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# **STUTTERING IN YOUNG FEMALES AND MALES**

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# Stuttering in young females and males

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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## ABSTRACT

Stuttering is a relatively common speech disorder and most people have met someone who stutters. Symptoms of stuttering are repetitions, prolongations and blocks that stop the natural flow of speech. However, the symptoms can vary greatly and often resemble repetitions, pauses and lengthening that also occur in the speech of people who do not stutter. In addition, many persons who stutter become skillful at covering the obvious stuttering symptoms. Thus, a person may stutter and find that the stuttering has a strong negative impact on their quality of life even though people around them do not perceive that the person is stuttering. Clinical experience suggests that females tend to use avoidance strategies more often than men as a way of coping with stuttering. However, whether there are differences between the way girls/women and boys/men experience stuttering and how this develops during childhood is scientifically a largely unexplored area.

This thesis includes four studies. In Study I, differences in self-reported experience of stuttering between teenage females and males who stutter were analysed. The results showed that stuttering had a more negative impact on females compared to males. Females reported, to a greater extent than males, that because of their stuttering they avoided speaking and avoided social situations. When attitudes to communication among teenagers who do not stutter were examined, a considerably smaller difference between the sexes appeared.

Study II again targeted self-reported experience of stuttering among young females and males, but also the relationship between self-rated severity of stuttering and speech and language pathologists' (SLPs) assessment of stuttering severity. The results showed that stuttering had a greater negative impact for females compared to males. There was only a weak correlation between the females self-rated stuttering severity and the SLPs' assessment, while the correlation between the males' and SLPs' estimates was stronger.

Study III investigated the self-reported experience of stuttering in 162 children, adolescents, and young adults who stutter and whether there were differences in self-reported impact of stuttering at different ages and between sexes. The result was that stuttering had an increasingly negative impact on older girls and boys up to the age of 18, after which the individuals were less negatively impacted. Females reported on average a higher level of negative experience than males, and the sex difference was the greatest in adolescence.

Study IV was an interview-study with young women who experience a problem with stuttering but due to covering coping strategies and avoidance behaviour, characteristic symptoms of stuttering are not perceived by listeners. The women's incentives for choosing the strategy, the behavioural changes required by the strategy, and its consequences, were examined. The analyses identified three main themes in the women's narratives: (i) Personal aspects, (ii) Stuttering as a phenomenon, (iii) Managing stuttering. Shame and the desire to fit in emerged as motives for hiding stuttering. The development of self-esteem and self-image had also been strongly negatively affected, resulting in social anxiety. Moreover, stuttering had come to control the women's life choices and daily lives to a large extent. A particular

vulnerability of being a woman who stutters was expressed, partly based on societal norms about women's expected behaviours, partly based on society's stereotypical view of stuttering.

In conclusion, the studies in this thesis provide insight into how females who stutter have a more negative experience of their stuttering and are more likely than males to cover overt stuttering symptoms. Females who stutter are therefore at risk of not getting adequate support because it may appear as if the stuttering has disappeared.



## SAMMANFATTNING

Stamning är en relativt vanlig talstörning och de flesta har träffat någon som stammar. Symtom på stamning är upprepningar, förlängningar och blockeringar som stoppar talets flyt. Symtomen kan dock vara mycket varierande och ofta likna upprepningar, pauser och fördröjningar som även förekommer hos personer som inte stammar. Dessutom blir många som stammar skickliga på att dölja den hörbara stamningen. En person kan således stamma och uppleva att stamningen har stark negativ påverkan på livskvaliteten trots att omgivningen inte uppfattar att personen stammar. Klinisk erfarenhet tyder på att det finns en tendens till att kvinnor oftare än män använder undvikandestrategier som ett sätt att hantera stamningen. Huruvida det finns skillnader mellan hur flickor/kvinnor och pojkar/män upplever stamning och hur detta utvecklas under uppväxtåren är dock vetenskapligt ett i stort sett utforskat område.

