



# Beliefs and behavioural intentions towards pharmacotherapy for stuttering: A survey of adults who stutter

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## ABSTRACT

**Purpose:** Although considerable efforts have been made to investigate the effectiveness of pharmacological treatments for stuttering, little is known about how the stuttering community perceives these treatments. This study aimed to assess and quantify beliefs regarding pharmacotherapy for adults who stutter and to establish whether behavioural intentions to undertake treatment were related to these beliefs.

**Method:** An adapted version of the Beliefs about Medicine Questionnaire was completed by adults who stutter. Participants also reported perceptions of their stuttering including its overall impact, ratings of previous speech therapy, and behavioural intentions to initiate pharmacotherapy and speech therapy in future.

**Results:** Necessity and concern beliefs were distributed widely across the sample and in a pattern indicating a relatively balanced perception of the benefits and costs of medication prescribed specifically for stuttering. Of the study's measures, the necessity-concerns differential most strongly predicted the behavioural intention to initiate pharmacotherapy. The overall impact of stuttering predicted intentions to seek both pharmacotherapy and speech therapy. Participants reported the likelihood of pursuing pharmacotherapy and speech therapy in equal measure.

**Conclusions:** The theoretical model of medication representations appears to be a useful framework for understanding the beliefs of adults who stutter towards the medical treatment of their disorder. The findings of this study may be of interest to clinicians and researchers working in the field of stuttering treatment and to people who stutter considering pharmacotherapy.

## 1. Introduction

Stuttering is a fluency disorder characterised by prolongations, repetitions and blocking of speech. These surface behavioural features are typically accompanied by private affective and cognitive reactions to the experience of being unable to speak fluently and to listener responses to stuttering (Bloodstein & Bernstein Ratner, 2008). Numerous studies confirm assumptions that stuttering can limit the speaker's ability to participate in daily communication activities (Sheehan, 1975; Yaruss & Quesal, 2006), that stuttering negatively impacts upon quality of life in terms of social, emotional and mental functioning (Craig, Blumgart, & Tran, 2009), and that the disorder can hinder educational and occupational attainment (Daniels, Gabel, & Hughes, 2012; Klompas & Ross, 2004).

The onset of stuttering occurs most often during childhood, between the ages of 2 and 5. Traditional estimates of incidence and prevalence are around 5% and 1% respectively, though in light of recent evidence, Yairi and Ambrose (2013) suggest there may be a case for revising these percentage estimates. Nevertheless, the marked difference between incidence and prevalence figures reflects the fact that most children who stutter recover either with or without treatment (Dworzynski, Remington, Rijdsdijk, Howell, & Plomin,

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2007; Mansson, 2000). For stutters whose disorder persists through adolescence and into adulthood, however, the prospects of recovery diminish dramatically.

Historically, the principal treatment for stuttering has been speech therapy, and approaches vary widely both in their theoretical grounding and in the extent to which they aim to ameliorate specific behavioural, affective and cognitive aspects of the disorder. Approaches for young children involve parents in the therapy and can be classified as either *indirect* or *direct* in nature. The former seeks the general reduction of communicative demands on the child in line with their existing capacities for fluency, while the latter employs operant conditioning principles, primarily positive reinforcement, to facilitate fluent speech (de Sonnevile-Koedoort, Stolk, Rietveld, & Franken, 2015). For adults who stutter, two broad categories of speech therapy exist. The first, known as *stuttering modification*, uses avoidance reduction, desensitisation, gradual modification of stuttering behaviour, and alteration of feelings and thoughts towards stuttering, and places little emphasis on fluency as a direct objective. By contrast, the second approach, termed *fluency shaping*, aims explicitly to establish speech that is free of stuttering by means of behavioural principles, and pays less attention to the emotions and attitudes accompanying stuttering. A third category of speech therapy seeks to integrate *stuttering modification* and *fluency shaping* (Blomgren, 2013; Guitar, 2013; Manning, 2010).

