

Clinical management of stuttering in children and adults

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Stuttering, also known as stammering, is a common speech disorder of neural speech processing that typically begins during the first years of life. An Australian cohort study (n=1619) of children recruited at 8 months of age found that 8.5% had begun to stutter at 36 months of age, and 12.2% by 48 months.¹ A review of 44 studies shows a prevalence of around 1% for schoolchildren worldwide (range 0.03-5.2%).^{w1} Stuttering is essentially a movement disorder of speech, with observable effects on the jaw and mouth, but also facial muscles and sometimes upper limbs. Those who stutter are at risk of developing social anxiety or mental health problems.

Evidence from randomised trials has shown that treatment before 6 years of age reduces the chance of stuttering becoming intractable. Children can recover without formal intervention, but it is not possible to predict who will recover spontaneously. It is therefore best to take advantage of the window of opportunity within which children may be treated with best effect, which is within one year of onset. For adults with long term stuttering, early randomised trials of behavioural and cognitive interventions show promise.

What causes stuttering?

Stuttering usually begins during the early years of life, and it affects all races and cultures. The cause of stuttering is not known, but the findings of research using brain imaging point towards a deficit of the neural processing that underpins spoken language.^{w2} A small case-control study found increased odds of structural and functional anomalies in areas of the brain responsible for spoken language in adult patients with persistent developmental stuttering.²

SOURCES AND SELECTION CRITERIA

We consulted our own archive and searched the Institute of Scientific Information Web of Science and PubMed databases of peer reviewed journals using the search terms “stutter*” and “stammer*”.

Similar findings have been reported for children.³ About two thirds of patients who stutter report a family history. Studies show greater concordance between monozygotic twins than dizygotic twins and suggest that 70% of cases can be accounted for genetically.⁴ A recent study that combined genetic linkage data and brain imaging data has generated what seems to be a tenable hypothesis—that the onset of stuttering is linked to abnormal myelogenesis of speech related fibre tracts.⁵

How is a diagnosis made?

The diagnosis is usually straightforward because affected adults and adolescents almost always describe their condition accurately.

What is not stuttering?

Stuttering is occasionally comorbid with a rare fluency disrupting speech disorder known as cluttering.^{w3} Cluttering is usually distinguishable from stuttering in that the speech pattern is typically rapid and irregular, and affected patients usually lack awareness of the problem. Disturbed fluency can occasionally be the result of an acute neurological insult, in which case the clinical presentation will be clearly different from that seen with stuttering.^{w4} Stuttering tends to occur on the first word of utterances and the first syllables of words, but “neurogenic stuttering” is distributed evenly across utterances, and extraneous non-verbal behaviours, commonly found with stuttering, do not occur. In rare cases, neurogenic stuttering can be psychogenic in origin.^{w5}

How do patients or parents usually present?

Young children

Parents will usually present saying that their child has begun to stutter. The onset of stuttering can be particularly distressing for parents, for three reasons. Firstly, stuttering usually begins unexpectedly after a period of normal and uneventful language development, often when children start to put words together into short utterances. The onset of stuttering

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- ▶ BMJ blog: Ivan Perry on stammering
- ▶ Personal view: The role of role avoidance (*BMJ* 2002;324:857)

SUMMARY POINTS

Stuttering is a common speech disorder of neural speech processing that usually begins during the first three or four years of life and may affect as many as 10% of children. Educational, occupational, and social problems are common if chronic stuttering is not treated early.

Mental health problems, in particular social anxiety, are likely to develop with chronic stuttering.

Early intervention is recommended, preferably within one year of onset of stuttering.

Randomised controlled trials have shown an early parent implemented behavioural intervention to be efficacious for stuttering control in preschool children.