I avhandlingen ingår fyra studier. I studie I analyserades hur självrapporterad erfarenheten av stamning skiljer sig åt mellan tonårsflickor- och pojkar som stammar. Resultaten visade att stamning hade en mer negativ inverkan på kvinnor jämfört med män. Flickorna rapporterade i större utsträckning än pojkarna att de på grund av sin stamning undvek att tala och undvek sociala situationer. När attityd till kommunikation bland tonåringar som inte stammar undersöktes, framkom en betydligt mindre skillnad mellan könen.

I studie II undersöktes återigen självrapporterad erfarenhet av stamning hos tonåriga och unga vuxna som stammar, men även överensstämmelsen mellan självskattad svårighetsgrad av stamning och logopeders bedömning av svårighetsgrad av stamning. Resultaten visade att stamningen hade en större negativ inverkan för kvinnorna än för männen. Överensstämmelsen mellan kvinnornas självskattning av stamningens svårighetsgrad och logopedernas bedömningar visade sig vara svag, medan överensstämmelsen mellan männens och logopedernas bedömningar var starkare.

I studie III undersöktes självrapporterad upplevelse och erfarenhet av att stamma hos 162 barn, tonåringar och unga vuxna som stammar samt om det fanns en skillnad med avseende på detta i olika åldrar och mellan könen. Resultatet visade att stamning hade en alltmer negativ inverkan på äldre flickor och pojkar upp till 18 års ålder, varefter individerna påverkades mindre negativt. Flickor och kvinnor rapporterade en genomsnittlig högre grad av negativ upplevelse än pojkarna och männen, och skillnaden mellan könen var som störst i tonåren.

I studie IV intervjuades unga kvinnor som upplever ett problem med stamning men där karaktäristiska symtom för stamning inte uppfattas av omgivningen, till följd av olika undvikandebeteenden som används för att dölja stamningen. I studien undersöktes kvinnornas motiv till val av strategi, vilka beteendeförändringar som strategin krävt, och de konsekvenser som det hade medfört. I analyserna identifierades tre huvudteman i kvinnornas berättelser: (i) Personliga aspekter, (ii) Stamning som fenomen, (iii) Att hantera stamningen. Skam och en vilja att passa in framträdde som motiv till att dölja stamningen. Utveckling av

självkänsla och självbild hade också påverkats starkt negativt, och resulterat i social ångest. Stamningen hade även i stor utsträckning kommit att kontrollera kvinnornas livsval och vardagsliv. En särskild utsatthet att vara kvinna och stamma framgick av berättelserna, dels utifrån samhälleliga normer om kvinnors förväntade beteenden, dels utifrån samhällets stereotypa syn på stamning.

Sammanfattningsvis ger studierna insikt om att flickor/kvinnor som stammar har en mer negativ upplevelse av stamningen och är mer benägna än pojkar/män att dölja de hörbara symtomen. Flickor/kvinnor som stammar riskerar därmed att inte få rätt hjälp eftersom det för omvärlden kan verka som om stamningen har försvunnit.

## LIST OF SCIENTIFIC PAPERS

- I. Samson, I., Lindström, E., Sand, A., Herlitz, A., & Schalling, E. (2021). Larger reported impact of stuttering in teenage females, compared to males – A comparison of teenagers' result on Overall Assessment of the Speaker's Experience of Stuttering (OASES). *Journal of Fluency Disorders*, 67, 105822.
- II. Samson, I., Lejon, S., Lindström, E., Sand, A., Herlitz, A., & Schalling, E. (2022). Life impact of stuttering by sex. *Manuscript*.
- III. Samson, I., Schalling, E., Herlitz, A., Lindström, E., & Sand, A. (in press). A cross-sectional investigation of the impact of stuttering on Swedish females and males in childhood, adolescence, and young adulthood. *Journal of Speech, Language, and Hearing Research*.
- IV. Samson, I., Nyberg, J., Lindström, E., Schalling, E. "I just want people to think I'm normal" - an interview study of young Swedish women with covert stuttering. *Manuscript submitted*



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## LIST OF ABBREVIATIONS

ASC	Attitude to Speech and Communication
CI	Confidence interval
ICD-11	International Classification of Diseases, Eleventh Revision
ICF	The International Classification of Functioning, Disability and Health
LSAS-SR	The Liebowitz' social anxiety scale – Self Rating
OASES	The Overall Assessment of the Speaker's Experience of Stuttering
PWS	Person(s) who stutter
PWNS	Person(s) with no stuttering
SLP	Speech and language pathologist
SSI-3	Stuttering Severity Instrument Third Edition
TWS	Teenager(s) who stutter
TWNS	Teenager(s) with no stuttering





