# Stammering: A Psychological Phenomena?

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# Egyptian Hieroglyph for Stammering



From Faulkner (1991) A Concise Dictionary of Middle Egyptian

"...The picture shows a person trying to speak but the speaking gets blocked by what looks like walls. The first figure of this hieroglyphic symbol shows a person seated, pointing to his mouth and to the ground. "Perhaps what this hieroglyph depicts is a tremor -- an earthquake -- being conducted from the ground to the mouth: If this is so, then the Egyptians used the earthquake as a metaphor for the moment of stuttering." (Silverman, p. 8) ..."

Ref: Kuster, J., Lundberg, A., DiGrande, A. (2000). A Picture Is Worth One Thousand Words. *Online International Stuttering Awareness Day Conference*, 2000. Retrieved from https://www.mnsu.edu/comdis/ISAD3/papers/kuster.html

#### **Abstract**

109 Indian people who stammered were asked through an online survey as to what they believed to be the real nature of stammering: a physical process which broke their verbal flow or a psychological phenomenon? A biological problem or a psychological one? Seven of them were randomly selected for follow up in-depth personal telephonic interview. We found that even though, neuro-biological component does play an obvious role, many participants were aware of the subtle psychological factors causing and sustaining stammering in adults. 63% of the responses favoured this psychological understanding. It was discovered that this understanding develops with passage of time (number of years with failed therapies). Specifically, frequent relapse forces the person to develop insights into the psychological nature of stammering. This has a deep significance for recovery. People who understand stammering as a "physical" process, often struggle and strain as if words were a physical object stuck in their throat. They continue trying out one therapist after another. But when they realise that it is a psychological phenomenon, based on emotions (fear, shame, guilt) and distorted cognition, they turn to those modalities which are effective in the long run and rooted in social context: desensitization, self-help groups, meditation, stress management etc. Deeper insights into the correct nature of stammering also helps by pursuing realistic goals: managing stammering rather than chasing fluency or cure – since there IS no cure, at present. Further, self-help groups appear to be a source of consistent support and of such insights. People who stammer have been abbreviated as pws, in keeping with "People First" linguistic tradition.

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#### Introduction

Stammering or Stuttering is a developmental communication disorder, generally characterized by involuntary disruptions in the flow of speech (WHO, 2010)<sup>i</sup>. It is also called Persistent Developmental Stuttering (PDS) i.e. It is a developmental process which has gone awry. While they mean the same thing, *stuttering* is popular in American English and *stammering* is preferred in UK, Ireland and India, where British English is in usage (BSA website) <sup>ii</sup>. It has been with us since ancient times. There is even an Egyptian hieroglyphic for stuttering (Hicks, R., 2003).

Two popular examples being Demosthenes and Prophet Moses in old times. Demosthenes overcame it by practicing speech against the roar of the Aegean Sea, having first put pebbles in his mouth. Moses took the help of his brother Aaron, as his spokesman, and led the Jewish people out of Egypt and captivity (Brosch, S; Pirsig, W., 2001). In modern times, James Earl Jones, Marilyn Monroe and Bruce Willis are often cited as "positive" examples of people who stammer (Wikipedia)<sup>iii</sup>. Bollywood hero, Rithik Roshan also has shared his struggles with stammering in Indian media (The Quint, 2016 <sup>iv</sup>). Many popular singers and actors have come out into the open about their issues with stammering like Gareth Gates, Megan Washington, Carly Simon, Emily Blunt etc. in recent times.

While as examples, they may be fine but life for an average pws continues to be difficult since there is no known cure for stammering in adult life (Ward, 2006). This is because Neuroscience in the 21<sup>st</sup> century, still does not offer a definitive explanation as to how stammering begins and is sustained in adult life:

"The growing consensus is that many factors influence stuttering. Current theories suggest that it arises due to a combination of several genetic and environmental influences. Some elements currently being examined include motor skills, language skills, and temperament. It is presumed that a child experiences disruptions in speech production due to an interaction among these (and presumably other) factors." (J. Scott Yaruss, 2005, in Scientific American<sup>v</sup>).

**Spontaneous Recovery:** It has been noted that about 75% of pre-schoolers who begin to stutter will eventually stop. Many children who "recover" from stuttering do so within months of the time their stuttering started. Nonetheless, there are some people who have stuttered for many years and then improve. Why some people recover and others don't, is unclear. Also, it is not possible to say with certainty whether the stuttering symptoms for any particular child will continue into adulthood. Children's recovery from stuttering may happen when they receive speech therapy. The role of speech therapy in the recovery process needs to be studied further, however, because some pre-schoolers appear to recover without ever having seen an SLP. In fact, some researchers believe that recovery reported as therapeutic success may just be these 75% cases of spontaneous recovery. These "successful" studies have also been questioned for poor design- for example, many of these studies report about only

those children who stayed in the program – and not those who dropped out (Weidig, T., 2006)<sup>vi</sup>.

Another dimension of spontaneous recovery is: girls recover more often than boys. Since boys are about four times less likely to recover from stuttering than girls, it is tempting to speculate that all stutterers have a slight abnormality, but only those that can use the right hemisphere for language can develop into fluent speakers. Language lateralization is less pronounced in women (McGlone 1980) and might therefore be related to the fact that women show an overall lower incidence in PDS.

It is unlikely that stuttering is inherited in a simple fashion. Currently, a multifactorial model for genetic transmission is most likely. Moreover, it is unclear whether a certain genotype leads to stuttering or only represents a risk factor and that other environmental factors are necessary to develop PDS (Büchel, C., Sommer, M., 2014)<sup>vii</sup>.

So, it appears that many factors are involved here and this is the reason why no cure for stammering has been found till date – despite many false claims. On the other hand, society fails to understand the problem and therefore the stigma prevails (Kenneth O. St. Louis, 2015) viii. There have been cases reported in media, where pws face discrimination in employment and education (Srivastava, S., 2007 ix). Relationship and marriage too is adversely affected.

In this scenario, it is understandable that a "cure" may not be found soon and the negative psycho-social effects faced by people who stammer may persist. On the other hand, academics in speech science have come up with useful insights. One such contribution is: Stammering may have a neurobiological basis (mediated by genes) to begin with, in childhood, but it soon acquires many psychological overlays, through negative social interactions over the growing up years, leading to a well-defined stammering "mindset" (Sheehan, J., 1970) x. This mindset is characterised by avoidance of threatening situations or words, excessive anticipatory struggle in speech, fear, shame, guilt, alienation and even loss of self, etc. Some sensitive pws may even commit suicidexi.

Yet, many educated pws keep on believing that it is a "physical" problem, so they submit themselves to tongue-tie operation, which of course is useless in stammering and may even be harmful – and such other physical interventions <sup>xii</sup>. Many Speech therapists never talk of shame, fear, guilt associated with stammering in adults. They emphasize "physical" measures or concepts like breathing, gentle onsets, modulating pitch, use of metronome like devices or tapping etc.

#### The Psychological Dimension

Dr Sheehan, himself a pws and a professor of Communication disorders in USA, talked about "stammering ice-berg" in the 1970s (picture below): More than 90% of the problems in an adult stammerer are psychological<sup>xiii</sup>. But Speech Therapists (not Psychologist) continue to treat stammering and many pws continue going to them,

even after frequent relapses. Many pws late in life, begin to realize that their speech mechanism was always fine- the problem was with cognition, affect, attitude and self-concept.



As the Sheehan's clinic brochure xiv mentioned, it is well known that only a small part of the iceberg is visible above the surface but the danger lies in the bulk which is beneath the surface of the ocean. So it is with stuttering. The obvious sounds and sights of stuttering behaviour apparent to the listener are a small fraction of the problem. The hidden attitudes, values, fears and feelings as a speaker are a large part of the problem which cannot be ignored. One can keep on chipping the upper part, the submerged part will keep on rising. A two-pronged therapy is needed to work with stuttering: behaviour/symptom change and attitude/feeling/self-esteem change about the role of the stutterer as a speaker.

To some extent, this is due to the fact that for a long time physical explanations of stammering and treatment modalities based on it, remained very popular. In 1942, The American Mercury, a newspaper, blamed Churchill's lisp and stutter both, to a defect in his palate – quite erroneously as we know now:

"Churchill struggled to express his feelings but his stutter caught him in the throat and his face turned purple" and that "born with a stutter and a lisp, both caused in large measure by a defect in his palate..."xv.

Based on this superficial understanding of stammering, many crude mechanical devices were developed in 20<sup>th</sup> century; These were forced on the pws to

change the manner of speaking, position of the tongue in mouth or respiratory dynamics (Molt, L. 2005)<sup>xvi</sup>. Interestingly, all these devices treated speech as a mechanical process with no or little role of emotions, cognitions and attitude etc. This trend continues today with gadgets like DAF/FAF machines, which are costly and provide auditory feedback (delayed or frequency altered) while talking.

However, there is one exception; It was discovered that "Eye Movement Desensitization and Reprocessing" (EMDR) therapy could reduce anxiety, which has a big role in stammering. Casa Futura, the company which developed DAF machines, also made such glasses, which could deliver EMDR therapy quickly, as the speaker is talking and comes upon a feared word (David, (2011)<sup>xvii</sup>. This machine never became popular. By and large, most of the assistive devices thus ignore the psychological aspect of stammering. It is only some blogs on the fringe that talk of stammering as a *mindbody* disorder (Louw, P. (2017)<sup>xviii</sup>.

For example, Delayed auditory feedback approach is based on the idea that while talking, we are listening to ourselves, monitoring our speech on various parameters including fluency. These inputs feedback into the forward motor loop of speech production. This function is attributed to auditory association cortex (planum temporale). When this auditory feedback is delayed by a few micro-seconds, normal speakers develop disfluencies. However, some pws slow down, become fluent and speak more deliberately. This beneficial effect in pws is however not predictable. Not all individuals who stutter experience a positive effect on speech fluency when speaking under DAF.

On the other hand, those who do show a positive effect, may differ considerably as to the degree and the conditions in which the effect is seen (Bloodstein, 1995; Ward, 2006). The outcome in a given client probably is a function of multiple factors- biological subtype, age, gender, severity etc. - and as such the decision whether or not to attempt the use of DAF is usually not straightforward. FAF (Frequency altered auditory Feedback) machines, likewise, worn as a hearing aid in the ear or carried in the pocket, plays back speaker's own voice with frequency altered (high pitched squeaky/ or baser low pitched)<sup>xix</sup>.

These technologies rely on neurobiology of speech production and auditory feedback - but give little importance to the role of emotions that accompany speech, to the role of cognitive framework within which communication takes place, to the role the listener plays, since communication is not just talking but listening too, like a well-choreographed dance with a partner. Also, because these technologies fail to take note of the complex nature of stammering, they have not been successful in the long run. Most DAF/FAF users face relapse in a few months. Some get dependence, tinnitus and other difficulties like background noises and stop using it after a few months (Stuttering Jack blog)<sup>xx</sup>, (Tomer, N., 2009)<sup>xxi</sup>.

This should not come as a surprise; Modern western medicine has inherited Cartesian dualism of mind-body; While approaching a problem, it relies on a reductionist approach, wherein measurable symptoms or correlates, connect a disease or disorder to a specific organ or system neatly – often ignoring the role of the "whole". Alternative explanations, especially based on mind, have often been resisted. An example is Dr Sarno's understanding and treatment of tension myoneural syndrome (TMS) on psychological basis, which is currently not accepted by mainstream medicine <sup>xxii</sup>.

#### Therapeutic Approaches

A big controversy in therapeutic field has been: can therapy "cure" stammering? Obviously not, since no one understands the cause of stammering beyond the fact that it is multi factorial and complex. But many therapists (and others) have regularly made such claims – misleading the clients and their families. This reached proportions of a global scam, till professional bodies around the globe raised ethical objections to advertising "cure" by clinicians in the context of the stammering. Some professional bodies had to be petitioned in this regard (Weidig, T., 2010)<sup>xxiii</sup>.

Currently, therapy for stammering is based on two approaches: Fluency shaping and stuttering modification. It is offered by Speech Language Pathologists in India and elsewhere. In fluency shaping/enhancing approach, such modalities are used like slow rate speech, gentle onsets of the voice, elongated initial sounds ("slides" or "prolongation"), and maintaining nearly continuous vibration of the vocal folds during speech. Here the goal is to maintain a fluent speech, without any blocks. As a wikibook explains, fluency shaping therapy programs typically begin with slow speech with stretched vowels, then work on relaxed, diaphragmatic breathing, then work on vocal fold awareness and control, and finally work on relaxed articulation (lips, jaw, and tongue).