Achieving a clear picture on the effectiveness of speech therapy for stuttering has long been a challenge for researchers, clinicians and consumers. As indicated above, there remains a lack of consensus amongst professionals as to the most effective speech therapy for children and adults who stutter. Consequently, there is disagreement about the criteria for satisfactory therapy, about the nature of, and indeed the existence of, therapeutic phenomena such as the “establishment” of fluency within the clinic and “transfer” of fluency beyond it (Sheehan, 1979), and about the most appropriate means of measuring therapeutic outcomes (Guntupalli, Kalinowski, & Saltuklaroglu, 2006; Quesal, Yaruss, & Molt, 2004; St Louis, 2006). As a rule, outcomes for standardised, behaviourally-oriented treatments have been published more often than those for individualised, psychosocially-oriented treatments. While systematic reviews have concluded that speech therapy for stuttering can be effective in reducing observable stuttering behaviour and in improving social, affective and cognitive aspects of stuttering for specific periods (e.g., Bothe, Davidow, Bramlett, & Ingham, 2006a), the longer-term maintenance of therapeutic gains continues to be a major issue for adults who stutter. Due to long reinforcement histories with their stuttering, advanced or “confirmed” people who stutter face significant challenges in speech therapy, and relapse during or following treatment is commonplace (Bloodstein & Bernstein Ratner, 2008; Craig, 1998; DiLollo, Neimeyer, & Manning, 2002). It is understandable then that researchers, clinicians and people who stutter have looked beyond speech therapy for alternative treatments.

Among a number of modern alternatives are pharmacological treatments of stuttering. These have a shorter history in comparison with speech therapy, with the earliest published research into medication for stuttering, using stimulants and sedatives, dating back to the 1950s (Brady, 1991; Van Riper, 1973). Early pharmacological investigations of dopamine antagonists such as haloperidol, used in the treatment of psychosis, have shown improvements in the speech fluency of adults who stutter, but due to risks of impaired motor function such as tardive dyskinesia, have not been commonly prescribed (Ludlow, 2006). Newer-generation dopamine-blocking agents such as risperidone and olanzapine, tested in randomised, double-blind, placebo-controlled studies, have also shown to relieve behavioural symptoms of stuttering and to pose fewer motor dysfunction risks, although other side effects such as weight gain and sedation are sometimes experienced (Maguire, Riley, Franklin, & Gumusaneli, 2010b).

Adverse side effects associated with medications decrease their tolerability, often cause patients to discontinue treatment and so increase the likelihood of relapse. Hence, regardless of the disorder, researchers are keen to develop medications which have good tolerability profiles. Pagoclone, originally developed to treat anxiety, is one such medication and is the first to be tested through the U.S. Food and Drug Administration process as a potential treatment for stuttering. In a double-blind, placebo controlled study with open label extension, pagoclone was found to reduce stuttering symptoms in 55% of the patients in the active medication group, was tolerated well and had high levels of patient satisfaction (Maguire, Franklin et al., 2010a). Notably, pagoclone, a selective GABA-A partial agonist, was shown to markedly reduce social anxiety, an effect not often associated with dopamine antagonist medications. Another relatively well tolerated medication, used in the treatment of bipolar disorder and schizophrenia, is asenapine. Its effects on developmental stuttering have been examined in three case studies. In these, asenapine was clinically observed to improve the fluency of adults who stutter (Maguire, Franklin, & Kirsten, 2011). In a more recent preliminary investigation, lurasidone, another antipsychotic dopamine antagonist, was shown to reduce stuttering symptoms in a sample of patients who stutter (Charoensook & Maguire, 2017).

To the authors' knowledge, at the time of writing, no drug has been formally approved for market as a treatment for stuttering. Therefore, prescription of medications for the disorder occurs presently in an “off-label” fashion. At the same time, data from neuroscientific research are increasing the understanding of the possible physiological basis of stuttering (e.g., Connally, Ward, Howell, & Watkins, 2014; Ingham, Grafton, Bothe, & Ingham, 2012; Sengupta et al., 2017). There is also an impetus to continue research on the efficacy of pharmacological therapies. Noting the methodological limitations of some studies to date, it has been argued that ongoing research should seek to be as rigorous as possible, employing large, carefully selected participant samples in randomised controlled trials, and using a range of outcome measures. A further recommendation is that the effects of pharmacological treatments are studied in comparison and in combination with those of speech therapy (Bothe, Davidow, Bramlett, Franic, & Ingham, 2006b; Maguire, Franklin et al., 2010a).

On the consumer side, anecdotal indications suggest that there is a strong desire among some people who stutter for an effective pharmacological treatment, i.e., one designed and approved specifically for stuttering (Maguire & Wither, 2010; McCauley & Guitar, 2010; Miller, 2016). The present study puts this proposition to the test, empirically, by examining a range of stuttering-related factors which may influence people who stutter to consider a medical treatment, whilst taking into account that people make rather complicated decisions about medication based on its perceived health risks and benefits.

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