# 1 INTRODUCTION

The human ability to communicate via speech offers a possibility to develop relations to others. Speech has therefore become an important tool for human development and survival. For some individuals, functional speech may be affected by neuromotor production deficits, manifesting as a difficulty in maintaining the flow of speech. The disorder, also known as a speech fluency disorder (here: stuttering), affects approximately 1% of the population (Bloodstein et al., 2021). Stuttering has been known to humankind through history and depictions of people with a speech deficit, interpreted as stuttering, have been found both in the Old Testament (Biblical Moses “slowness of speech and tongue”, Exodus 4; 10-13) and in Egyptian hieroglyphics (Manning & DiLollo, 2017).

Because the prevalence of stuttering among adults is larger among males, research has primarily focused on stuttering in males. Thus, our understanding of stuttering builds on an implicit proposition that stuttering mainly affects males. By challenging this assertion and allowing for the possibility that there may be differences in the manifestations and experiences of and coping with stuttering between females and males, new knowledge could be added to the existing literature on these aspects of the disorder. Only when we have a comprehensive description of how a health condition affects and influences people, where their inherent dispositions and characteristics are part of the story, will we understand the breadth and depth of the condition.

My research interest originates from my clinical experience. In my clinical practice I observed that females, more often than males, seemed to develop a coping strategy that involved concealing the obvious stuttering symptoms by becoming silent or avoiding situations where they were expected to speak.

I was unable to confirm my clinical experience with scientific evidence, as the field that addresses sex- and gender differences in stuttering is largely unexplored. Therefore, my primary aim with this thesis was to include more females into studies on stuttering. From clinical experience and the published literature it is evident that many male persons who stutter (PWS) have a variety of negative experiences due to their stuttering, and none of these experiences should be diminished. However, my assumption was that many females who stutter are more negatively affected by their stuttering than males, than has been made clear by the literature. It is hoped that this doctoral project can contribute to the understanding of stuttering by exploring the experience of stuttering depending on whether the PWS is female or male. Developing an understanding of whether there are differences between females and males, and if so, how these differences are manifested, may provide additional perspectives on stuttering and lead to improvements in the clinical care of PWS.

## 2 SPEECH FLUENCY

A typically fluent speaker does not usually have to pay any attention to the way he or she wants to say something. For most people, speech is automatically produced with an appropriate rate and speech timing, smooth transitions between each phoneme and appropriate force and effort in the way each phoneme is produced (Starkweather, 1980). There is not yet consensus on a single definition of speech fluency in the literature, but the concept is often referred to as flow and smoothness of the speech production process (De Jong & Perfetti, 2011). In everyday language, the expression “speaking fluently” most commonly refers to someone who can use spoken language effectively, above all someone who speaks a foreign language like a native (Chambers, 1997). Lennon (1990) describes fluency both as general oral accuracy of speech motor functions and linguistic complexity, in combination with adequate temporal measures, e.g., number of pauses and hesitations.

Although there is no unanimous definition of fluent speech, the literature shows that it is possible to recognize speech that is not fluent. Disfluencies, often recognized as interjections, phrase repetitions, and revisions are prevalent in everyone’s speech, especially in young children in ages critical for language development. Criteria for normal disfluencies are however not uniform across studies (Geetha et al., 2000), and therefore it is sometimes difficult to distinguish normal *disfluencies* from *dysfluencies* in the realm of speech fluency disorders. This is particularly difficult when deciding on onset of stuttering in young children where speech has just begun to develop (Ambrose & Yairi, 1999).