These fluency shaping techniques are all abnormal. They all produce "weird"-sounding speech. The idea is to go to extremes when practicing (in the speech clinic or at home), and then in "real world" conversations one reduces the techniques so that you sound normal, and speak fluently<sup>xxiv</sup>. This approach does not help the pws rise above the fear: what if I stammered? It does not prepare the pws to deal with negative listener reactions constructively and creatively. It promotes the idea that by speaking fluently, pws will pass for a "normal" speaker and everything should be fine.

In Stuttering modification approach, the pws is encouraged to stay in the "moment" and change her/his reactions to stammering. It needs some courage and it uses such techniques as voluntary stuttering, freezing of the stuttering moment and relaxation of the speech muscles during stuttering (pull-outs), slow and easy bounces of initial sounds, exaggerated smooth mouth movements during speech, "preparatory sets" which allow the person to relax and deal with anxiety before speaking, and cancellations or repairs of stuttered words after they are spoken. The purpose here is not to stop stammering but to stammer smoothly in a forward manner, with less

struggle and less psychological reactions. The main goal of stuttering modification is not to speak more fluently but to stutter easily (Van Riper, 1973).

Stuttering Modification uses a progression of having the client:

- 1. Learn to correct a stutter immediately after it occurs by saying it again in an easier fashion
- 2. Learn to change a stutter into an easier production of the sound while it's still going on
- 3. Learn to start a word the client expects to stutter on in an easy, slow, relaxed fashion that makes the stutter very mild"

Many pws spend a long time checking out various therapies or programs without finding lasting relief. One pws (Adrian), for example had had 18 attempts at therapy or stuttering programs till date. Please see the comment to this blog post about insatiable desire of the pws to get "fixed" and achieve fluency: <a href="http://thestutteringbrain.blogspot.in/2006/12/are-you-king-of-therapies.html">http://thestutteringbrain.blogspot.in/2006/12/are-you-king-of-therapies.html</a>

It is not surprising that relapse is very common in various stammering therapies (Pollard, 2012)<sup>xxv</sup>. There are two common reasons why relapse is so common: first, constantly using speech restructuring techniques is difficult and exhausting. Pws get tired of focusing on the content as well as on the techniques to be used for delivery ALL the time. Secondly, many pws find the unnaturalness of one's speech following such therapy unacceptable. Sometimes, they receive discouraging feedback from the close relatives or friends: *Your stammering sounded better than this contrived manner of speaking*. Therapists usually blame the pws for not sticking to the techniques long enough, for it to become natural. Some believe that this resistance to change is because a pws continues hanging onto his/her identity as "stutterer" subconsciously.

When therapy fails, or there is a relapse, many pws tend to blame themselves. Therapists make matters worse by finding fault with client ("poor compliance") rather than with therapy or its basic assumption that stammering can be "fixed", in the first place.

**Social model of disability**: There are two models- Medical and Social – to conceptualise disability. The social model says that disability is caused by the way society is organised, rather than by a person's impairment. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

The medical model of disability says people are disabled by their impairments or differences. Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness. The medical model looks at what is 'wrong'

with the person, not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives<sup>xxvi</sup>.

Some pws posit that unless society permits them to radically change their identity and the perception of stammering, no lasting progress can be made by <u>any</u> therapy. Loriente, C. (2009) offers that we need to look at stammering, not as disfluency, requiring therapy and rehabilitation – but as Trans-fluency, a different manner of speaking altogether, a diversity <sup>xxvii</sup>. Transfluency is a concept which challenges and transcends both Dysfluency (popular among SLPs) and Fluency (chased by pws). This is what he has to say:

- "At the beginning of this century, stuttering has two social meanings: 1) Stuttering is constructed as a deviant behaviour, because stuttering is an uncommon behaviour. Stuttering is dramatically different from the accepted speech pattern, the fluent one.
- 2) Stuttering is constructed as a pathological (or medicalized) behaviour, because stuttering is classified as a mental disorder.

It looks like stuttering does not belong to human nature. Stuttering seems to be unnatural, something added to our nature. I (Loriente) want to present a new construction of stuttering named Transfluency. We should change the social meaning of stuttering, because the present one harms the stuttering community. Below I indicate some behaviours which were constructed as deviant and pathological (or medicalized) but afterwards, society and physicians reconstructed them as common and even healthy behaviours. Therefore, illness and deviance are social constructions..."

He offers a parallel with Gay movement: Homosexuality was removed from DSM (1.2) in 1973. This removed the pressure that a counsellor had to "help" a LGBTQ person to reach a "cured" state. The community was de-stigmatised and was set on the path of empowerment.

A group of social activists are also trying to see stammering through political lens: *Speech assimilation is an ongoing cultural process in which we are shamed and subtly forced to conform with dominant speech patterns xxviii* (Did I Stutter blog). This blog further states:

"Following the disability rights movement that took hold in the 60s, we understand disability and stuttering not as an individual defect, but first and foremost as a social discrimination against certain forms of human speaking. We can speak of "ableism," just like racism or sexism. The experience we call stuttering must fundamentally be understood as a discrimination against dysfluent ways of communicating and using one's body..."

These social scientists at *DidIstutter* blog, question the disability labels, including stammering, and attribute a central role to Culture, rather than biology, for the construction of these labels and stereotypes:

"Stuttering is only a problem—in fact is only abnormal—because our culture places so much value on efficiency and self-mastery. Stuttering breaks communication only because ableist notions have already decided how fast and smooth a person must speak to be heard and taken seriously. An arbitrary line has been drawn around "normal" speech, and that line is forcefully defended..."

It appears that dissatisfaction with therapeutic approaches is forcing the stammering community to increasingly explore new ways of looking at stammering, de-medicalise it and accept it as a diversity to be celebrated, rather than "cured" or carried as a burden.

On the other hand, relapses also create doubts in the mind of the pws as to her/his understanding of the nature of stammering. Some, start to develop insights into the psychological nature of the problem, as a result. This study has tried to explore this phenomenon: how and when pws begin to develop these insights.

## Objective of the study

- 1. When and how do people who stammer (pws) become aware that stammering has a large psychological component?
- 2. What are hindrances to/promoters of the evolution of this understanding?

#### Literature review

Most of the research and documentation in the field of stammering has focused on what causes stammering (neuroscience, genetics) and how to manage it better from clinician's point of view. Only in the last 2-3 decades, studies have begun to explore the sufferer's own understanding and the prevalent social attitudes. Here are some books, papers and websites on these themes, which were consulted by the author and found useful:

- 1. What Causes Stuttering? (Christian B, Martin S, 2004) xxix: This paper explores how "physical" understanding of stammering led to erroneous "plastic" surgery, mutilations, prosthetic devices in medieval ages; In the 20th century, another erroneous belief took over that stammering is purely a psychogenic phenomenon. This gave rise to psychoanalytic attempts to understand stammering and blaming parents in many cases. Instead of understanding stammering "here and now", therapist often dug deeper in remote past, conflicts and events.
  - This paper also explores if Stuttering is a Sensory, Motor, or Cognitive Disorder. It leaves some valid questions for future research too.
- 2. **American Speech Language Hearing Association** website<sup>xxx</sup>: ASHA is the American national professional, scientific, and credentialing association for 191,500 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students. Audiologists specialize in

preventing and assessing hearing and balance disorders as well as providing audiologic treatment, including hearing aids. Speech-language pathologists identify, assess, and treat speech and language problems, including swallowing disorders.

This website discusses causes and differentiates them on two levels: Genetic causes which predispose a child to develop stammering. Environmental causes which may or may not promote expression of stammering. As the child grows, psychological factors come into play and lead to development of secondary behaviours.

This page by ASHA offers basic understanding of the issue- the speech science behind stammering. It is interesting to note that this page hardly makes a mention of psychological issues faced by pws. It talks about the symptoms (what you see and hear, a pws doing), treatment approaches, how it is diagnosed etc. But nothing about what goes on in the head of a pws on a typical day: fear, shame, guilt, anxiety and the emotional disconnect. Some quarters have questioned the trend that PWS are straightaway referred to a speech therapist – and not to a Psychologist.

- 3. **Veils of Stuttering,** website<sup>xxxi</sup>: This website offers interesting insights into the psychological dimension of stammering. As it states, it is an exploration of the "veils" (self-images, projections, and lack of awareness) that must be worked through during therapy or self-therapy to begin and continue the process of stuttering recovery, and how these veils are largely protective mechanisms that people who stutter use to (unconsciously) cope with the disorder, just as all humans use similar "veils" to cope with other disturbing or discordant aspects of their lives. It also offers a Reactive Inhibition model of stammering (Dodge, D.M., Colorado, L., 2016) \*xxxii\*.
  - Elsewhere, Dodge explains that for every person, self-images acquired in early childhood and reinforced through the course of life are the cause of much suffering because they prevent access to our true nature. These self-images (for example, "I'm an introvert" or "I'm an avoider") perpetuate the notion that the personality is the self, preventing people from realizing their full range of human capabilities. For the person who stutters (PWS), the "veils of stuttering" tend to perpetuate the disorder by reinforcing the illusion that the self and stuttering are the same thing. These veils also shroud the true nature of stuttering in self-judgments, lack of self-acceptance, fear and threat anxiety, distorted projections, and the acquired opinions of others - all unhelpful activities of a psychological process called the super ego or inner critic. Ironically, the overt behaviours of developmental stuttering are largely the result of attempts to preserve the identity and the self in the first place. To the child who begins to experience difficulties with speech disruptions, the first threads of the veils are woven in the instinctual attempt to control and hide abnormality.
- 4. **Stuttering meets stereotype, stigma and discrimination**: an overview of attitude research by Kenneth O. St. Louis. West Virginia University Press,

- 2015. A collection of papers by different authors and based on the inaugural Stuttering Attitudes Research Symposium held in the US back in 2013, this book takes stock of what has been the stuttering attitude research so far and to identify areas where further research would be most fruitful. The evidence for research extends beyond fluency disorders to other areas like mental illness, obesity, and race. The book has potential for increasing under-standing, ameliorating negative attitudes, and informing research on any of a host of other stigmatized conditions.
- 5. **The Stuttering Brain**: This is a blog by Dr Tom Weidig, highlighting *The Science, The Treatments, and The Controversies of Stuttering*. This blog critically reviews claims of efficacy by various therapeutic approaches and research studies. It has specially examined and debunked claims of cure by many "respected" programs (like Lidcombe) and other experts. It can be freely accessed at <a href="http://thestutteringbrain.blogspot.in/">http://thestutteringbrain.blogspot.in/</a>. This blog has also been awarding "Crackpot" awards, to those individuals who claim to have found a cure, without doing the necessary research or scientific homework "xxxiii".
- 6. **Stutter Rock Star Blog:** This is a blog by a woman who stutters. As Pamela states, "Make Room For The Stuttering blog" was created by her (initials: pam) after realizing that she had a story to tell. She was a covert stutterer for many years, and was afraid to stutter publicly. Her defining moment was getting fired from a job that she loved and had held for more than 20 years, because she had stuttered publicly. In that instant, she decided that she could not live in hiding anymore and out of the closet she came. They say that difficult experiences can break one or transform one. She was transformed. She has also discovered that she loves to write and do it rather well. The fact is, women who stutter and who write about it in public are a minority within minority.
  - In telling these stories on her blog, she claims, that she is growing and evolving as a person. Stuttering has value, and it is important for her to share this with the world. Since opening up about her stuttering, she thinks that her world has opened up, profoundly and deeply. Now, she feels that it is her responsibility to share her journey with others whose lives have been touched by stuttering. It can be freely accessed at <a href="https://stutterrockstar.com">https://stutterrockstar.com</a>.
- 7. **Kuster's Stuttering Home Page:** The Stuttering Home Page is an exhaustive online resource, dedicated to providing information about stuttering and other fluency disorders for both consumers and professionals who work with people who stutter. It includes information about research, therapy, support organizations, resources for professors who teach fluency disorders courses, materials for kids who stutter, and much more. It was created by Judith Maginnis Kuster and is maintained at Minnesota State University, Mankato. Kuster is an American Speech-Language and Hearing Association certified speech-language pathologist and a professor emerita in the Department of Speech, Hearing and Rehabilitation Services, Minnesota State University, Mankato.

