

Awareness, Advocacy and Acceptance –Unifying Science with Experience

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Abstract Names and words can be fluid or specific depending on their agreed-upon definitions. In the scientific and medical professions, precision is the key to ensuring that the right person gets the right treatment; this is doubly true in the field of speech language pathology, where effective communication between therapist and client can be even more challenging. In this presentation, with reference to my own history as a person who stutters as well as the academic literature on the subject, I ask that we re-examine the words we use for the condition commonly known as “stuttering” and less commonly as Childhood Fluency Disorder. The suggestion is made that the word “stuttering” be used to describe the symptom of either Developmental Fluency Disorder (neuro-developmentally based), Habitual Fluency Disorder, (learned or habitually based) and Stuttered Speech Syndrome (associated with clinically significant anxiety). In this way recognition can be given to Social Anxiety Disorder with stuttering, and awareness can be brought to safety behaviour formation that complicates treatment.

1. Introduction.

Few understood the power of words better than philosopher Ludwig Wittgenstein, who famously stated “the limits of my language mean the limits of my world”. Perhaps this insight can partly be explained by the fact that he was – according to the reports of several who knew him – a person who stutters. But of course Wittgenstein’s words do not just apply to speech. Six decades on – having experienced many different therapies, having explored extensively the science of stuttering, having finally reached the point where I am largely free of both dysfluency and the anxiety that surrounded it – I still have considerable difficulty when trying to talk (and write) about differences in my stuttering experience. This is because of the lack of agreed words available in my language. Language, according to Wittgenstein, is not just an *expression* of thought, but an *essential building block* of thought. Ideas can only become crystalline once they are given a unique name. It is my belief we require the development of unique names if we are to build on our understanding, investigation and treatment of the condition known as stuttering.

Websites like ASHA and IFA now highlight the wide ranging nature of stuttering and its impact (ASHA, 1999). But because terminology has not yet been developed to name various areas of the stuttering spectrum, there continues to be a limitation to the ability to convey succinct public awareness messages and conduct specific research. A review of the Journal of Fluency Disorders from the last decade will show research has centred on social anxiety disorder and dimensions of it such as fear of negative evaluation, performance anxiety, perfectionism, self stigma, and anticipation of stuttering. Broadly these components have been lumped together as the cognitive and affective components of the stuttering disorder. However the extent of the broader disorder is not directly related to percentage syllables stuttered (Stein, 1996) (Kraaimaat, 2002) meaning that the measure of percentage syllables stuttered does not predict the degree of affective and cognitive limitation. The accuracy and usefulness of many scientific investigations continues to be restricted by the assumption that the frequency of syllables stuttered is the predictor of the full severity of the disorder. This has been shown to be not the case (Blumgart, 2010). In other words, frequency of

stuttering needs to be distinguished from severity of the stuttering disorder. Currently this distinction is difficult to make given the word stuttering is used to refer to both the symptom and the disorder itself.

This presentation sets out to provide a convincing case for using the word “stuttering” to describe a symptom only, rather than giving it the additional meaning of the name of a disorder or syndrome. To conflate this term is to miss the complexity of the relationship with Social Anxiety Disorder (SAD) existing as a significant additional disability independent to dysfluency severity. I have lived with the stuttering for over 60 years, and during that time my disorder has come in different forms. The most difficult form, the most restricting, the most disabling was when stuttering was linked to what I realise was Social Anxiety Disorder. I believe it would be extremely useful to differentiate this form of stuttering as the presence of SAD not only compromises successful outcomes in speech restructuring therapy (Iverach, 2009), it also significantly compromises quality of life. (Blumgart, et al., 2010).

2. Reports from Personal Experience.

Internet chat groups have allowed more communication between people who stutter than in any other time in history. Groups made up of individuals who can report recovery from stuttering are worthy of special interest. One such group is neurosemantics@yahoo.com. This group contains many individuals who report significant improvement in social attitude and fluency, chiefly as a result of reframing their social world rather than by the use of a particular fluency technique. Like many other people in this group who, even in their forties, felt their lives were significantly handicapped by stuttering, I am now relatively fluent. Like others I am now able to deal easily with significant speaking challenges like introductions, joke telling and public presentations. Most people are surprised by my stuttering disclosure and my passionate interest in the subject. After my stutter first presented at age 3, I had undergone series of speech therapy sessions on three separate occasions aged 4, 12 and 22 without success. At 30 years old I could not use a telephone without significant blocking particularly on my name. To cope I developed a strategy of recording my telephone introduction on a tape recorder and pressing the machine once the telephone had been answered. While this enabled me to pass as fluent, it was far from good therapy. I did not realise that this strategy, along with word substitution and avoidance, was making my fear of stuttering worse thus compounding my speech difficulty. (Years later I came to know these strategies by the psychological term “safety behaviours”, the formation of which is to be avoided when dealing with social anxiety disorder (Lovibond, 2009)). I also noted that in my occupation as a dentist my dysfluency would vary for every dental patient I consulted on any given day. I finally realised my stuttering was more a function of my perception of the interaction between myself and the other person than it was about any neurological or speech planning or production deficit. At this point I discounted the value of speech therapy and set out to change my social perceptions through formal and informal studies in psychology and anthropology as well as psychological and psychiatric consultation. My efforts involved cognitive behavioural therapy, desensitisation, and mindfulness. All these approaches have since been shown as effective therapies in helping people who stutter improve the quality of their lives (Menzies, 2008). This was my experience as well.