## 3 STUTTERING

The speech fluency disorder known as stuttering is a speech disorder most people have come across. In the medical classification list by the World Health Organization, ICD-11 (International Classification of Diseases, Eleventh Revision) its description follows:

“Developmental speech fluency disorder is characterised by frequent or pervasive disruption of the normal rhythmic flow and rate of speech characterised by repetitions and prolongations in sounds, syllables, words, and phrases, as well as blocking and word avoidance or substitutions. The speech dysfluency is persistent over time. The onset of speech dysfluency occurs during the developmental period and speech fluency is markedly below what would be expected for age. Speech dysfluency results in significant impairment in social communication, personal, family, social, educational, occupational or other important areas of functioning. The speech dysfluency is not better accounted for by a Disorder of Intellectual Development, a Disease of the Nervous System, a sensory impairment, or a structural abnormality, or other speech or voice disorder.”

The opening sentence of the description most likely reflects how people in general would define the characteristics of stuttering. However, to the speaker, there is much more to stuttering than just dysfluencies in the speech.

### **3.1 EXPLANATIONS OF STUTTERING**

While the disorder has been clinically well described for many centuries, its underlying causes have remained unknown. Many potential causes of stuttering have been suggested, however clear data supporting the ideas have been lacking. Depending on the profession of the person studying the disorder (e.g., psychiatrists, physicians, psychologists, neurologists, linguists), different knowledge bases, perspectives, and sources of information have been used. The reference literature on stuttering also points out that the overall scientific outlook of the time, and the prevailing zeitgeist, came to influence the theories (Bloodstein et al., 2021; Manning & DiLollo, 2017; Van Riper, 1982; Yairi & Seery, 2021). The last century's explanatory models for stuttering can be broadly divided into three main areas: 1. Psychological theories, 2. Learning theories and 3. Organic/Physiological theories (Manning & DiLollo, 2017; Van Riper, 1982).

In the early part of the last century, Freudian theories had a strong influence on theories of stuttering which could be seen in for example Blanton (1916), defining stuttering as a psychoneurosis involving the mind as an important part and Fletcher (1916) describing the symptoms of stuttering as being a result of physiological, psychophysical, or mental underlying mechanisms. Coriat (1928) attributed the onset of stuttering to the child's fixation at the oral stage, whereas Fenichel (1945) suggested that stuttering was a neurosis that had arisen in the anal phase of psychosexual development. These theories have largely been disproven.

The organically/physiologically based theories have the oldest intellectual history (Bloodstein et al., 2021). In particular, the tongue appeared in older writings from the Middle Ages onwards to be of decisive importance for the development of stuttering (Van Riper, 1982). In the beginning of last century, Travis (1929, 1931) proposed the Cerebral dominance theory, based on the assumption that the simultaneous movements required to produce accurate speech gestures, with adequate speech production as a result, were dependent on left hemispheric dominance. For those who stutter, however, the necessary dominance was lacking. A lack of hemispheric dominance, Travis reasoned, leads to the speech muscles receiving unsynchronized neural impulses from both hemispheres of the brain, which in turn causes the disruption in the fluency of speech. Heritable factors in combination with biochemical changes were seen in West et al. (1939) reasoning on how stuttering could be explained.

Learning theories came to influence stuttering theories around the middle of the last century (Bloodstein et al., 2021; Yairi & Seery, 2021). In the 1940s, the diagnosogenic theory came to dominate the understanding of how stuttering developed. It was believed that stuttering

developed after the diagnosis, usually set by parents, rather than before, and was therefore seen as a consequence of the diagnosis (Johnson, 1942). Stuttering was seen as an anxiety state, which had developed because of situational fear and anxiety conditioned by previous experiences of stuttering in the child's environment. This view was shared by other researchers who also concluded that the parental standards for fluency seemed to play a definite part in the onset of stuttering (Bloodstein et al., 1952).

A current position on the cause of stuttering at that time was the conflict hypothesis (Sheehan, 1958). This theory emphasized a need to simultaneously speak and hold back from speaking. The holding back was either due to learned avoidance or to unconscious motives. An increasing interest in Skinner's models of operant conditioning (Skinner, 1953) spilled over into explanatory models for stuttering, with the idea that the speaker gradually learns to stutter. Whether or not the initial fluency breaks were normal was long debated. The demands-capacities model is one of the psycho-behavioural theories of stuttering (Adams, 1990; Starkweather & Gottwald, 1990), a theory of behavioural responses in relation to stimulus demands, in short: fluency breaks down when environmental and/or self-imposed demands exceed the child's capacities and abilities.