- 8. Self-Therapy For The Stutterer: It is a popular book, compiled by a pws (Malcolm Fraser), who helped himself by practicing various self-help approaches and ideas. First published in 1978, it has undergone eleven editions since them and continues to be more popular than books written by academics and therapists. It is formatted as a self-help workbook: Practical steps explained and supported by theoretical concepts. This book, while offering "physical" techniques, also gives due coverage to role of Fear, Motivation, sadness etc. and how to deal with them. It is freely available at <a href="http://www.stutteringhelp.org/sites/default/files/Migrate/book0012\_11th\_ed.phg">http://www.stutteringhelp.org/sites/default/files/Migrate/book0012\_11th\_ed.phg</a>
- 9. **British Stammering Association (BSA)**\*\*xxiv\*: The BSA is a registered charity which helps people who stammer. It helps by providing inspiration, encouragement, information, support and advice, funded through a mixture of trust grants, fundraising and donations. Their website provides a resource section. BSA is speaking up for people who stammer. Whether it's fighting for the retention of NHS speech and language therapy services, whether it's arguing for a better system to support children who stammer in school, or whether it is in the field of employment where we believe that people who stammer should be able to enjoy the full protection of the Equality Act we have a loud voice. One of the more unusual (and successful) campaigns was to restrict advertising for commercial stammering therapies which offer a 'miracle cure'.
- 10. **Stuttertalk:** StutterTalk is a non-profit organization based in USA, dedicated to talking openly about stuttering. StutterTalk is the first and longest running free podcast service on stuttering. Since 2007 it has published more than 600 podcasts. StutterTalk is heard in more than 170 countries. It was awarded Best journalism award for 2015. Stuttertalk interviews, questions, critiques various therapeutic approaches and programs and puts it up as free podcast. In recent times, it has investigated claims by "Speech Easy" device makers, Hollins Precision Fluency program, McGuire Program etc.

11. **Redefining Stuttering:** This book by a recovered pws, John Harrison, offers a holistic understanding of stammering through a hexagon (below).

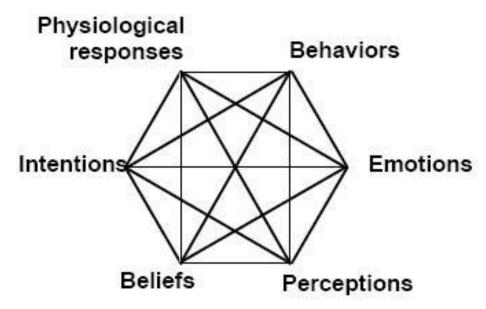


Figure 2: Harrison's Stuttering Hexagon

John Harrison, the author, has been a member of the National Stuttering Association in America for 34 years. Through participation in a variety of personal growth programs throughout the 60s, John discovered that stuttering was not what he thought it was. It was not just a speech problem, but a problem that involved many different sides of himself.

His extensive self-help work with pws and recovered pws, gave him an unusually good vantage point from which to explore the stuttering phenomenon. In preparing a presentation for the NSA's first annual conference, held in San Francisco in the mid-80s, John came up with a new model, or paradigm, for stuttering that was inclusive enough to answer all his questions. This book is freely available at:

 $\frac{http://www.mnsu.edu/comdis/kuster/Infostuttering/Harrison/redefining-stuttering.pdf}{}$ 

## Hypothesis

PWS at young age, tend to interpret their stammering difficulties in terms of physical (biological) explanations. With maturity, understanding and introspection, they develop insights into the predominantly psychological nature of stammering.

## Methodology

**Sample**: An online survey was done using a google form (vide appendix). It was promoted by individual emails to members of stammering self-help groups across

India. The link was also shared on the website of The Indian Stammering Association (stammer.in). 109 pws, mostly young (18-35) males, completed the form. Obviously, this group is a **convenience sample** and not representative of pws, in general, across this diverse country. For example, women were only 6 (0.6%) and no one was from rural background. It should be noted here that there is a sex differential in stammering: it is one woman to 4 or 5 men who stammer in adult population. This could be on reason why so few women completed this questionnaire.

**Survey Instrument**: The online form had 14 items. Of these five key questions asked respondents to show their preference among two statements: one based on physical/biological understanding of stammering and the other, on psychological understanding. Respondent had to choose only one, even though both statements appeared equally true and had equal chance of being chosen. This set of questions indicated their understanding of stammering as a mindset, a psychological phenomenon OR as a mechanical/ physical problem (block in throat / brain - or genes for example). Here are the questions:

- Stammering is caused by closing of vocal cords OR Stammering is caused by expecting the worst in every situation.
   The first part is not the cause, rather the effect of mis-directed Valsalva reflex (Perry, W. D., 2010)<sup>xxxv</sup>.
- 2. Stammering is caused by delay in speech signals from the brain OR Stammering is caused by shame associated with the act of speaking
- 3. Stammering is caused by replay of painful memories OR Stammering is caused by the lack of air in the lungs
- 4. Stammering is caused by the pressure to conform ("I must talk like others") O R Stammering is caused by a lack of thoughts/ words.
- 5. Stammering is caused by fear of what the listener might think, say or do OR Stammering is caused by a gene.

The score for the above 5 questions was converted into a Psychological Score (SyTot), as below:

- 0 None of the Psychological options chosen. (Minimum score)
- 1 Psychological option chosen only in one question.
- 2 Psychological option chosen only in two question.
- 3 Psychological option chosen only in three question.
- 4 Psychological option chosen only in four question.
- 5 Psychological option chosen in ALL five questions. (Maximum score)

**Ethical consideration**: The instrument did not collect email IDs or other personal identification data like name. However, people were only requested to leave their

email ID or phone number, in case the researcher wished to do a follow up interview. Respondents could not see others' response. Refusal to participate in the survey did not prejudice their access to services offered by the platform- TISA, The Indian Stammering Association.

**Data Cleaning**: The data was cleaned in Excel 2016; Names of variables were edited to make better sense. Some data was recoded or relabelled. For example, "aircraft maintenance engineering" was relabelled as "Graduation" under Education, for record number 43. Response to five core questions was recoded into a SyTot (Psych) score, as explained above.

**Data Structure**: There were total 109 records and 8 variables. These variables are:

- 1) Sex
- 2) Age
- 3) Education (highest)
- 4) Current Employment status (yes/no)
- 5) Stammered for (years)
- 6) Stammering Difficulty (self-rating, 1 to 5)
- 7) Received most help from
- 8) SyTot (0-5, Psych score, as explained above).

**Data Analysis**: It was done using R (ver. 3.2.1), a free statistical package. Initially frequencies were checked, then box-plots were made, for distribution of the data and finally regression studies were done to establish correlations.

**Qualitative data**: Seven one-on-one in-depth telephone interviews were conducted with random and available respondents. These telephone interviews could not be recorded but notes were taken. The text was manually analysed. Following questions were used:

- 1. Please tell us briefly about yourself? Name, age, gender, education, job, city etc.
- 2. Tell us something about your stammering in growing up years? What did you/ family do to help yourself? Did it work? Why or why not?
- 3. As a child / adolescent, what did you think was the cause of your stammering? How did you reach this conclusion? When and how, these ideas of causation began to change?
- 4. As an adult, what do you now believe about the nature of your stammering and its cause? Is it a physical problem or a psychological one? How? How did you reach these conclusions?

- 5. How this understanding has changed your approach to therapy or self-help?
- 6. What have you learned from your stammering?
- 7. Anything else you would like to share? (Thank you)

### Data Analysis

Demographics of the respondents (n=109) was analysed by running frequency for age, gender, highest educational attainment and current employment status. These demographic characters were studied using R - and confirmed using pivot table in Excel. Correlations were studied using R.

#### Who are the respondents?

Most are young men, from IT background, living in cities. Females are only 6 (0.6%). 87% of pws answering this survey are between 18-35 years (see the chart below). Though we did not ask for the name of the city, since we were administering the instrument online through a google form, it is safe to assume that all the respondents were city dwellers, with access to good IT facilities and skills. This excludes pws from rural background – a constraint of the study design.

Many pws have shared that they opted for IT career because they felt that communication demands are much less in this sector than elsewhere, like management, medicine etc. Of course, later on they discovered that their assumption was wrong. Communication skills are needed in IT sector as much as elsewhere.

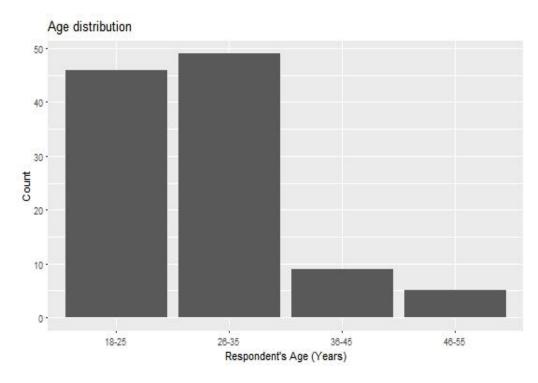


Figure 3 Most respondents are young urban men

Educational background of the respondents was mostly Graduation (30%) or Professional graduate degree like B.Tech etc. (45%), as is to be expected in a young urban group.

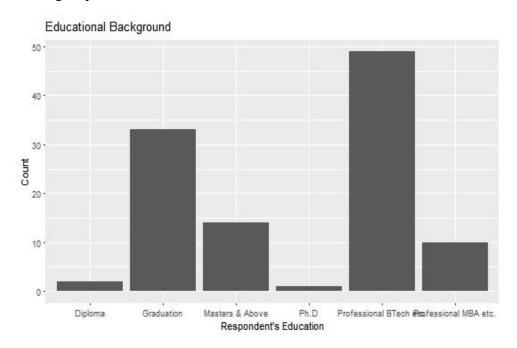


Figure 4 Most respondents are graduate or with a professional degree

73% of respondents are currently employed.

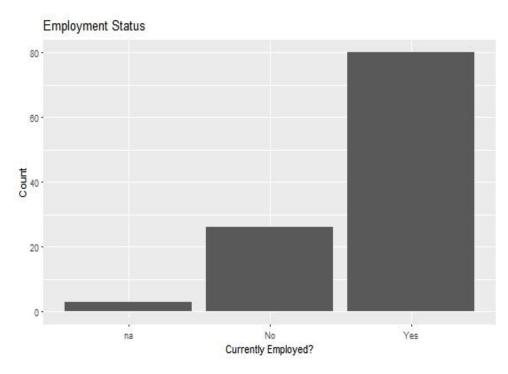


Figure 5 Most respondents are currently employed

#### **Speech Difficulties**

Next section dealt with self-reported duration and level of difficulty, they have faced due to stammering. Unfortunately, stammering is such a complex phenomenon

that there is no satisfactory comprehensive scale to measure it – other than subjective measures (Josh, 2015 xxxvi ; Yaruss, 1997 xxxvii). Respondent had to report his/her difficulties on a scale of 1 to 5. The related question was: how long have you been stammering? The answer obviously correlates to age, as Persistent Developmental Stammering begins in childhood. Since most respondents were in their twenties, most have stammered for 17-20 years.

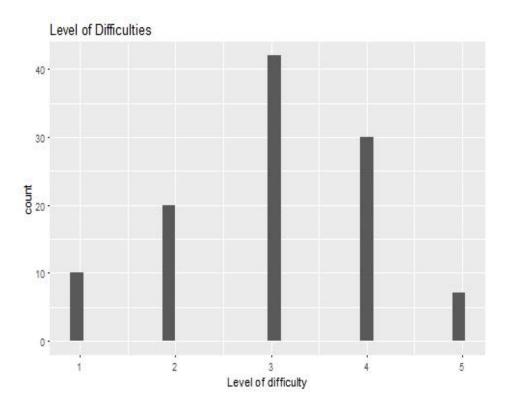


Figure 6: On a scale of 1-5, most respondents ranked their speech difficulties at 3

Most people ranked their difficulties somewhere in the middle, around 3, on a scale of 1-5. This translates in practice to difficulties giving presentations in office or college, talking to colleagues/ seniors, answering phone calls, buying train tickets, talking to "opposite" sex etc.

Stuttering is characterized by repeated words, sounds, or syllables and disruptions in the normal rate of speech. For example, a person may repeat the same consonant like "K," "G," or "T" till he or she is able to move on. They may have difficulty uttering certain sounds or starting a sentence. The stress caused by stuttering may show up in the following symptoms:

- Physical changes like facial tics, lip tremors, excessive eye blinking, and tension in the face and upper body
- Frustration when attempting to communicate
- Hesitation or pause before starting to speak
- Refusal to speak

- Interjections of extra sounds or words into sentences, such as "uh" or "um"
- Repetition of words or phrases
- Tension in the voice
- Rearrangement of words in a sentence
- Making long sounds with words, such as: "my name is aaaaaaaaaaanand"
- Some adults develop elaborate rituals / strategies of avoidance: They may have severe difficulty in saying "Namaste" or "Hello". Therefore, they may cut the phone and then, redial and complain about the line- thus bypassing the need to say either of those initial words.