Another relevant personal experience was the development of an inability to execute what were relatively simple golf shots. Interestingly I had the realisation of the similarity between my thinking when missing putts and my thinking when my stuttering was at its worse. Golfers know the inability to carry out a once simple movement, like putting from less than a metre, to be a sign of performance anxiety and over-monitoring. The term is known in golfing circles as the “yips”. This anxiety based poor performance phenomenon is known in other sports as well and has been given the general term “choking”. At this time in my life it was clear that performance anxiety and over-monitoring were exacerbating my level of dysfluency, giving to my speech the equivalent of the golfing “yips”. (Performance anxiety and over-monitoring are dimensions of Social Anxiety Disorder as are perfectionism and fear of negative evaluation). I was not alone. Research shows that 40 -75% of people who stutter show significantly elevated levels of social anxiety to warrant the additional diagnosis of Social Anxiety Disorder (Stein, 1996; Menzies, 2008 and; Blumgart, 2010). In addition, Arnstein (2011) reported AWS are hypervigilant in their speech monitoring, and Lickley (2005) reported AWS engage in hypervigilant monitoring of their own speech and the speech of others. However the key point to make is that physical practise will not combat the yips, only psychological work can do that. Similarly practicing a fluency technique will not combat Social Anxiety Disorder.

3. Social Anxiety Disorder and Stuttering.

It is reasonable to assume SAD may exist as a result of stuttering experience. However some commentators have suggested that a diagnosis of SAD (aka social phobia) with stuttering is inappropriate. They argue that since the term phobia implies irrationality of belief then it cannot be used in stuttering where social fears are rational given the social penalties of stuttering. They quote examples of the fear developed by fluent speakers when given the task of deliberately stuttering publically and subjecting themselves to possible public humiliation. However this argument misses a central point discussed earlier namely that research has shown that some PWS with only minor stuttering can have significant SAD. (Stein, 1996 and Blumgart, 2010). It is clearly not rational for people to allow relatively minor dysfluency to impact significantly on their life choices. Therefore not to allow a diagnosis of SAD with stuttering would be to miss the variability in experience and the full nature of the sufferer's disability.

People who stutter can be either categorized as experiencing "stuttering with SAD" or as experiencing "stuttering without SAD". Over the course of my life I have experienced both. Now stuttering has little impact in my life; I do not anticipate it and rarely notice it. If I do there is no stigma, I simply take it as a reminder to slow down my speech rate and allow more breath support to make my speech less effortful. However when my stuttering experience was at its worst it ruled my life. I would spend hours highly anxious about forthcoming speaking situations, and ruminating excessively about "failed" social encounters.

This phenomenon of two different stuttering experiences based on presence or absence of Social Anxiety Disorder allows an explanation for both the Finn (2005) and Plexico (2005) observation that adults who stutter who report recovery still demonstrated dysfluencies. How can this be? They report what feels like full recovery but still stutter. The explanation is that like me they have recovered from the significant disorder of "stuttering with SAD" but still show some habitual stuttering (no anxiety associated) stuttering.

4. Why awareness of Social Anxiety Disorder is important –Disability, Therapy, Understanding, Advocacy

My stuttering experience now reflects an old speech habit. Formerly it reflected an all-consuming anxiety disorder. These two experiences are too dissimilar to be known by the same disorder name. The presence of SAD adds enormously to the disability. It explains too why some PWS who have largely recovered from stuttering, still have difficulty with aspects of their social anxiety disorder. As reported by Blumgart (2010) some PWS have social fears beyond speech. They fear using a public restroom, eating in public or writing in public. Clearly the disorder these people suffer from is more than a speech problem. No amount of fluency shaping therapy will help them feel comfortable about using a public restroom. A two disorder concept would prevent the under recognition of social anxiety disorder in people who stutter. As reported by Menzies (2008) social phobia is a remedial disability in people who stutter.