Audiology was a scientific field that developed in the 1950's and researchers in this area also took an interest in tracing the causative mechanisms of the stuttering. Findings from this area suggested that the auditory feedback system of PWS differed from those of typically fluent speakers, and that these differences were involved in the onset of stuttering (Stromsta, 1959).

In the second half of the 1900's century there was an increasing interest in genetic studies, as it for many years had been noted that stuttering tends to run in families. Family studies of stuttering provided evidence showing that those who stutter were more likely than fluent speakers to have stuttering relatives, indicating that genetic factors may be important in the expression of the condition (Ambrose et al., 1993; Andrews & Harris, 1964; Andrews et al., 1991; Kidd, 1980). Today, thanks to constantly refined DNA analysis, specific gene clusters have been identified as candidate genes for stuttering (Han et al., 2014; Kazemi et al., 2018; Kraft & Yairi, 2011). By now, the notion there is a genetic component has become unquestionable (Yairi & Seery, 2021).

### **3.2 CONTEMPORARY THEORETICAL FRAMEWORK**

The wide diversity of definitions and explanations of stuttering as either a psychiatric/psychosocial, organic/motor disorder, or learned disorder demonstrate the complexity of the disorder. Today's research on stuttering has moved into the age of neuroscience and is seen a more multi-faceted picture where not one, but several factors interact (Smith & Weber, 2017). Some claim that many recent theories are really the same as some of the earlier theories but with a new conceptual framework as technological advances progressively provide an improved understanding of underlying mechanisms of human production of speech and language (Manning & DiLollo, 2017).

Research conducted in the 21st century has provided sufficient evidence demonstrating both functional and brain anomalies in PWS, compared to typically fluent speakers. The findings that are most consistent have indicated right hemisphere hyperactivity, and functional anomalies in sensorimotor cortical areas in the left hemisphere relevant for speech and language (Chang et al., 2009; Garnett et al., 2018; Watkins et al., 2008). A theory that was presented by Karlin already in the 1940s (Karlin, 1947), was a delay in the myelination process in brain areas critical for speech. Experimental research of today have confirmed the theory; white matter in interrelated neural circuits that enable skilled movement control, has proved to be anomalous in adults who stutter compared to typically fluent speaking persons. (Chang et al., 2018, 2019; Connally et al., 2014). With non-invasive neuroimaging technology it has been possible to examine children who stutter, and here it has been found that children who stutter exhibit significantly reduced white matter density relative to age-matched peers with typical speech production. It has been hypothesized that developmental changes in white matter determine persistence or recovery (Chang et al., 2015). It has also been observed that grey matter volume in subcortical centers is reduced in PWS compared to typically fluent speakers, implicating difficulties in the speech planning phase (Chang et al., 2008). Thus, stuttering is nowadays ultimately considered an impairment in speech sensorimotor processes with disrupted motor commands to muscle activity required for fluent speech (Smith, 1989). Speech motor instabilities are affecting the speech motor system, and even typical speech in adults who stutter shows signs of atypical patterns generated for motor commands (Kleinow & Smith, 2000; Zimmermann, 1980). Kleinow and Smith (2000) further concluded that speaker motor stability seems to be influenced by linguistic complexity, suggesting that stuttering is not limited to the speech-motor neural network but also involves interactive language. Their assumptions is in line with Walsh et al. (2021) who found that several interacting factors increased the likelihood of developing persistent stuttering (in addition to positive family history of stuttering), such as poorer articulation/phonological performance, higher frequency of stuttering-like disfluencies during spontaneous speech, and lower accuracy in the production of non-words.

Additional factors related to stuttering, reflected in increased linguistic and psycho-social demands, seem to have an important impact on the development of stuttering over a lifespan (Smith & Weber, 2017; Yairi & Seery, 2021; Yaruss & Quesal, 2004). In 2018, Chang and colleagues discovered, from a large sample of fMRI scans collected over a number of years from stuttering and non-stuttering children, that stuttering status and stuttering persistence were associated not only to deviant network connectivity in areas responsible for speech motor control, but also to attention, somato-motor, and fronto-parietal networks (Chang et al., 2018). Consequently, it has been emphasized that situational, linguistic, emotional, and attentional factors should also be taken into consideration when the onset, persistence, and/or recovery of stuttering is explained.