Social settings and high-stress environments can increase the likelihood that a person will stutter. Public speaking can be terrifying for those who stutter. In one instance, a brilliant student stopped studying, because he was not able to either ask questions in the class, nor answer any question; so he decided that there is no point in studying and trying to excel xxxviii.

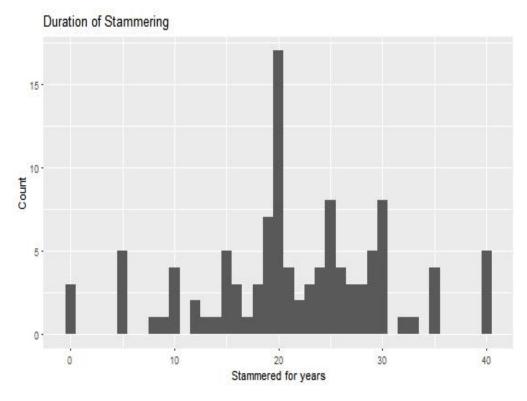


Figure 7: Most respondents had spent 21.6 years facing stammering difficulties

Mean for Duration of stammering was 21.58 years, i.e. it began sometime in childhood in most cases and persisted ever since.

Many pws are not aware of their stammering in early childhood. It is only when they change schools, graduate to class ten or some other life change event – that they become aware of it or due to stress of change, their stammering increases and intrudes into their consciousness. For example, parents may say that the child stammered for the first time when in class 4. But the child may say: *No, I spoke fine till class ten. Then I had to go to this new college and I began stammering*. This

phenomenon illustrates that memory is not like a video tape. It is reconstructive and often interpreted in terms of salient life events.

#### Change in Perception with Age

Respondents have given a lower rank to their difficulties with increasing age: Older pws seem to perceive their stammering as less of a difficulty, compared to younger people. Even though there are only 5 respondents in 46-55 year age group, a trend is visible (see below).

	Table 1: Percept	on of speech	difficulty ones	down with age
--	------------------	--------------	-----------------	---------------

	Age groups (yrs)			
Difficulty Level	18-25	26-35	36-45	46-55
1 (low)	4	5	0	1
2	4	13	1	2
3	15	20	6	1
4	18	10	2	0
5 (High)	5	1	0	1
Average	9.2	9.8	1.8	1

This could be because they are settled in a job and the worst years are behind them. It could also be that they have developed some acceptance/ indifference with the passing of years, that they have become desensitized to negative listener reactions.

Louw, P. (2010) offers deeper insights into how age diminishes severity of stammering xxxix:

"In later life, however, the social and occupational areas of life look very different from when young. By this time most of us have found a significant other who has accepted our disfluency; No longer is there the overriding need to be accepted as you are by peers, friends and the broader community; at this age you probably already have a few friends with whom you feel comfortable and who share your values. Psychologically you've probably left behind some or all of your youthful insecurities which contributed to your high tension levels and related stuttering. You know so much more about life, people and yourself, and this huge knowledge base has helped you cope not only with stress and stuttering, but with sorting out, understanding, accepting and making sense of so many things that in the past made your life miserable...

Last but not the least - as you age you will probably find that stuttering is no longer the primary health issue affecting your life. High blood pressure, excessive

cholesterol and other age-related ailments can present themselves, so that stuttering becomes part of a much wider health spectrum that needs to be managed..."

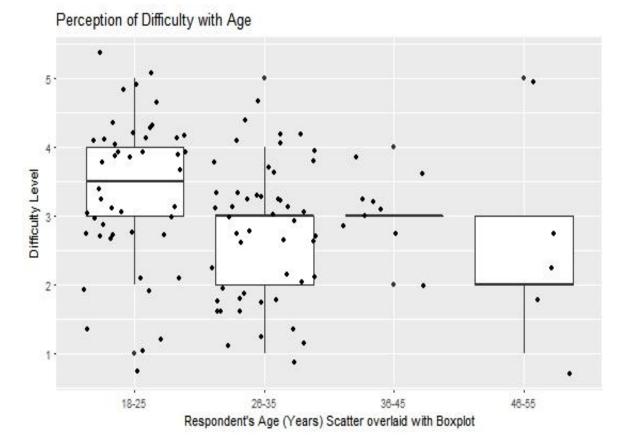


Figure 8: Older respondents have given a lower rank to their stammering difficulties.

#### Correlation with Age and 'stammered for years'

Linear regression shows better correlation with StamFor (duration of stammering in years) than with biological age:

Linear regression analysis for 'Difficulty level ~ Age', generated these coefficients:

It can be seen above that none of the coefficients are below 0.05. This is not a strong correlation. However, here are the coefficients for 'Difficulty level  $\sim$  stammered for (years)':

(Intercept) D\$StamFor 3.34293 -0.01419

It can be seen that, here the coefficient (-0.01419) is less than .05 and is negative (minus), meaning that there is some inverse correlation between duration of stammering and perception of speech difficulty, as discussed above.

There was no significant difference in the male/female perception of their difficulties, even though the size of their population in this study was highly unequal (Women = 0.6% only), making valid comparisons problematic.

#### <u>Understanding of Psychological nature of Stammering</u>

Last section of the survey instrument was about the understanding of stammering as a predominantly Psychological or Biological phenomena. The set of five questions were chosen carefully and options were presented in a random order. For example, stammering has a genetic element which has been discovered recently, and reported widely in media (Yairi, 2006 xl ; National Institutes of Health, 2010 xli ). The alternative option to this, is "Stammering is caused by fear of what the listener might think, say or do" – which is clearly a psychological phenomenon, a cognitive distortion.

If a pws believes or prefers the second option, chances are she or he will seriously work on desensitization in social situations. But if he believes in the first option, genetic origin of stammering, he may wait for technological solutions — a drug or genetic engineering intervention. So, these questions were seen to be important from therapeutic point of view too.

Therefore, all the responses to the five questions were aggregated into a SyTot score, as explained above and was used to explore correlation with other variables-like age, employment status, educational background. In other words, people who score high on this psychological score, do they show any similarities on other variables like age, number of years they have stammered or the rank they have given to their stammering difficulties, education etc.

Overall, 63% Psychological ("Sy") options were selected as against 37% Physical ("Ph") options for all the five questions (Pie chart below).

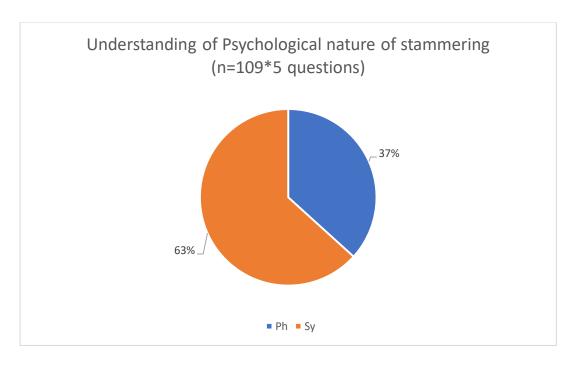


Figure 9 Two thirds (63%) of the times, respondents have selected Psychological options in preference over Biological ones.

For individual questions, we can see that only one question (number 4 below) received higher score in favour of physical factors: Lack of air in lungs versus role of painful memories in stammering. Based on personal communication, it is true that for some pws, continued repetitions or prolongation of a syllable – OR – continued exhalation with failed phonation can create a situation where lungs may have little or no air left for production of sound (Hogan, 1982 xlii). This understanding is quite experiential for some pws. So, it may be "intuitive" and easy for a pws to believe that stammering is caused by lack of air in lungs – nothing more.

But we need to look deeper: why does it happen sometimes like while talking to an authority figure? Why does it not happen when we are singing? Or talking to a child? After all, for singing too, lungs need air. So, why don't pws stammer while singing? Such insights obviously are earned over the years by the pws.

On the other hand, the second option: stammering is caused by replay of painful memories is equally true, based on Gestalt Psychology: a thought or a trigger brings back the gestalt of stammering- struggle, helplessness, oppression and related motor behaviour – reproducing our characteristic stutter. But this insight is not intuitive, not easily accessible to average pws.

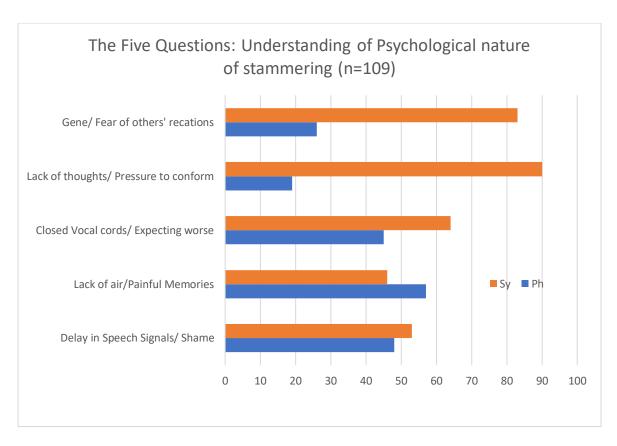


Figure 10 Psychological options outnumber Physical ones, except in question 4, as discussed above.

In the first two questions, it seems that respondents found it easy to identify with psychological explanations: fear of others' reactions and pressure to conform. This could also be because genetic mutations responsible for stammering are not yet widely known in India- some researchers even doubt it (Harrison, J C., 1999) xliii and a controversy is going on (Casa Futura, 2013) xliv.

Even though stammering is known to run in many families, a young pws may never get to know it first hand: his uncle who stammered in youth, may have learned to mask it in later years and may pass for a normal speaker. Also, due to natural reserve or family etiquette, she/he may not be free to ask: does anyone else in my extended family stammer? OR, even when asked, may not get the honest answer, because families consider it a stigma, more so, when more than one family member stammer.

Also, genetic transmission of stammering, may skip a generation and/or manifest with varying severity. So, it may happen that only grandfather and grandson stammer in a large extended family and may not actually get to hear each other stammering ever, separated by many years.

The second question, lack of thoughts versus pressure to conform is an interesting comparison. Many PWS claim that they exactly know what they want to say, but cannot say it. There are some who, overtaken by embarrassment and confusion, "forget" what they wanted to say. Some pws use it as ruse when they are in a silent block: *Let me think, I just can't recall it now*. They behave as if they have

forgotten what they wanted to say. But peer pressure to speak "normally" is felt by most pws, wherein authority figures (teachers, parents) also weigh in.

But as in the chart above, most respondents identified with psychological explanations. Most SyTot scores had stayed somewhere in the centre (2-3-4). See below.

# Understanding of Stammering as Psychlogical phenomena 20100 1 2 Psych Score

# Figure 11: Most respondents have answered 2-4 questions with a psychological understanding of the stammering phenomena

#### <u>Understanding improves with Age?</u>

It seems that it does. Higher age group have their Psych score moving up, towards 4-5 (see below). Could it be that with age, we get exposed to these deeper ideas? ideas that stammering is more a mindset than disfluency? While as young people we are selectively looking for a straightforward "cure", hence quite willing to believe physical/mechanical models?

This tally well with perception of speech difficulties, which eases with age (above, Table 1: Perception of speech difficulty at page 24).

Another mechanism could be: with advancing age, physical energy and will to struggle at every word is no longer there and one stammers effortlessly – as one ideally should and which is the goal of Stuttering modification therapy too. In other words, pws is no longer jumping into the battle and as a result speech is much less choppy and stressful (Van Riper, 1991 xlv). Along with this, probably there are attitudinal changes too, as mentioned above (Louw, P., 2010. xlvi).