Furthermore the presence of SAD impacts on therapy. SAD is known to predict relapse from speech restructuring therapy which indicates that screening for SAD would assist therapists and clients. (Iverach, 2009). The Liebowitz Social Anxiety Scale and the SPIN score are two examples of easy to use questionnaires that have been validated against clinical diagnosis (Fresco, 2001; Connor, 2000 and; (Ranta, 2007). Another advantage of recognition of SAD to therapy is that it points to particular therapy strategies which have been proved most beneficial by SAD research. Meta-analyses of SAD therapy outcomes (Holaway, 2004) have shown SAD therapy is most effective when the client undertakes exposure therapy (desensitization), while taking an external focus and dropping safety behaviours. Safety behaviours are strategies which allow coping but do so at the expense of maintenance of threat belief. In "stuttering with SAD therapy" safety behaviours would include client developed covert strategies such as word avoidance, substitution and circumlocution. In addition research has shown some therapists, unaware of the safety behaviour issue in the development and maintenance of SAD, may offer fluency improving advice which inadvertently acts as safety behaviours thereby making the communication anxiety worse. Helgadottir (2014) showed that significant percentages of speech pathologists in Australia have offered fluency improving advice around limiting display of stuttering with recommendations to clients to avoid anxiety provoking topics, encourage the listener to talk more, and chose safe or easy conversational partners. While this advice might minimize the clients stuttering display it does not deal with the rest of the syndrome. It

does not deal positively with elimination of Social Anxiety Disorder or elimination of fear of stuttering. Furthermore the possibility exists that fluency shaping technique itself may come to act as a safety behaviour. In this case the client uses their speech technique to achieve fluency but comes to depend on their technique rather than restructure their feelings of social threat. They continue to fear stuttering and social encounters and may even become more and more socially anxious even though their speech technique provides fluency. This possibility has been evidenced by qualitative research (Cream, 2002) showing that clients reported they felt more socially anxious after speech therapy than before it.

Before the construct of Social Anxiety Disorder was fully developed by the American Psychiatric Association, which of course was before recognition of the detrimental effects to SAD therapy posed by safety behaviour formation, psychologist and person who stuttered, Joseph Sheehan developed the iceberg analogy for the stuttering disorder. He did this to draw attention to the psychosocial pathology associated with speech dysfluency. In this metaphor stuttering existed above the waterline, while existing below were listed low self esteem, anxiety, fear and avoidance which can now be seen as dimensions of SAD. Sheehan said

"Defining stuttering as a fluency problem ...ignores the person: it ignores his feelings about himself, it ignores the significance of stuttering in his life; it ignores ...the 'double boiler' function of maintenance of the handicap in many cases; it ignores the principle that just because an individual stutters, that is necessarily the chief problem with which a clinician need be concerned." Perkins (90, p. 379).

Given that this quote predates the formation of Social Anxiety Disorder in its current concept, I believe it can now be recognised that the "maintenance of handicap" refers to safety behaviour formation and the "chief problem" refers to Social Anxiety Disorder. Since the extent of stuttering is not related to the extent of Social Anxiety Disorder then the condition is best described as a Syndrome. I have in the past proposed a name for such a condition "Stuttered Speech Syndrome" (SSS). But whatever names we use, all that matters is that we give unique, specific names to each kind of stuttering experience. Only then can we begin to talk about the real impact of dysfluency, and only then will speech pathologists be able to address the different needs of their clients – from the speakers who need fluency shaping to the speakers who need a more psychologically sensitive approach. Improved stuttering terminology, and a greater awareness of the potential for social anxiety disorder to exist in people who stutter, are necessary changes. Sheehan's iceberg then becomes the metaphor for SSS leaving stuttering to refer to the speech dysfluency existing above the water with SAD existing below.