As mentioned above, evidence for a strong genetic factor in stuttering has become indisputable, as advanced genotyping techniques have allowed scientists to come close to identifying specific candidate genes (Kraft & Yairi, 2011). The disorder is genetically based

but highly responsive to epigenetic and environmental factors as a concordance rate for stuttering in monozygotic twins is about 70% and about 30% for dizygotic twins (Felsenfeld et al., 2000; Howie, 1981). The differences in monozygotic twins suggest that the onset of stuttering and whether or not the stuttering persists over age, is critically dependent on epigenesis, i.e., the timing and intensity of gene expression during development, health conditions, or changes that may result from external or environmental factors in the shaping and development of the brain in childhood. For example, Alm (2020) has proposed that childhood streptococcal infections may have been an important cause of stuttering until the introduction of antibiotics in the 1940s. The dynamic developmental context in which stuttering occurs and either persists or attenuates, referred to by Smith and Weber (2017) as the Multifactorial dynamic pathways theory of stuttering, is illustrated in Figure 1.

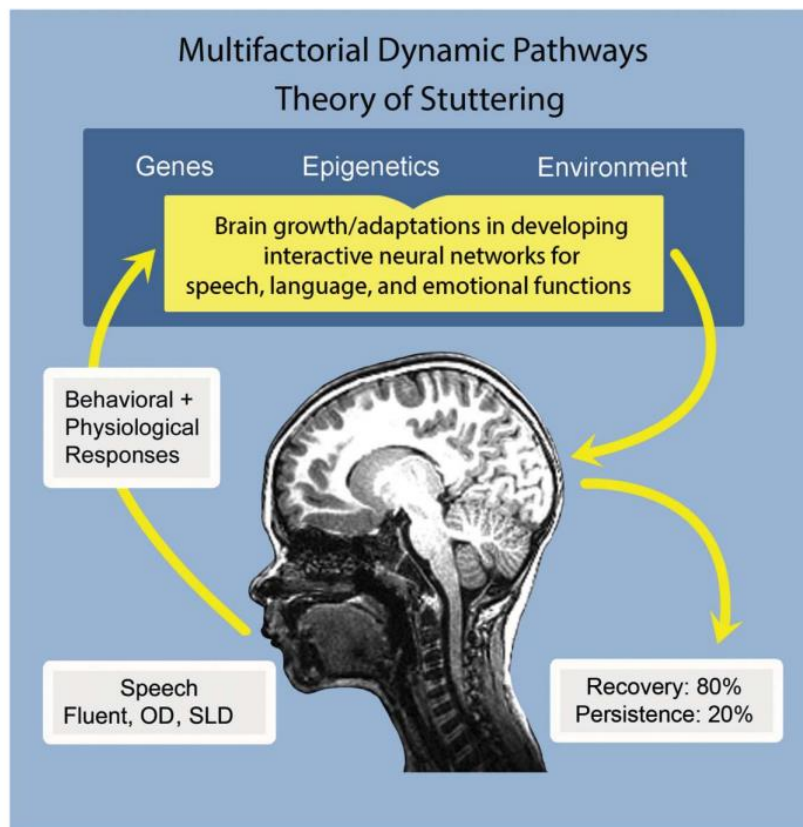


Figure 1. An illustration of the major features of the multifactorial dynamic pathways theory of stuttering. OD = other disfluencies; SLD = stuttering-like disfluencies. Reprinted from “How stuttering develops: The multifactorial dynamic pathways” by A. Smith and C. Weber (2017). *Journal of Speech, Language, and Hearing Research*, 60(9), 2483-2505. Copyright © 2017 Anne Smith and Christine Weber. Reprinted with permission of the American Speech-Language Hearing Association (ASHA).

### 3.3 INCIDENCE AND PREVALENCE OF STUTTERING

A five percent life-span incidence for stuttering seems to have been a recurring statistic over decades (Yairi & Ambrose, 2013). Although several studies have been conducted and reported from the early 1900s and onwards (Bloodstein et al., 2021, pp 43 – 45) the figure of 5% has primarily referred to the longitudinal study performed by Andrews and Harris in 1964. In their survey, over one thousand children were tracked from birth and up until their 16th year and it was found that approximately 4.9% of the children in the group were stuttering for some period of time.

