harden, 2008). It adds to the synthesis of effectiveness evidence by enhancing our understanding of experiences relating to stuttering and interventions for stuttering.

However it was not possible to integrate the qualitative synthesis with the synthesis of effectiveness evidence as qualitative data is rarely specific about which intervention has been applied. This is due to qualitative and quantitative studies being carried out separately rather than using a mixed methods approach to evaluate the same intervention. Another contributing factor is that a large proportion of the included qualitative data is retrospective rather than being gathered at the time of accessing the intervention.

Future research could address this issue by ensuring that intervention evaluations incorporate data collection from both clients and therapists on the acceptability of the therapeutic process and the perceived impact of interventions. This would allow the acceptability of new technologies for new and continuing participants to be explored at the point of implementation. It would also contribute to the meaningfulness of integrating quantitative and qualitative findings in future evidence syntheses.

Conclusion

There is a lack of consensus in the literature about which stuttering interventions work best for different people. A synthesis of qualitative evidence has shown that changes over the life course impact on stuttering in positive and negative ways. These changes can be accounted for when designing individually tailored interventions. In addition, barriers to implementation are highlighted from the individual level to the social. Facilitators that address these barriers can be considered when discussing aims of intervention with clients.

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Figure 1 The process of qualitative study selection and exclusion
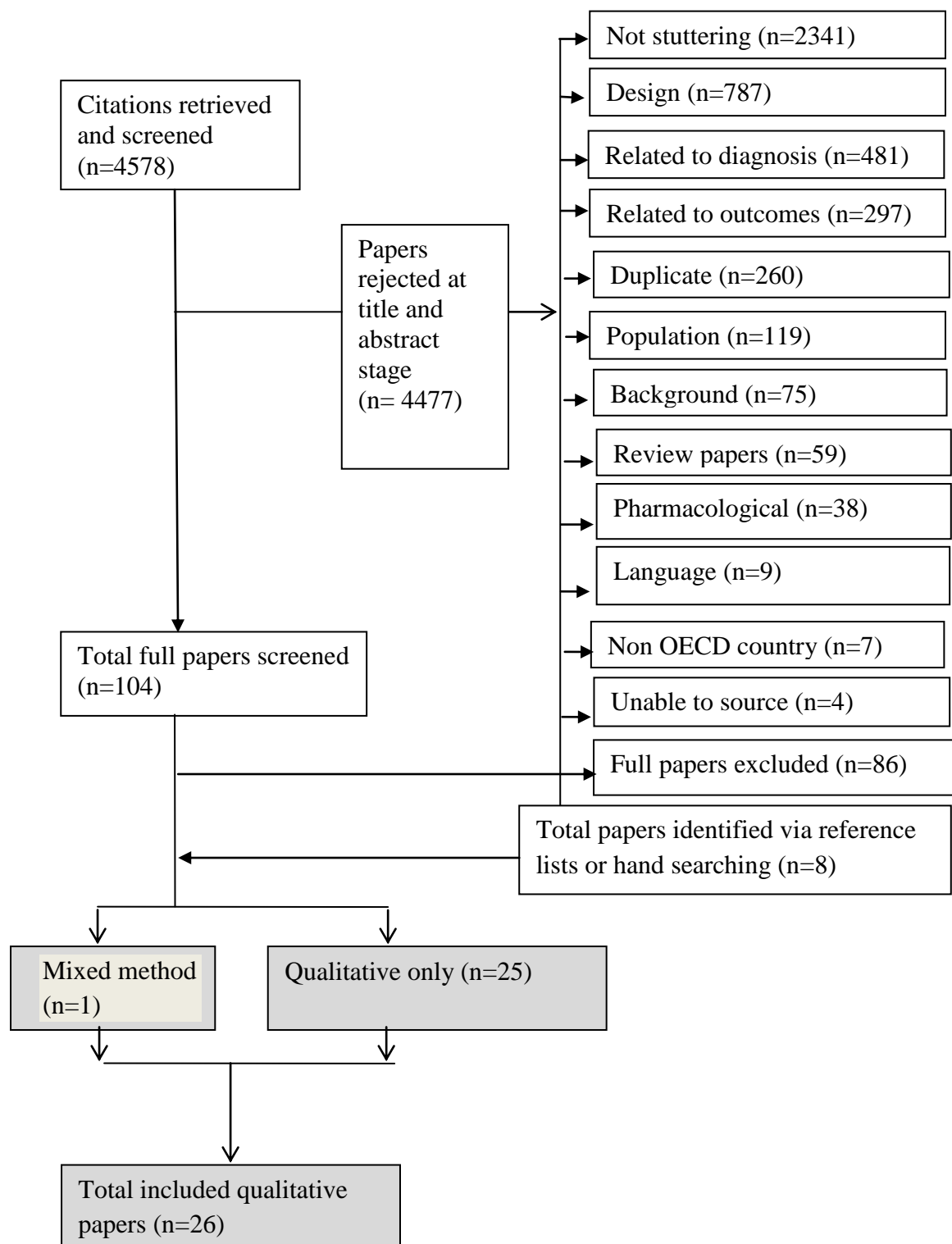
Table 1. Quality appraisal tool for qualitative studies