Besides the advantage of naming the full impact (cognitive, behavioural and affective) of what has simply previously been known as the stuttering disorder, expanded terminology enables the development of the stuttering condition to be discussed. That is having the SSS label recognised as a term for "stuttering with SAD" then a distinguishing label for the "stuttering without SAD" is required. Given speech is a highly habitualized activity then, in the absence of any Social Anxiety Disorder, the possibility exists for the stuttering experience to be conceptualised as existing as an Habitualized Stuttering Disorder. This could be said to arise from either neurodevelopmental factors or from a period of emotional upset. That is the habitualized speech pattern remains after the causative agents of the Developmental Stuttering Disorder, and the anxiety component of SSS, have gone. My personal experience with the symptom of stuttering can be said to be in the conditions of Developmental Stuttering Disorder, Stuttered Speech Syndrome and now Habitual Stuttering Disorder. I can report that each disorder was a different experience even though the symptom of stuttering was a common feature. I believe my view can be supported by reference to the studies on bilingualism and stuttering, late onset stuttering, and natural recovery. If stuttering were only the result of neurological deficit in the speech mechanism then it would likely have equal impact in both languages spoken by bilingual speakers, it would only arise during the period of speech development, and it would be impossible to recover from spontaneously. In all 3 situations this is not the case. In a study of 16 high school educated bilingual stutterers Nwokah (1988) reported there a difference in severity of stuttering and there was a trend for subjects to stutter most in the language with which they had had more negative experiences at home or school. Late onset stuttering by definition occurs sometime after normal speech development. The

“emotional upset” hypothesis would also be consistent with its development. Finally recent epidemiological investigations have reported the likelihood of a 80%- 90% natural recovery rate particularly before age 7. (Yairi & Ambrose, 2013). Again it would be reasonable to hypothesize that stuttering resolved because emotional conflicts also resolved. Neurological studies indicate the same brain area, the anterior cingulate gyrus, is a common area for emotional regulation and speech. An inability to regulate emotion as being the initial cause of stuttering is consistent with neurological explanations of stuttering.

So having divided people who stutter into these sub-groups based on the internal and external effects of their dysfluency, what then? What does this mean when it actually comes to treating people? The goal is obviously to create a system that works, but in doing so we should aspire to cause as little disruption to the current system as possible. To that end, it is not my suggestion that we draw a line and place speech pathologists on one side and psychologists on the other, each to lord over their separate domains. Rather, I believe a holistic treatment option is possible, integrating the principles of psychology into speech pathology training. Indeed we have been aware for some time that speech pathologists have been offering psychological tools such as anxiety reduction (Menzies, 1999) and Acceptance and Commitment Therapy (Beilby, 2012) to manage clients. Of course if a screening test like the LSAS or SPIN revealed an extremely socially anxious client then a psychological referral would be appropriate particularly for the inexperienced clinician. With regards to the stigma associated with mental illness; it is true that some clients may resist terminology that they feel implies mental instability and impairment. Hopefully we can find a way to combat such stigmas, not by hiding or ignoring our conditions but rather, by educating the clients and the general public that Social Anxiety Disorder and Social Phobia are nothing of which to be ashamed.

5. Summary.

Associated with stuttering behaviour is often the additional disability of Social Anxiety Disorder existing independently to degree of dysfluency. Stuttering severity is unrelated to life impact. That is the percentage syllables stuttered do not convey the full extent of the disability. In addition a treatment evidence base built solely on percentage syllables stuttered is meaningless if the full nature of the disorder is to be considered. The continued lack of recognition of SAD in stuttering is resulting in compromised treatment outcomes and an inability to convey the full impact of stuttering in the lives of many sufferers. While a degree of fear around dysfluent speech is to be expected, at some point the fear can be so great that it impacts negatively on quality of life and must be treated by re-evaluating thoughts and emotions. The listener understands stuttering as dysfluent speech. However awareness must be brought to the fact a dysfluent speaker not worried about social consequences has a very different condition to one who has clinically significant (life impacting) fears about social settings. The former has stuttering as a symptom of Habitual Stuttering Disorder while the latter has stuttering as a symptom of Stuttered Speech Syndrome. In this latter case the experience of stuttering compounds the social anxiety in a positive feedback loop. Comprehensive therapy requires more than fluency shaping for this would be just to treat the symptom of stuttering. It also requires the Social Anxiety Disorder component of Stuttered Speech Syndrome be treated as well. Diagnosis requires therapists screen for Social Anxiety Disorder in their stuttering clients. The value to therapy of recognising and treating Social Anxiety Disorder has already been made by Stein (1996), Iverach (2009) and Blumgart (2010). The complication of not treating it, and having unintended “safety behaviours” form, has been highlighted by Helgadottir (2014). As Chair of the IFA’s Self Help and Advocacy Committee I call for action by therapy associations to implement these diagnostic and treatment standards in professional practice as they reflect both scientific research and personal experience (mine and many others).

As a consumer advocate for over 20 years I believe more succinct messages concerning “stuttering” are needed for awareness and advocacy, and that these messages can be given by specific reference to the word “stuttering” as a symptom of either Developmental Stuttering Disorder (neurodevelopmentally based), Habitual Stuttering Disorder, (learned or habitually based) and Stuttered Speech Syndrome (associated with Social Anxiety Disorder).

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