# Understanding of stammering mindset with Age

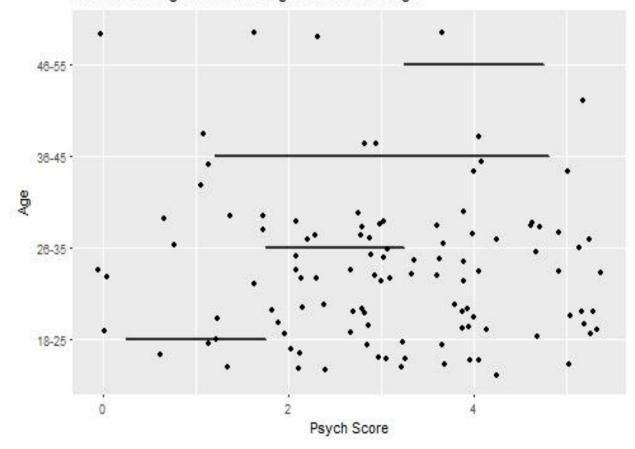


Figure 12: Insights into Psychological nature of stammering improves with age of the respondents

#### **Insights with Age?**

Psychological insights (SyTot variable) appear to correlate well with duration of stammering – than with age (except for 26-35 year age group). Here are regression coefficients:

```
(Intercept) D$Age26-35 D$Age36-45 D$Age46-55 3.130435 -0.007986 -0.241546 -0.530435
```

Regression between SyTot and Duration of stammering, shows greater and significant correlation (0.001655):

```
(Intercept) D$StamFor 3.046854 0.001655
```

Multiple regression, shows that duration of stammering remains significant factor in developing psychological insights; We used following formula:

(Intercept)	StamFor	DifLevel	Age26-35	Age36-45	Age46-55	EmplNo	EmplYes	SexMale
0.78881	0.01842	0.10716	-0.11804	-0.71204	-1 02355	0 64798	0.97750	0.90757

It is clear above that when all other variables are thrown in, StamFor still retains a strong correlation with SyTot, proving the hypothesis.

#### **Gender & Employment status**

Employment status had no impact on Psych score ("SyTot"). Though women numbered only 6 (0.6% only), making gender based comparison invalid, but here are the comparative boxplots below. It is believed that women and men, react to stammering differently (Mertz, P. 2013 xlvii, xlviii). While women may get away under the garb of being "naturally shy" in the Indian context, men may be considered "dumb" or "coward" for not speaking up under the similar situations. All the same, both may equally wonder as to the real cause of their speech difficulties: is it a physical affliction or a psychological phenomenon?

#### Understanding stammering mindset

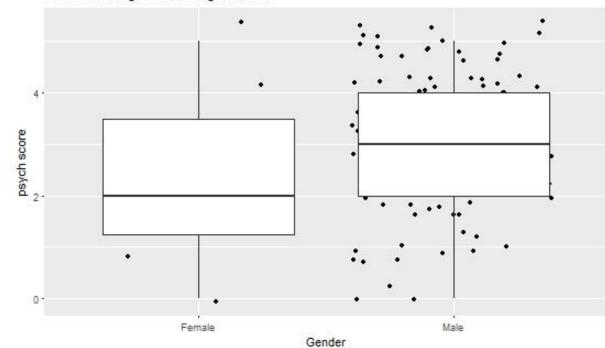


Figure 13: Insights into psychological nature of stammering appears to be higher in males, but since sub-sample is highly unequal, this can NOT be concluded with any certainty

Psych score shows improvement with years of stammering but shows a hump and downward trend beyond 15 years duration of stammering (below).

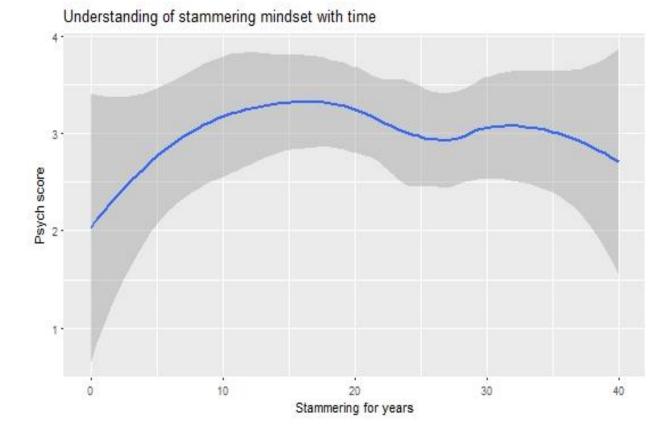


Figure 14: Evolution of psychological insights into the nature of stammering over the years

This bump could be because sample size in latter age groups (36-45, 46-55) is quite small (below).

Table 2: Sample size is smaller in older age group (36 yr onwards) and therefore relationships are not clear cut. But it can be seen that with age, SyTot has increased on an average.

Age Groups	Sample size	Average Duration of stammering (yrs)	Average of SyTot score
18-25	46	16.1	3.1
26-35	49	22.9	3.1
36-45	9	32.2	2.9
46-55	5	40.0	2.6
<b>Grand Total</b>	109	21.6	3.1

#### Source of Help/Understanding

Internet and Self-help groups emerge as important sources of help and understanding about stammering in this group. The respondents may have a bias towards Internet & SHG since most have access to Internet and some connection with SHG. The survey itself was offered as an online survey through a self-help channel. Studies indicate that participation in SHGs offer distinct psychosocial advantages to pws (Boyle, MP, 2013 xlix). But what about rural pws who do not have access to internet or a self-help group? Nothing can be said about that on the basis of this study. Though, it is believed that in the villages stammering is not considered a "big deal"; there is not much discrimination or stigma since life and livelihood is not so communication intensive in villages.

Subramaniam U., and Prabhu B., mention in a 2005 paper: *Rural population* of India has a greater tolerance for stuttering than do urban people. The reasons could be that demands on communication in those social settings are less as most people are known to each other and livelihood is mostly through manual labor. In the light of many other pressing health and economic problems, stuttering is not considered a disability and there is a philosophical acceptance of any disabling condition <sup>1</sup>.

Urban PWS often feel isolated, alienated, with a condition that others, however sympathetic cannot understand. Many pws have never talked about stammering and their struggles, with colleagues, family members and even partners – let alone strangers. A young woman who stammers, wrote her story in third person and shared this:

"When the girl (herself) left her native place for college, she got new surroundings, so she had to introduced herself in every situation. At that time, her consciousness about her stuttering came for the first time. From that time, she was always thinking about stuttering. And when she joined engineering, she got to know that she had to b fluent in every situation. And in this stage, she had some hell like experience in seminar and presentation. So, she was just stuck in her stuttering all the time irrespective of her other talent.

During final year of engineering she joined a speech therapy for 6 months. But end of the day she found relapsing of stuttering. She just thought that her life had no colour remaining at all. The main thing was she never talked about her stuttering to anyone, neither to her family nor any close friends. Even time came when the girl was just ready to leave all the relationship..." li

When pws do share about their stammering issue, it is usually a life-changing moment. This is where self-help groups come into play. These groups can be physical, as well as online – Facebook, WhatsApp, Skype/ Google hangouts etc. These groups

may be run by pws themselves – older recovered pws taking the lead OR it could be set up by a therapist, in which case Support group would be a correct term to use.

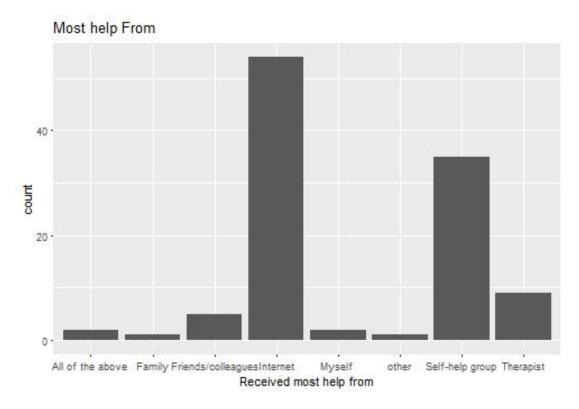


Figure 15: In this sample, most help has come from Internet and Self-help groups

Some pws, in this study, had received valuable help from a family member<sup>lii</sup>, colleagues, even teachers. Some teachers encouraged by providing more opportunities of speaking in the class, by asking questions and through praise. Many colleagues helped by maintaining a professional attitude of focusing on the content rather than the delivery- and by giving positive strokes for other good qualities of the pws. Family members often helped by encouraging the pws to go to a therapist or to the local Self-help group.

In India, self-help groups began in 70s and were the backbone of many rural women's savings and micro-enterprise initiatives<sup>liii</sup>. They have also been used in health context: recovery from addictions etc. Self-help groups, also known as mutual help, mutual aid, or support groups, are groups of people who provide mutual support for each other. In a self-help group, the members share a common problem, often a common disease or addiction. Their mutual goal is to help each other to deal with, if possible to heal or to recover from, this problem (Ahmadi, K. (2016))<sup>liv</sup>.

Through self-disclosure, members share their stories, stresses, feelings, issues, and recoveries. They learn that they are not alone; they are not the only ones facing the problem. This lessens the isolation that many people, especially those with disability experience.

Stammering Self-help movement in India, began in 2008 and has been steadily becoming popular with many SHGs in big cities. Many pws are participating in the self-help movement and reporting benefits. An American pws (Jacquelyn Revere) participated in a get-together in 2014 and was positively affected <sup>lv</sup>. Another Indian pws, in the same conference was overwhelmed because he met hundred plus pws for the first time in his life <sup>lvi</sup>. These interactions convince pws that they are not alone in their difficulties and that they can move ahead in life despite stammering; Because many participants in these get-togethers are married and settled in various walks of life – from business to IT to state services etc.- they act like a role model for young pws.

Self-help in India is adopting online format too because PWS constitute only 1% of the population and many of them are IT savvy. Getting online and meeting other pws is often easier and cheaper - than trying and meeting them face to face. *Stammerfreely* is one such free online conference facility dedicated to pws. It can be reached at stammerfreely.com.

It uses Google Hangout as platform, which is free. Every day they have a Hangout, at 10pm (Indian time). Anyone, from India or outside, can join the hangout by just subscribing to them and then getting the hangout link. The invitation link is available on Facebook too.

These Hangouts are fun-filled activity to improve your speech, learn about stammering from others and to attend mock interviews etc.

## In-depth Interviews

Seven random Individuals (6 men,1 woman), interviewed on phone, shared following information; The questions asked were as follows:

- 1. Please tell us briefly about yourself? Name, age, gender, education, job, city
- 2. Tell us something about your stammering in growing up years? What did you/family do to help yourself? Did it work? Why or why not?
- 3. As a child / adolescent, what did you think was the cause of your stammering? How did you reach this conclusion? When and how, these ideas of causation began to change?
- 4. As an adult, what do you now believe about the nature of your stammering and its cause? Is it a physical problem or a psychological one? How? How did you reach these conclusions?
- 5. How this understanding has changed your approach to therapy or self-help?
- 6. What have you learned from your stammering?
- 7. Anything else you would like to share? (Thank you)

Here is the brief synopsis of their replies:

#### 1. MK, 26 Male, Delhi

MK, 26, male, resident of Delhi is a junior accountant in a firm in Delhi. As a child, he believed that words get stuck in his throat for some reason (he blamed his disciplinarian father) - and that by using force, he could force them out and help himself. Sometimes, it worked but quite often it did not help him; with passage of time, he realised that using force, gave rise to jerky movements of hands and facial contortions. He was taken to a speech therapist at age 13 but it did not help. He again had some speech therapy a few years later around 18 years of age. It helped for a few weeks and then he had a relapse. This time, his secondary behaviours had evolved further: he was jerking head back, blinking and sometime stamping his right foot. He would also forget what he wanted to say. He was having serious difficulties in class room- giving roll call, answering teacher's questions, small talk with batch mates and making presentations.

He developed an elaborate system of denial: *I just hesitate sometime*. He began bunking classes and other social obligations- like wishing relatives during festival season or on their birthday, anniversary etc. Every time, he avoided this, he felt bad, even guilty. But he rationalised that it is better not to speak than to inflict his stammering on well-meaning people.

He was quite puzzled and confused when he got in touch with a self-help group in Delhi- at the age of 21. The group met most Sundays at Connaught place and did "Desensitization" activities, as he learned: like talking to strangers and stammering on purpose in an open public park. Now, he believes that stammering is 90% psychological and only 10% biological phenomenon ("90% dimaag me hai.."). He got to this understanding through discussions in his self-help group and researching the issue on internet. He claims that no therapist ever discussed these things with him.

#### 2. AK, 33, Male, Nainital

AK, 33, male, resident of Nainital, working in a PSU, is originally from Bihar. He has a B. Tech from a prestigious university. He has stammered since early childhood and considers it a significant source of difficulties in his life, career and relationships. As a child and adolescent, he believed it to be a mechanical failure of speech and therefore tried many ways to manage his fluency by breathing out before speaking, slowing down consciously, changing words or syntax etc. Later, he began blaming people, circumstances and certain words for his speech difficulties and began avoiding them in ingenuous and subtle ways.