1. Was there a clear statement of the aim of the research?	Y/N
2. Is a qualitative methodology appropriate to address the aims of the research?	Y/N
3. Was the recruitment strategy appropriate to the aims of the research?	Y/N/Unclear
4. Were the data collected in a way that addressed the research issue?	Y/N/Unclear
5. Has the relationship between researcher and participant been adequately considered?	Y/N
6. Have ethical issues been taken into account?	Y/N/Unclear
7. Was the data analysis sufficiently rigorous?	Y/N
8. Is there a clear statement of findings?	Y/N

Table 2 Characteristics of included qualitative studies

Author/ year/ country	Sample	Data collection Method	Population	Focus of research	Data analysis methods as reported
Anderson 2003 USA	N=6	Interviews	Adults	Experiences of late recovery from stuttering	Thematic analysis
Beilby 2013 Australia	N=20 (10 dyads)	Mixed methods: Interviews and Questionnaires	Dyads (adults who stutter and their current life partner)	Impact of stuttering on adults who stutter and their partners	Phenomenology
Boberg 1990 Canada	N=15	Interviews	Wives of people who stutter	How spouses are affected by their spouse's stuttering.	Not reported
Bricker-Katz 2010 Australia	N=11	Focus Groups	Adults over 55 years	PWS perceptions of limitations to activity and participation.	Thematic analysis
Butler 2013 UK	N=38	Focus Groups (self-help meetings) and interviews	Adults	PWS perspectives on and responses to their speech dysfluency.	Grounded theory
Corcoran 1995 Canada Corcoran 1998 Canada	N=7 N=7	Interviews	Adults	Experiences of adults who stutter.	Immersion and crystallization in the data to identify what is meaningful.
Cream 2003 Australia Cream 2004 Australia	N=10 N=10	Interviews	Adults	Experiences of adults who stutter	Phenomenology Line-by-line, holistic and selective thematic analysis.
Crichton-Smith 2002 UK	N=14	Interviews	Adults who have / have not received therapy	The communicative experiences and coping strategies of adults who stammer.	Framework analysis
Daniels 2006 USA	N=10	Interviews	African American men who stutter	How African American men who stutter view communication, identity and life choices.	Thematic analysis
Daniels 2012	N=21	Interviews and focus	Adults who stutter	Primary and secondary school	Phenomenology