Speech restructuring can rehabilitate speech in people with chronic stuttering.

has not been associated with child temperament, social, or environmental variables. Secondly, the onset of stuttering may be sudden. Observational evidence suggests that half of cases develop over the course of a week and a third of cases over a single day.¹⁻⁶ Parents may report that their child went to bed speaking normally but was stuttering at breakfast the next morning. Thirdly, the disfiguring features of the disorder described below do not develop insidiously but can be present soon after onset.⁷ Parents may report that their preschool child is distressed by the onset of stuttering.⁶

Older children and adults

The speech problems of stuttering can mean a lifelong struggle to speak. Patients openly complain of stuttering and often mention associated anxiety. Repeated movements of the jaw and mouth occur for sounds, syllables, words, or phrases. Normal speech involves continuous movements of the mouth and jaw, but stuttering can be associated with periods when movement stops, giving the impression that the speaker is “blocked.” Tic-like movements and extraneous vocalisations often occur and cause disfigurement during speech. With severe stuttering fixed postures can last for more than 30 seconds. These “blocks” can be accompanied by extraneous non-verbal behaviours such as grimacing, twitching, and other body movements. Stuttering may cause the patient to speak slowly and effortfully, with reduced speech output. People who stutter speak, on average, at three quarters of the rate of controls, but in severe cases the rate of speech may be less than a quarter of normal. The severity of stuttering ranges greatly, from people who are mildly affected (just a few stutters each day), who often never seek help, to those who are very severely affected and essentially cannot communicate. Patients who stutter may fail to fulfil their educational and occupational potential. A survey of more than 200 adults who stutter found that about 70% thought that their stuttering had stood in the way of a promotion, whereas 20% had turned down a promotion because of it.⁸ In addition, a seminal survey of employers’ attitudes found that many employers agreed that stuttering reduces employability and promotion prospects.⁹

Patients with long term stuttering may have mental health problems, and these may begin early in childhood after the onset of stuttering.¹⁰⁻¹¹ A recent observational study in adults who stutter found that stuttering affects quality of life as adversely as life threatening conditions such as neurotrauma and coronary heart disease,¹² but in contrast to those diseases it is present for a lifetime. People who stutter may be affected by social anxiety, and an observational study estimated that people with chronic stuttering have a 34-fold increased risk of having a formal diagnosis of social phobia compared with matched controls.¹³ Case reports of social phobia and stuttering are common,¹⁴ and comorbid stuttering has been reported in 40-60% of clinical cohorts of people with social phobia.¹³⁻¹⁵⁻¹⁶ Anxiety disorders, mood disorders, substance misuse, and personality disorders are also highly prevalent in people who stutter,¹⁷⁻¹⁸ and the presence of mental health problems reduces the likelihood that speech rehabilitation will be successful.¹⁹ We suggest that healthcare personnel fully explore anxiety experiences of patients with stuttering because of their potential clinical relevance.

Why not let stuttering resolve naturally?

Although natural recovery from stuttering does occur and published estimates have been generally similar to the 74% reported from a prospective cohort,²⁰ much “natural recovery” may be attributable to treatment. In the absence of control for such interventions, and without studies of children before the onset of stuttering, we think that the correct natural recovery rate is much lower. In our opinion, the important question is how many children recover naturally during the known window of clinical opportunity. Findings from the above prospective cohort suggested that less than 5% of children recover within a year of the onset of stuttering, although many more recover later. It is not possible to predict which children will recover naturally, so intervention shortly after onset is best practice.

In addition, negative conditioning experiences during the school years may be implicated in the development of mental health problems in those who stutter. An observational study showed that in children who stutter, negative attitudes to speech and communication measured in 6 and 7 year olds worsened progressively during later school years (7-12 year olds), whereas attitudes to communication in control children become healthier.²¹ Schoolchildren who stutter are more susceptible to bullying than those who do not.²² Non-stuttering peers perceive stuttering school age children negatively,²³ and schoolchildren who stutter find it more difficult to establish peer relationships than controls.²⁴ Adults often report that their stuttering had catastrophic effects on their school life. In a survey of 276 adult members of a national association of stutterers,²⁵ most (96%) reported immediate negative emotional effects of childhood bullying and 46% reported some long term effects on social and emotional functioning.²⁶

How is stuttering treated?