He discovered as a teenager that he could say a feared word (mostly beginning with B, P, K etc.) if he could have a running start with easy words. So, instead

of saying in class "Bipin is absent today", he would say "Well, today, I think, Bipin is absent...". Sometime, this would lead to a very complex and unnatural-sounding sentence. But he suppressed such doubts and carried on talking like a "normal" person. Sometimes he will get obsessive thoughts to say those difficult words and when alone, he will repeat "Bipin" many times for no rhyme or reason. Even at this stage, he was not sure if stammering is a psychological problem.

He came in touch with an online self-help group in 2013, when he was 30. He recalls that one therapist he went to, taught him "Continuous phonation" (singsong way of talking), which eventually became a troublesome habit. He found that he could not use this sing-song method of talking in formal situations like presentations or interviews. Having no other technique, he would either keep quiet or stutter helplessly. Later, a time came, when every time he had to speak, his mind will go in a severe conflict: *should I use the technique or should I just talk- and take my chances?* 

He thought for a long time that stammering is a physical problem and some wise doctor can cure it. Now, in his self-help group, he focuses on "forward communication" rather than finding a cure. Now, when he stammers, he does not feel bad or ashamed. Earlier, he would feel bad for many days. He is no more avoiding speaking situations, as earlier. He has also understood that there are no "difficult" words. It is just that his mind has associated past painful experiences with some words. If he can give up the fear of stammering, he can say any word, anywhere. He says that attitude plays a big part: ham pehle se hi soch lete hain ki presentation kharab hoga...

#### 3. KV, 29, female, Mumbai

Dr (Ms) KV is a young Ayurvedic doctor in Mumbai: 29, female. She remembers her stammering difficulties becoming noticeable when she graduated to class nine in a different school. She had difficulty opening up to strangers, especially if they were older than her. She also had difficulties when she had to speak in a public situation – like attending roll call in the morning school assembly. She also had difficulty talking to boys – more than it was supposed to be for a girl her age. On deeper thought, she realised later on, that this fear had something to do with her stammering. She thought that if she stammered people will pity her and THAT she did not want, at any cost.

As an introvert child, she kept analysing her difficulties and realised that everything was OK with her throat, since she could sing well, talk to her friends easily and rarely stammered on phone. Still, she went to a speech therapist in her early twenties, just to be sure. The therapist explained that her voice box was fine and that it was only a matter of signals failing to come

from her brain. The therapist initially made her talk to the signals of a metronome and then, taught her "tapping" technique. But the therapist did not talk about the role of shame, fear, guilt, anxiety etc.

She had to tap with her fingers on her legs or in her lap (some place invisible to her audience), as she spoke. With every tap, she was supposed to say just one word. This slowed her down, made her more deliberate in her speech. But at times, this was difficult- like when she was eating (e.g. using fork and knife) or driving. There were occasions when conversation was so spontaneous that she had no desire to use any technique at all. Also, this created an inner conflict: whenever she failed to tap or stumbled on a word, she would feel guilty and low for some time.

She attended a get-together of pws in Bangalore in 2013, where she first time learned about these psychological factors playing a significant role in stammering ("Stuttering Iceberg" by Dr Joseph Sheehan). About hundred young pws were there in this three-day event. She had met so many stammerers for the first time in her life and she felt a sense of belonging to this group. She felt accepted by others and at peace with herself.

Today, she believes that may be, "missing signals from brain" theory is right, but what is important for her to deal with is: this sense of alienation which stammering has generated over the years. She regularly participates in SHG and when it is not possible physically, she keeps in touch with other pws over the phone and whatsapp.

She thinks that may be there are more than 2 or 3 factors, working in combination, to produce stammering. She thinks that stammering moment itself is not so troublesome- but thoughts that pounce on you soon after a block, are the real reason behind our suffering. It is these thoughts which we need to understand, even question and learn to deal with, for a lasting relief from stammering.

### 4. AD, 31, male, Gurgaon

AD, 31, male, is a young Software engineer in Gurgaon. He became aware of his stammering in class eleven, when he joined a new school and the teacher asked, everyone to introduce themselves, in the first session. Some children and the teacher reacted with surprise to his disfluency. A time came when giving roll call became nearly impossible for him. Instead of saying "Yes, Ma'am", he began saying "Present, Ma'am". But after few days, he had difficulty saying even that. A friend began to give his roll call, till teacher questioned him about it- and asked him to just raise his hands. This helped but he felt stigmatised by this accommodation.

His initial thoughts about the cause were centred around breathing because he had noticed that whenever he had to give roll call (or at other challenging speaking moments), his stomach used to tighten up and he could not breath out. He tried *Pranayam* and *Singhasan* (the lion pose) on advice of a friend, in his teens but these measures worked only for a short while. He felt good by doing *Pranayam* and postures but after about 2-3 months, his speech difficulties returned. He felt cheated and disillusioned.

Around 24, he began browsing internet to learn about stammering. This helped him to understand the psycho-social factors responsible for stammering in adults. For example, he came across an explanation which resonated with him: we stammer more with authority figures, because we have a fear of being "judged" by them- a fear which we have learned from childhood. He also learned that the brain of a stammerer is wired differently – affecting the pathways responsible for spontaneous speech- but not singing etc.

He joined a self-help group, began studying the pattern of his stammering and confronting it with the help of his group: he would take a "buddy" and interview strangers about their view on stammering, walk into a shop and do some stammering on purpose. He was told to smile whenever he stammered. He was also encouraged to ask the strangers afterwards if they had any difficulty understanding him. He found that most people had no problem with his stammering. These activities made him rise above his fear and sensitivity.

Today, he thinks that being a little "shameless" is all that is needed, because stammering is all about "fear of what the others will think". He is beginning to see the role of psychological factors in his speech difficulties. Now he thinks that Psychology is more important than Physiology or Biology, of speech.

#### 5. AK, 36, Male, Lucknow

AK, 36, male, is a mid-level manager in an IT firm in Lucknow. As a child, he believed that there was something wrong with his tongue, because his family, on the advice of a religious person, offered a silver tongue at the temple of a Goddess, near Kurukshetra. It cost over Rs 10,000. When it did not help, his family took him to a doctor, who did a "tongue tie operation" (cutting the frenulum at the base of the tongue). It cost him Rs 15,000 in total.

The doctor was convinced that once the restricting fold under the tongue is cut, he will speak smoothly. He did not speak much because of the pain, for few days. After a few weeks, he noticed that his stammering has returned. The doctor than referred him to a ENT specialist in the city, 50 km away. At this point his family gave up. His family was now convinced that it is AK who must make up his mind to speak clearly and give up this 'bad habit'. For quite

some time, he too thought that stammering is a bad habit, which he has picked up through carelessness.

After joining an IT firm at 26, he had a chance to attend a self-development workshop, where in he came across the idea that attitude is important and difficulties are actually "opportunities". Later, he began participating in skype sessions organised by a self-help group. In these sessions, 8-9 pws from different parts of globe, discussed their problem-solving approaches over skype. Here he learned about "acceptance" and "transcendence".

He began by sharing about his stammering issues with his boss and other colleagues. His boss did not react. Later his boss explained that he knew that he stammers and it has never bothered him because his work was always good. His manager gave him more opportunities to make presentations in the company. Finally, he was attending even overseas client calls. He does have to prepare a little more than other colleagues, for the overseas calls. Sometimes, at the very outset, he informs the client that he is a person who stutters. Today, he thinks that attitude is the key – not the tongue.

### 6. DK, 42, Male, Kanpur

DK, 42, male, is a self-employed entrepreneur, with an MBA, living in Kanpur. He recalls his difficulties while doing MBA: giving presentations was a daily challenge. During group work, he would prepare the slides and let a colleague make the presentation. When the presentation would attract praise and claps- he would feel bad! He felt that if he could just present his own ideas himself, he could have earned all that praise and recognition.

He changed jobs couple of times – for the same reason: his ideas and contributions were not getting the acknowledgement that he deserved, in his opinion. He also felt that he did not belong here- in a group of "normal" people. He felt that he was not-normal, an alien. He felt that no one could understand him- even his colleagues. He felt even more uncomfortable in presence of women colleagues. By hiding his stammering, he felt that he is acting like a con-man; that he could be found out any day.

Finally, he decided to opt for a start-up in BPO sector at the age of 37. About this time, on the recommendations of a friend, he attended a ten-day residential *Vipassna* course in Lucknow. In this course he learned, how to focus again and again on the movement of breath, as it moved in and out. On second day onward, he felt that his thought processes had slowed down considerably. He could see that he had carried the guilt of hiding his stammer for a long time. Instead of resisting and shying away from that thought, he stayed with it and questioned it. Over next few days, it seemed that his mind had gone through the entire collection of painful memories and there was

nothing else for his consciousness to do. He was in silence. He felt peace and self-forgiveness.

He continued this meditative practice even at home. As he claims: *I am able to see my thoughts as they emerge, quite often- and able to question my negative self-talk. I no more put myself down because I stammered on phone...* 

In younger years, he felt that there is something really wrong with his speech mechanism, leading to block and facial contortions. Over the years, and especially after practicing Vipassna for last 3 years, he is beginning to see that most of his difficulties were being caused by his own wrong thoughts, biases and prejudice.

Now, he encourages new comers to his self-help group, to attend Vipassna course. Every SHG session begins with a ten-minute silence.

#### 7. VK, 44, Male, Gwalior

VK, male, 44, is in a government job and lives in Gwalior. As a child, he was bullied on a few occasions. He noticed that his father was concerned about his future ("What will this child do in life?"). These events made him worry about his speech. Whenever he had to speak, his face will crinkle up, he will hold his breath, as if to strain. Often no words came out.

Around 12-14 years, he began word substitution and changing the order of the words (syntax) so that he could have a running start before reaching the difficult word. Every time he substituted a word or changed the syntax, he would feel guilty. Sometimes, he would tap himself (at waist or leg) to help the word come out. So, while he was able to manage his speech, these tricks would sometime cause funny situations like during job interviews.

During his first interview, the panel, noticing the mannerism, directly asked him: Do you stammer? Since the question was asked suddenly, he spoke the truth: Yes. He noticed that he felt lighter and rest of the interview went well. Since then, he began talking about his stammering casually in most social encounters. Later, he went to a therapist who gave him a card ("Please, pay attention. I stammer..."), to be worn round the neck, for approaching shop-keepers and strangers on the street, for speech practice.

Now, he has stopped using the technique taught by the therapist. He has joined an online self-help group, as he says, just for the sake of social interaction with other pws. Now, he believes that stammering is all in the mind and can be dealt with easily through courage and open-ness. He also says that if you accept your stammering, you need not do anything more.

### Discussion

**Acceptance**: It seems that with age, many pws learn to accept the fact that sometimes they will stammer, whether they want it or not. They learn to give it a lesser rank as a difficulty. Perhaps, their horizon widens with experience and they begin to see that stammering is just one of their issues – not the biggest one, not the only one. Many participants mentioned Self-help group as a significant source of change in their perception and attitude towards stammering. This is understandable since, in a SHG they have more than one person, acting as a source of reliable peer-reviewed experiential information.

When they meet in large numbers, the feeling of alienation is lessened. As KV said: she had not seen or heard another PWS till she joined the SHG at the age of 26. Later, meeting 100+ pws in the national conference of her self-help group, was like an inner revolution. She stopped being surprised by her own stammering after that conference.

Since pws constitute only 1% of adult population, it is possible to grow up believing that only you stammer in this big lonely world. When pws meet, especially in large numbers, this alienation is replaced by a sense of acceptance, a sense of belonging to a community. This becomes the first step towards, deeper exploration, which often leads to psychological insights into the nature of stammering.

For many pws accepting in public that they stammer and that it causes problems on a daily basis – and that life still goes on, is the first big step towards acceptance. They may or may not seek therapy or relief, but just owning up their feelings and experiences is a step forward. Here is how a pws reviewed his seven month journey on the path of acceptance:

"Even when I stammer very severely at times and later recall the incident, I do not feel as bad as I used to feel earlier. I can also recall what was actually happening at that instant. For example: I was using helping words; I was looking down towards floor so that people won't see my distorted facial expressions; I was not taking breath-there was no air in my lungs but I was trying to force out the words...

After stammering so openly and in front of virtually everyone- boys, men, women, girls, kids, seniors, juniors..., I realized that my job is safe! No one can take away my job due to stammering. This was the biggest fear in my mind the moment I got my job- how would I talk? Now I realize that people appreciate the good qualities in me, my knowledge of my field, my sincerity towards the job at hand. My coworkers are ready to give a few extra minutes to listen to me..." (Kumar, A., 2014)<sup>lvii</sup>

Another pws extrapolated acceptance of his father's untimely death, to other issues in life- especially stammering. While his father was alive, he did not enjoy a good relationship with him, because he held his father responsible for his stammering.