USA		groups		experiences of adults who stutter.	
Goodhue 2010 Australia / NZ	N=16	Repeat face-to-face and telephone interviews (9 with each participant)	Mothers of children who stutter	Mothers experiences of implementing the LP with their child.	Phenomenology Thematic analysis
Hayhow 2009 UK	N=16 (14 children)	Face-to-face interviews (repeated once with 6 of the participants)	Parents of children who stutter	Parent's experiences of implementing the LP with their child.	Thematic analysis Use of NVivo
Hearne 2008 Australia	N=13	Focus groups and interviews	Adolescents and young adults who stutter	Experience of stuttering and therapy for stuttering during the adolescent years. Reasons for reticence in seeking out therapy.	No particular analysis named. Familiarisation and categorisation of themes.
Hughes 2011 USA	N=7	Interviews	Adults who stutter	Exploration of family experience of PWS related to their interactions with family members, speech therapy and stuttering management.	Phenomenology Thematic analysis
Irani 2012 USA	N=7	Interviews via web-conferencing technology.	Adults who stutter	To gain a deeper understanding of clients' perceptions of an Intensive Stuttering Clinic for Adolescents and Adults (ISCAA) programme and measure long-term treatment outcomes.	Phenomenology Thematic analysis
Kathard 2004 South Africa	N=7	Biographical interviews	Adults who stutter	To explore processes shaping self-identity formation and the actions of people who stutter.	Cross case and thematic analysis
Klompas 2004 South Africa	N=16	Interviews	Adults who stutter	Life experiences of a group of South African adults who stutter and the impact of stuttering on their quality of life.	Content analysis
Plexico 2005	N=7	Interviews	Adults who stutter	Understanding of how adults have been able	Phenomenology Thematic

USA				to successfully manage their stuttering.	analysis
Plexico 2009a and 2009b (companion papers) USA	N=9 N=9	Interviews	Adults who stutter	To identify patterns of coping responses by adults responding to the stress resulting from the threat of stuttering. To develop a model of coping and a better understanding of the complexities within the coping responses of people who stutter.	Grounded Theory
Plexico 2010 USA	N=28	Interviews	Adults who stutter	The underlying factors that contribute to a successful or unsuccessful therapeutic interaction between clients and their clinicians.	Phenomenology
Plexico 2012 USA	N=12	Interviews	Parents of children who stutter	To describe in detail the underlying factors that may be relevant to being a parent of a child who stutters.	Phenomenology
Stewart 2004 UK	N=8	Interviews	Adults who stutter	Experiences of adults who have completed a course of therapy for stammering.	Phenomenology
Trichon 2011 USA	N=12	Interviews	Adults who stutter	To understand the lived experience of individuals who attended a self-help conference(s) for PWS from the perspective of a PWS	Phenomenology

Table 3. Barriers and facilitators to positive outcomes

Domain	Barriers	Facilitators
Individual (PWS or parent)	Emotional: Fear elicited by negative situations. Anxiety /apprehension about current / future communication -threat to self-identity. Avoidance of situations. Denial of stuttering.	Attending to emotional, psychological and knowledge-based needs. Breaking out of the cycle of fear – epiphany. Leads to increased confidence and acceptance.
	Informational: Lack of knowledge. Lack of skills.	Raising awareness in schools. Information from therapist. Shared experiences with other PWS.
	Practical: Extent of effort/commitment. Lack of time. Forgetting to practice.	Adopting strategies such as integrating practice into daily routines, visual reminders, asking for practical support.
Interventions	Approaches to Therapy Limited to techniques only. One-size fits all approach. Unrealistic aims. Difficult to implement in "real world."	Encompass emotional/ psychological/social. Tailored to client's needs. Accessible aims. Incorporates "real world" practice.
	Maintenance Practice not reinforced. Long periods without therapy.	Strategies to reinforce practice. Intensive courses. Regular follow-up sessions.
Interpersonal /social	Therapist characteristics Lacking knowledge. Lacking patience. Blaming.	Client-centred approach.
	External Support: Lack of knowledge. "Silencing" stuttering. Non-acceptance of dysfluency. Teasing/ bullying /socially discrediting.	Involving parents, teachers, partners and peers in therapeutic process. Meeting other PWS and their parents /partners. Raising public awareness.