Children

A meta-analysis of clinical cohorts established a guideline that early intervention should begin within a year of onset.²⁷ Although delaying the start of the intervention for one year after onset within the preschool years did not seem to jeopardise responsiveness to subsequent intervention, the possibility of intractability during the school age years (presumably because of decreasing plasticity within the speech motor system as neural networks for speech become established) leads us to advise early referral for intervention. A monitoring period of up to one year after onset may be appropriate in some cases, particularly when natural recovery clearly is occurring. Referrals can be made in the first instance to speech-language therapists (United Kingdom), speech-language pathologists (North America), or speech pathologists (Australia).

A simple intervention known as the Lidcombe Programme, developed in Australia, has been evaluated in randomised trials. This programme is a behavioural treatment, which is administered by parents under the direction of a clinician. The child and parent visit the speech clinic for an hour each week, during which time the clinician teaches the parent how to control the child’s stuttering. This is done with a method that relies on laboratory findings that early stuttering is one of the many

problem behaviours with operant properties, meaning that “stimulus control” can be attained with environmental contingencies for those problem behaviours. With the Lidcombe programme, the contingencies for stuttering are verbal; parents are taught to indicate to the child occasionally during the day when they hear a stutter, and occasionally to ask the child to self correct a stuttered utterance. Children can normally make such a self correction. Most importantly, parents are taught to praise their children during the day when stuttering does not occur. To confirm that the treatment is proceeding satisfactorily, parents measure the child’s stuttering severity each day, using a scale where “1” equals “no stuttering” and “10” equals “extremely severe stuttering.” This scale is also useful if the clinician decides to delay treatment to determine whether natural recovery is occurring. The treatment ends when stuttering is absent or at a very low level. The manual for the Lidcombe programme is publicly available at the website of the Australian Stuttering Research Centre.

There is much low level evidence from phase I and phase II clinical trials for this early stuttering intervention.²⁸ Two independent phase III randomised controlled trials (total n=100) have been published—one with New Zealand preschool children and one with German preschool children.^{29–30} The studies show that the treatment can control stuttering and resulted in normal speech in these children, and that the programme reduces stuttering more quickly than allowing natural recovery to occur. A meta-analysis of all sources of randomised controlled evidence for the treatment—including brief exposure experiments not considered here to be clinical trials—indicated an odds ratio of 7.7.²⁸ This result means that preschool children who received the Lidcombe programme in clinical trials were 7.7 times more likely to recover than children who did not receive the treatment. A randomised phase II trial showed that the treatment can be adapted to telehealth delivery.³¹

Although treatment might simply speed up the natural process, at the very least it shortens the exposure of these children to the negative effects of early stuttering. However, the Lidcombe programme may control stuttering with mechanisms that are independent of natural recovery. Studies showing that this treatment reduces stuttering in school age children who are unlikely to recover naturally support this possibility.^{w6 w7}

Two other treatments are currently being evaluated in phase I and phase II clinical trials—two phase I trials of parent-child interaction therapy,^{w8 w9} and phase I and II trials of the Westmead programme.^{w10-w12} Parent-child interaction therapy is a family based treatment designed to modify the parental style of everyday interaction with the child. In the Westmead programme, children are taught to control stuttering with a syllable-timed speech pattern, similar to talking in time to a metronome. However, until randomised controlled trials are published, the efficacy of these treatments is not clear.

Adolescents and adults

Speech rehabilitation for adults and adolescents requires a different approach. Nearly all recently published clinical

trials investigating treatment for chronic stuttering have incorporated variants of a technique called “speech restructuring.”^{w13} Patients are trained to use a new speech pattern to reduce or eliminate stuttering while sounding as natural as possible. During speech restructuring, patients learn to speak initially with a slow drawling speech pattern that is stutter free. The speech pattern is then shaped toward stutter-free speech that is reasonably natural sounding. The bulk of the evidence comprises low level phase I and phase II clinical trials, some of which have been replicated. Those trials suggest that a 70-90% reduction in stuttering severity can be maintained at follow-up. However, a randomised trial with a no treatment group has not been published, so it is not clear how efficacious the treatment is; non-randomised clinical evidence typically overestimates effect sizes. Two phase III randomised trials have evaluated speech restructuring (total n=129) with adults and adolescents. These have shown that a telehealth version of the treatment is not inferior to in-clinic treatment,³² and that a self modelling procedure added to the treatment improves speech outcomes.³³ Self modelling is a simple procedure where patients regularly watch videos of themselves displaying the required behaviour, in this case stutter-free speech. In contrast to early intervention, this treatment is not suitable for all patients, because many cannot master and sustain the requisite speech pattern for stuttering control. Relapse is common, particularly for those with comorbid mental health problems.¹⁹ Unnatural sounding speech may occur, and for treatment to be successful patients must pay constant attention to speech.