But afterwards he realized that his stammering had nothing to do with the discipline his father may have given to him as a child (Kushwaha, A., 2013)<sup>lviii</sup>. Later he wrote that the way he learned to accept his father's death, he should accept his stammering and everything else in life too, in the same way.

**Understanding of the Nature of stammering**: Many pws may not realize the psychological nature of stammering, even though such ideas have been around for quite some time. Notably, Dr Sheehan gave his Iceberg explanation in 1970, "Stuttering Iceberg"- to emphasize the role of psychological factors in persistence of stammering and frequent relapses after therapy (Hicks, R., 2003 lix).

But there are many new developments which continue to portray/ emphasize stammering as a "physical" phenomena. Stammering genes were identified in 2010 (National Institutes of Health, 2010 <sup>lx</sup>). Such genes lead to "faulty" neurobiological developments of speech area in the brain. This explanation goes well with present day paradigm of sickness: every departure from "normal" has to have a material (medical) cause, which in most cases can be and must be "fixed".

Another popular stammering Intervention program teaches "Subcostal" breathing as an integral part of their strategy to manage stammering – as if stammering was caused by the lack of pressure inside the lungs (Quesal R, Reitzes P, 2011 <sup>lxi</sup>). May be this is just a clever strategy to help pws be more focused and deliberate while speaking? But it certainly treats speech and stammering as a physical process of air pushing through vocal cords and articulators – somewhat like bellows. Is it that simple? And in simplifying, don't we detract from the seriousness of the underlying psychological issues, highlighted by Sheehan?

There are similar examples where complex psychological issues have, unfortunately, been seen and explained as "physical" medical problems. There is a long history of discrimination against "mental" issues, in favor of physical ones. Suffering from Diabetes is preferable to suffering from Schizophrenia or Depression. It is also often believed that if the sufferer exerted a little self-control or will power, they could be over their mental problem<sup>lxii</sup> lxiii.

Even the sufferer and the doctor may find it easier to discuss physical problem than the psychological ones (Gaillard, LM., Shattell, MM., Thomas, SP. 2009)<sup>lxiv lxv</sup> lxvi; Sometime a popular bias may interfere in this communication: For example, some people were told that their loss of memory is part of the normal ageing process, while they were actually suffering from Alzheimer's disease. Similarly, people suffering from Psycho-somatic disorders lxvii have often been treated as a medical problem (for Headache, pain in stomach etc.) and sometimes they have been operated upon needlessly, under this erroneous belief lxviii.

So, what are these psychological aspects of stammering? On the cognitive front - the way we perceive and interpret things - some distortions are very common:

If the listener looks at us a second longer, we think that s/he has noticed our stammering and is reacting negatively to it. We brace up and struggle more. If we get a rejection in an interview or in a relationship, we assume that it must be because of our stammering. If we stumble on a word, we recall it as a total catastrophe: *It was a horrible interview; I went into a block for ever and ever...* In fact, a time comes when we start anticipating bad outcomes habitually, all the time and for everything.

Coming to emotions, many negative emotions get associated with the act of talking, social interactions, relationships, new projects etc. Whenever we have to speak or present, we get excited, we anticipate and brace ourselves for difficulties. Anxiety and Fear dominate our mindscape. When we do stammer, we develop intense feelings of -

- 1. Self-blame, self-hatred and shame (*I made a mess again; I am no good; could not tell my name even!*)
- 2. Guilt (*By stammering, I have let down my colleagues, my therapist, my technique, my friends, my family, my employer etc.*). The guilt can have many origins; First source is: family and well-meaning strangers often advice: *Take a breath, speak slow* etc., assuming that stammering is a simple problem. The fact is, in almost all cases, the pws has tried all these and has failed. But not being able to stand up to these expectations of friends and family, generates guilt. Second source of guilt is connected with inevitable realization that *by stammering and facial grimace etc. I am punishing my audience*. PWS may not become free of this kind of guilt even when the audience assures him that it is OK to stammer.

Therapy induced guilt: Almost all therapy expect client to collaborate and achieve fluency or some kind of resolution. Client centered therapies may further accentuate the role and responsibility of the pws. Many pws may not be ready for the big change, which fluency may bring into their life style. Earlier they could conveniently hide behind a "shy reticent persona" but after successful therapy, they are expected to call relatives and be social. In addition, relapse is very common. Even slightest setback can leave the pws with a feeling that s/he failed her/his role in this therapeutic partnership.

Clinician induced guilt is also a common phenomenon. When therapeutic goals are not achieved in spite of best efforts, clinician may unwittingly generate guilt by talking about compliance. Here is what a therapist had to say: "I agree with you on thinking that therapists' focus on the other, non-speech stuff may be because deep down they know (or soon realize) that fluent speech maintained over time isn't likely to occur due to their therapy; and that it's too easy to blame it on the patient when the therapy doesn't work…" in the collapse of the patient when the therapy doesn't work…"

3. **Anxiety, Fear** (*What will happen next? Wil I be able to do this or that?*): Speech is often taken for granted. Offering words, even if empty, is supposed to be the least that one can do, in almost any situation! So, when pws fail in

this simplest task, they become doubtful, if they would be able to do other things in life. Stakes are high as they finish training and enter the job market. Another significant source of anxiety is: will they manage to find a mate?

4. "All or none" phenomena; PWS often demonstrate Black or White thinking. For example, they may set their hearts on a career – Army or IAS - and will not settle for anything else: *It has to be IAS or nothing else*.

I am either successful or a failure..

I am either smart or stupid..

My presentation was Great or pathetic..

This propensity affects their career and relationships.

- 5. **Over-attribution**: Over the years, feelings of worthlessness, low self-esteem, desire to play safe (PWS stop taking risks), PWS become secretive (even where it does not matter). They start thinking of themselves as great men/women, who could have moved the world, if stammering was not holding them back ("Giants in chain" syndrome). PWS may start overattributing their failures to stammering and believe that if only they could become fluent, all their problems will vanish magically.
- 6. **Loss of Self**: Over the years, some pws may even feel "loss of self": we feel alienated from our own real nature. We feel as if we are a comman: an imperfect replica of our true perfect Self. Relating to others, mixing in a group etc. becomes increasingly difficult and painful.
- 7. **Self-concept**: In the long run, we may develop a limiting persona, a poor self-concept: *I am a victim of my circumstances. What can I do? I can just wait for things to change OR for someone to come and rescue me.* We may even project these attitudes on to others: *My child is three. He has started to stammer. I am worried for him. What will he do in life?*

How does this understanding change our behavior? Our belief about the nature of stammering often gets directly reflected in our attempts to deal with it. It is reflected in our choice of therapist or solution we seek. Most of us keep on going to therapists because we believe that it is a medical/physical problem which someone can surely fix. That the problem is with my own perception, thinking and "acting out" – and therefore I can do something about it- rarely occurs to us. Every time a relapse occurs, we blame our efforts ("I stopped practice therefore I had a relapse") or therapist - and go looking for the next therapist, or Hypnotist or "Past life regression expert".

Most participants went through an early stage of rationalization - figuring out the "real" reason behind their stammering: One pws (MK) considered his disciplinarian father responsible for it; another pws felt that teasing by a sibling is the reason for his stammering: i.e. the problem and the possible solution both were situated "outside" (External loci of causation). Another pws was convinced that

talking is a difficult task and hence he must use extra force. Some were told that *your brain works faster than your tongue* – again a mechanical model based on a linear demand and supply kind of intuitive but erroneous thinking.

Visit to therapists often promoted such partial/ half-baked ideas, oriented to a technique: *You have this habit of stammering. You must use prolongation for more than a year to replace that habit.* Another therapist (a Hypnotist) asked a pws to rub Almond oil on his tongue to smoothen it and then, exercise the tongue since his tongue was considered "weak"! lxx

The respondents at some point began to understand that there is something psychological at play here. In this process, they were helped by information available on Internet, by practice of meditation, their self-help group etc. For many, with this, naturally came early experiments in open-ness and acceptance, often beginning with their self-help groups.

Most respondents now believe that stammering has a physical (=Neurobiological) component in early years, which soon gets overlaid with many layers of psychological phenomena – shame, fear, guilt, anger, regret etc. These Psychological overlays become much more problematic in adult life, while original neurobiological factors, become increasingly un-important.

One of the big changes in their attitude was: while earlier they sought one to one clinical therapy, after this awareness of psychological dimension, many of them have tried to become social and courageous (going out in public and talking about it) and explored other alternative avenues- Vipassna meditation, Brahma Vidya, Toast Master, Self-help groups, Google hangouts etc.

A young Muslim pws had these realizations during a ten day Vipassna course in 2015:

"...Life's like a necklace made up of passing moments, sliding on a thread of impermanence. A moment can be boring, exciting, blissful or torture, Life cannot be labelled like that. It's an amalgam of emotions, arising and passing away like respiration.

When you start living in the moment, you stop labelling your moments. You can only feel bored when you compare this moment with a moment of the past or some fantasy of the future. You call yourself anxious because you compare the discomfort of the present with the relaxed state of the past. Once you truly start living in the moment, all you feel is nameless sensations. Sensations without labels-without perceptions of good or bad. Mindfulness is the art of observing these sensations with an understanding of their impermanent nature. "This too shall pass" is one of the most permanent laws of the universe…" lxxi

If stammering is a "mind game" then Vipassana helps you to excel at this mind game. This is how another young Indian pws saw the connection between stammering and Vipassana:

"...As per the definition of stammering, "Stammering is what you do when you try not to stammer." This explains almost everything about my stammer. For me stammering has always been a struggle with myself. A struggle before speaking the word (whether I'll be able to speak it!). A struggle while I am in a block. A struggle after I stammered where I didn't want to.

I knew it for so long if I could learn to be just in the moment 100% and stop worrying about future and stop relating it to the past, my struggle with my stammer would have stopped. Intellectually it always sounds so easy but it is very-very difficult to be in the moment completely.

This is what Vipassana teaches you to be in the moment without being judgmental. Stammering too has become an inseparable part of our mind and body. When we try to speak it's not just our speech but our whole body and mind caught in the act stammering. While practicing Vipassana you learn to observe each little sensation in your body without being judgmental to it. Sensations create thoughts, thoughts create worries and worries create struggle and sometimes just watching the sensations without judging them can be the solution. Our body creates many visible and non-visible sensations while we stammer and if we could be aware of these sensations it can be a way out for our struggles with stammer. Stammering also creates very strong aversions with our past experiences. Vipassana also helps us in getting rid of it..." <sup>1xxii</sup>

Communication, the essence: Another effect is: many respondents are now focusing on communication goals rather than on Cure or mere Fluency. Many are paying attention to their inner emotional states rather than external fluency. Feeling OK during and after a presentation is more important to them, than being fluent during presentation. Speech Therapy for a long time focused on speaking, as a motor skill, in vacuum. Recently, speaking is being seen by therapists, as a small part in a bigger and complex game of communication- which means putting the meaning across- not just saying words fluently.

Excessive desire for Fluency is often based on a mechanical/ Physical model: *If I make sure that there is enough air in the lungs, I can speak the whole sentence fluently etc.* This is quite feasible in a one to one calm clinical situation. But in a real life setting, being understood becomes more important. This is how respondents coming from a SHG background shifted their goals from fluency to communication with good long term results. Even those who had had formal speech therapy, find SHG useful as a safe place to practice their skills, share ideas and help others (Bradberry A, 1997 lxxiii).

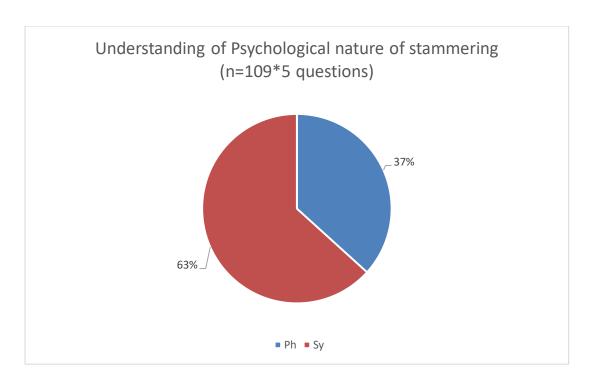
## **Findings**

About 37% "Physical" options were chosen by the respondents, indicating that physical/ mechanical/ intuitive explanations of stammering continue to be popular even in this educated and not-so-young group of pws. These explanations may be TRUE but they also make us blind to the extensive role played out by subtle psychological reactions and factors, in causing and maintaining stammering behavior and mindset in adult life. It generates lot of anxiety, fear, guilt and feelings of worthlessness. When pws fail to say a word day after day, instead of blaming their speech, they begin to see themselves as inherently flawed. This further gives rise to alienation, disharmony, strained relationships at work and in family. There is scope and need to discuss and promote the psychological nature of stammering, especially in adult life. Self-help groups and Internet seem to be the perfect vehicles for this.