Cognitive behavioural therapy is the most efficacious intervention available for treating social anxiety and has been evaluated extensively in non-stuttering populations.^{w14} Historically, speech restructuring treatment has incorporated components of cognitive behavioural therapy. Cognitive behavioural methods specifically aimed at treating the social anxiety of patients who stutter have recently been developed, and a small amount of evidence has emerged from clinical trials. Evidence from a randomised phase II clinical trial suggests that patients who stutter and have social phobia will no longer be diagnosed with social phobia after the intervention.³⁴ Predictably, that report showed that speech restructuring treatment alone did not control social phobia. Evidence from phase I clinical trials suggests that standalone, internet driven cognitive behavioural therapy may also be a viable treatment.^{w15}

The holy grail of research into the treatment of stuttering is a machine that the patient can wear to alleviate stuttering, but for decades efforts to develop one have been disappointing. A recent commercially available device resembling a hearing aid, which distorts the patient’s hearing of speech output (“SpeechEasy”) is no exception. After a series of encouraging clinical trials a phase I trial of the device reported it not to be efficacious when worn during everyday life.^{w16} Some attempts have been made to develop in-clinic machines to alleviate stuttering. Electromyographic feedback showed some promise in a non-randomised trial with adolescent patients,^{w17} but again that promise was not sustained, with subsequent

QUESTIONS FOR FUTURE RESEARCH

- Can we develop simpler and more efficient treatments than are currently available for preschool children?
- Are standalone internet driven interventions for stuttering and associated mental health problems viable?
- On the basis of prospective cohorts ascertained in the community before the onset of stuttering, what are the true prevalence and incidence of stuttering?
- What is the natural recovery rate during the short window of clinical opportunity after onset?
- Using brain imaging soon after the onset of stuttering, can we determine whether structural and functional problems with neural speech processing are the effects of stuttering or its cause?

TIPS FOR NON-SPECIALISTS

- The onset of stuttering and its associated behaviours in children may occur over a remarkably short period of time
- The problem involves neural speech processing and is not aetiologically related to social or environmental factors
- Refer children who stutter early to a speechlanguage therapist (United Kingdom), speech-language pathologist (North America), or speech pathologist (Australia), preferably within the first year after onset
- Without early intervention the child is at risk of being bullied and developing mental health problems

ADDITIONAL INFORMATION RESOURCES

Resources for healthcare professionals

Australian Stuttering Research Centre (http://sydney.edu.au/health_sciences/asrc)—Provides an overview of the disorder and its treatments, links to prominent and reputable related sites worldwide, and downloadable clinical materials for clinicians free of charge

Australian Stuttering Research Centre. Lidcombe Programme Trainers Consortium (http://sydney.edu.au/health_sciences/asrc/health_professionals/lptc.shtml)—Provides locations and contact details for international members of the Lidcombe Programme Trainers Consortium

Resources for patients

British Stammering Association (www.stammering.org/)—Information and support for patients

Australian Stuttering Research Centre (http://sydney.edu.au/health_sciences/asrc)—Provides links to related sites worldwide and to self help groups for patients and parents

trials of adolescents and school age children showing no effect.^{w18} A phase I trial of a machine that induces a variant of speech restructuring (“modification of phonation intervals”) showed initial promise with five patients,^{w19} but no subsequent trials have yet been reported.

The many attempts at alleviating stuttering with the use of drugs have also been disappointing. A review of 31 reports concluded that no worthwhile treatment effects were obtained using a range of drugs.^{w20}

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