Almost all the participants were connected with some self-help network. Internet and communication technologies like Whatsapp had brought them in touch with each other, across the country. This had generated a sense of "community" and belongingness. Further, they understood that just listening to each other respectfully was often enough to help the other person. They did not have to play the role of a professional counselor or speech-therapist.

Since they understood that stammering has a predominant component of psychological suffering, they were open to exercises which meant little from the perspective of fluency therapy: One of the desensitization activities – stuttering interviews with strangers, emphasizes that pws stutter and ask all the questions about stammering and conclude: *I stammered while interviewing you. Did it matter?* 

On the contrary, many therapist will insist that pws must not stammer and do everything possible to keep it under control. Wiser pws have understood that accepting that they stammer, is the first step towards overcoming it. This psychological perspective takes on other creative forms too in the self-help groups: putting on tea shirts with affirmative messages – *Haklao magar pyar se*, *Buffering me Time to lagta hai lxxiv*, *If you stammer, one crore Indians are with you* - and performing *Hakla Hakla* song to a general audience lxxv etc.



# Conclusion and its applications

Stammering is a confusing developmental disorder: It is not a disease. It is a part of the complex process of regular development of communication skills in a child, which has gone a little haywire, so to say. If we consider that not all children begin to speak, stand, walk, do sums at the same age or with the same success – then it may be possible to see stammering as a DIVERSITY among the human population. One instant benefit of such an approach will be: PWS will face less stigma and will be willing to help themselves, instead of waiting for the "expert".

Causation: It appears to have a neurobiological ORIGIN, which later gets overlaid by many layers of psychological reactions: shame, guilt, fear, worthlessness, regret etc. These psychological components which come to constitute most of the stammering phenomena in adult life, is not easily grasped by young pws. They may continue to believe that stammering is a mechanical/ Physical problem and hence, may continue seeking "physical/ medical" solutions: Riboflavin, Magnesium laxvi, Baking Soda solutions: Nogue tie surgery etc. After many relapses and hardships, pws begin to look deeper. With this often, comes a change in their problem-solving approach: They are open to social and alternative avenues.

Of all the options, 37% selected were based on a Physical/ mechanical model of stammering. The rest were Psychological options. These choices may also influence how we try to deal with stammering. So, there is scope and a need for promoting the psychological nature of stammering, which is not a new idea but has not been promoted enough. Even today, we come across cases where 'Tongue Tie' operation is done for a young person suffering from stammering – quite erroneously and unnecessarily. Similarly, if pws have been taught to think of speech as a

mechanical process – bellows pushing air through vocal cords – then, they are likely to "strengthen" their lungs through exercise, *Pranayam* or they may end up using "air flow technique" or subcostal breathing. If pws accept that stammering is a psychological issue, more amenable to psychological approaches (like desensitization) and group therapy, self-help groups becomes a viable and cost effective choice.

**Self-help**: Who will promote this message? Obviously pws and their self-help groups. Because Self-help groups and Internet seem to be a predominant source of information for the stammering community in this study. Availability of Speech Therapists is less, compared to the population and is mostly limited to big urban centers. In a vast country with 1.22 billion population, the number of speech therapists in India is barely 2,000. So, millions of people in India, across the lifespan, suffer from hearing and communication disorders and are just not getting the services they need (Varindani, R., 2013)<sup>lxxix</sup>.

Another recent study indicated the need for increase in the man power development in speech therapy. This study on Parkinson's Disease (where speech therapy is often needed) was a preliminary estimate of one of the many communication disorders that come under the treatment purview of a Speech and Language Pathologist. As per the study, though more than 50% individuals with Parkinson's Disease face communication difficulties only 5% are getting therapy. Over 50% medical professionals stated difficulty in finding a speech therapist to refer the individual. Only 10% of practicing speech therapists treat individuals with Parkinson's Disease on a regular basis. On an average only around 27 post graduates pass out per year in Mumbai and roughly 50% of the same opt for a career in Speech language pathology (Shah PK, Gore G., 2016) lxxx.

So, even if speech therapy was effective in stammering (which is not the case as discussed above), it will be difficult to provide these services to 1-2% of the population scattered all over the country. On the other hand, since stammering is a largely psychological phenomenon - but fortunately not as severe/ serious as major psychotic or neurotic disorders - pws should be encouraged to explore self/mutual help through groups. Communication disorders often isolate / alienate people and a group process will have a psychological advantage over one on one clinical speech therapy.

Nevertheless, self-help may have its limitations. Some pws get obsessed with what may have helped them and begin to believe that *my technique is the only cure*. Instead of acknowledging that stammering is a complex multi-etiology disorder, instead of respecting the diversity present among the stammering community, they may start forcing everyone to practice one technique or use one approach. Many approaches and techniques have a temporary psychological (placebo) effect. In one case, a young educated pws was convinced that blowing conch shell has helped him

and therefore his self-help group should promote it for other pws (Srivastava, S., 2009)<sup>lxxxi</sup>.

Another danger is: for many pws their SHG becomes a comfort zone and Acceptance of stammering becomes an excuse to do nothing to help oneself: *I accept that I stammer. What more do I need to do now? Nothing!* They fail to realize that having accepted that they will stammer at times, does not set them free from the need to prepare well for presentations, interviews, need to attend professional courses, cultivate extra-curricular skills, need to work on relationships etc. Accepting stammering and sitting back becomes a new insidious denial.

Some fluent PWS turn SHG into personal turf, where they are supposed to do all the talking. Instead of listening to others patiently, they start giving advices or recommending a particular Therapist or a program. Some may use the group for reasons other than stammering self-help: promoting their other interests or hobby. They may even insist on inviting their particular therapist, thus defeating the self-help agenda.

**Disability Movement**: As long as pws believes that his stammering, can be cured like any other physical ailment, s/he does not care to understand the broader socio-cultural context of stammering and discrimination. After many relapses, when they begin to appreciate the deeper psychological factors, operating under the garb of stammering, they open up to the wider debate: what is disability? What is normal? Who gets to decide these questions? Then, they begin to see similarities in their issues and other mainstream disabilities.

Often, this takes the shape of debate about- should pws ask for reservations? Should Indian pws ask for stammering to be covered under disability acts, as it is in USA? PWS with superficial understanding of stammering, often revolt at the idea of being seen at a par with a blind or deaf person. Others, would talk about a third category- Temporary disabilities and would be open to work with and educate teachers, employers, other service providers and public at large.

A recent short film ("Stutterer") won Oscars in 2016 lxxxii. This film, for the first time in media, tries to depict a pws reaching out to a deaf girl. To save himself from the difficulties of stuttered speech, he had started to use sign language. When he meets, the girl for the first time and sees her signing- he is immensely relieved, because he feared rejection from a "normal" girl. This gave rise to a debate-should/can dysfluent and deaf community collaborate for a broader struggle within a Rights based framework? Is it right for PWS to seek accommodation within deaf community?

Here is a review, which brings up these concerns:

"A scene later in the short film, in which the main character uses sign language to avoid unwanted socializing shows a different way of being speech impaired than is commonly imagined. In this instance, the stutterer uses membership within the disability community to claim the accommodation of not having to communicate with a random stranger on the street. Where the film is successful is showing that unexpected social encounters do put extra difficulty in the way of the stutterer, the use of sign language and requests for accommodation as part of stutterer self-advocacy may be seen by some to be a solution.. At this moment in stuttering activism, we see a dysfluency politics unwilling to articulate its opposition to normative culture and uninterested in providing new techniques to counter the conformity of the communicatively abled society..." lxxxiii

Further on the reviewer adds: "We have to use the intimacy established in The Stutterer between Dysfluent and Deaf characters as a way of envisioning a communication disabled coalition politics. Stutterers' gaps in communication may cause Deaf cultures to recognize them as allies in speech difference and potential beneficiaries of Deaf culture. Likewise, speech impaired people may find increased fluency in the use of sign language to bridge gaps in speech…"

These thoughts point to a trend, where pws is no more looking for a cure or accommodation. Instead, he is looking at the politics of 99% "normal" speakers stigmatizing and forcing the 1% pws to believe that their speech is "abnormal" and that they need to seek therapy. This development and this maturity, in the stuttering community could not have surfaced if pws continued to believe outdated and erroneous ideas like *my brain thinks faster than my tongue moves, that my tongue is small and thick, that my lungs are not strong enough* etc.

## Limitations and recommendations

The study was limited only to those pws who had access to Internet and who were in touch with a self-help group. The study shows significant correlation between Psychological understanding of stammering and number of years a pws has stammered but correlations with participants' age, gender and education is not very clear due to poor design and insufficient data. But it does show that with increasing age, pws perceive their stammering as less of a difficulty and they also begin to see it as a psychological phenomenon. These conclusions also rely on qualitative data — Interviews. A better designed study with a larger and diverse sample size should be attempted to explore other correlations — gender, education, work status, residence etc.

A conceptual problem however, was to correctly interpret respondent's understanding into "Physical/Physiological" versus "Psychological" categories. There is some overlap and danger of over-simplification. For example, if a pws believes that he stammers because his brain works faster than his tongue – this explanation could belong to both categories. As the stammering science stands today, both approaches have been found to be correct: neurobiology as well as psychology is involved in stammering.

Another limitation was: exploration of insights into stammering was limited to just 5 questions. This aspect deserves many more open ended options, to capture pws's understanding of the issue better and in a richer way.

The sub-sample of women was very small to make any gender based comparisons. Also, how people change their beliefs over years, should ideally be approached through a longitudinal study of a cohort. This was a cross-sectional study about what the subjects believed now- at this point of time. How they arrived at their current beliefs is being explored indirectly and is largely based on their memory/ recall. A longitudinal study would have served the purpose better.

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# **Appendix**

This Questionnaire was used for online survey:

NOTE: All information will remain private and confidential with the researcher (Dr Satyendra Srivastava). Final conclusions/report will be based on anonymous groups – and not individuals. Whether you complete this form or not, you will continue to get the services from TISA, as in the past. Researcher may discreetly get in touch with you through emails/phone, based on the analysis of your answers, to further clarify a question, ONLY if needed. The study will help us serve you better. Thank you.

- 1. Name (optional)
- 2. Sex: Female Male Other
- 3. Age Mark only one oval. 18-25 / 26-35 / 36-45/ 46-55 / 56 and above

- 4. Highest Qualification: Graduation / Masters & above / Professional-B Tech/ IT/Engineering/ Medical/ Commerce/ Law etc./ Professional- MBA /Other
- 5. Currently employed: Yes / No / No comments
- 6. How long (years) have you been stammering? write a number between 0 and 40.
- 7. How do you rank your level of difficulty?

  Dont worry about what the others may have said. Just state your own understanding.

  Mark only one oval. 1 2 3 4 5 (1= Mild according to you. 5= Lot of difficulties).

Following sets of two statements are all true. So, please tick that option you feel like going with. The one you prefer. You cant be wrong because all are true. Please answer all FIVE sets.

8. You prefer to go with:
Stammering is caused by delay in speech signals from the brain OR
Stammering is caused by shame associated with act of speaking

- You prefer to go with: Mark only one choice.
   Stammering is caused by replay of painful OR
   Stammering is caused by the lack of air in the lungs
- 10. You prefer to go with: Mark only one Choice: Stammering is caused by closing of vocal cords OR Stammering is caused by expecting the worse in every situation
- 11. You prefer to go with: Mark only one choice: Stammering is caused by the pressure to conform (I must talk like others) OR Stammering is caused by a lack of thoughts/ words.
- 12. You prefer to go with: Mark only one choice: Stammering is caused by fear of what the listener might think, say or do OR Stammering is caused by a gene
- 13. What has been the predominant source of your information about stammering (choose one)? Mark only one oval. A) Internet (pdf files, videos, websites etc.) B) a therapist / doctor / expert, C) self-help group D) friends, colleagues E) family F) Other
- 14. Just in case, I need to get in touch, you MAY share: (Mob. or email ID)

Thank you, very much!

For more information on stammering, you may check stammer.in The researcher can be reached at satksri@gmail.com

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