More recent studies indicate higher rates of incidence. A study by Felsenfeld et al. (2000) yielded an incidence of 8.8%, Dworzynski et al. (2007) 8.4%, and Reilly et al. (2013) 11.2%. With reference to recent data, stuttering incidence has been suggested to be adjusted to 8% (Yairi & Ambrose, 2013). A divergent result was presented in a study by Craig et al. (2002), where data was collected from more than 12 000 persons from 2 to 99 years of age. Here, the mean life-span incidence was found to be approximately 2.2% (with variations between age groups).

The prevalence in children under six years of age is considerably higher than in older ages, indicating that many children recover from stuttering (Zablotsky et al., 2019). Stuttering onset has been found unlikely to occur after six years of age, and most individuals who stutter have a history of stuttering since childhood, with onset around 3-4 years of age (Dworzynski et al., 2007; Reilly et al., 2009; Yairi & Ambrose, 2013). Consequently, prevalence data on stuttering is expected to vary with the age group sampled. Last century studies on prevalence have primarily targeted schoolchildren and aggregated findings center around 1% (Brady & Hall, 1976; Conradi, 1904; Louttit & Halls, 1936; Yairi & Ambrose, 2013). Prevalence studies carried out during the 21st century confirm that the highest prevalence of stuttering is found in pre-school children, after which it decreases (Bloodstein et al., 2021). Craig et al. (2002) conducted a prevalence study including over 12 000 participants in all ages, and from the results the lifetime prevalence of stuttering was concluded to be 0.7%. Thus, the frequently cited figure of 1% for the general prevalence of stuttering in the population may be slightly lower (Yairi & Ambrose, 2013).

Research that examines prevalence and incidence is afflicted with a number of difficulties and possible pitfalls. For instance, what should be the minimum length of time that symptoms need to persist to qualify for inclusion in a study of incidence? What symptoms should be included in the definition of the impairment? Since the symptoms of stuttering are highly variable and often overlap with normal disfluencies, a perceptual assessment alone is seldom sufficient (Brocklehurst, 2013). Moreover, there are significant aspects of stuttering that are difficult to observe, why a focus only on observable behaviours of speech may lead to compromised judgments and measures of stuttering (Jackson et al., 2012).

Researchers often engage secondary informants (teachers, parents, and family members) to gather data and determine who stutters to obtain a large basis for evaluation. If clear descriptions of symptoms characterizing the disorder are lacking or if preparatory training in identifying stuttering prior to the investigation has not been performed, it is doubtful if the result can be fully trusted. Absolute definitions of stuttering have proved to be almost impossible to develop, as no consistent, applicable perception or description of the speech disorder has been shown to exist neither among experts, nor among people in general (Cordes & Ingham, 1995; Ham, 1990; Kully & Boberg, 1988). Apart from the fact that there has been a longstanding discussion and debate among researchers and clinicians on how stuttering shall best be defined and measured, a layman's view of disabilities or illnesses and their symptoms is still often different from the professional models. Thus, what is obvious to a specialist may be unclear or incomprehensible to someone without that particular competence and experience (Sander & Shorvon, 1987).

### 3.4 PREVALENCE OF STUTTERING IN FEMALES AND MALES

Stuttering affects males to a larger extent than females with an overall ratio of approximately 3:1 (Bloodstein et al., 2021). The sex ratio in the youngest age group (2 – 5 years) is relatively balanced, however, the younger the age, the more balanced the gender distribution (Table 1).

Table 1. Preschool stuttering incidence and sex ratio among children ages 2 – 5 years

Study	Age	Total n of participants	Male PWS	Female PWS	m:f ratio
Briley et al., 2021	3 - 5	12391	224	120	1.87:1
Craig et al., 2002	2 - 5	720	14	6	2.33:1
Månsson, 2000	2	1021	33	20	1.65:1
Reilly et al., 2013	<4	1619	106	75	1.41:1

Research findings for older ages also vary depending on age group, from 1.4:1 to 5:1 (Craig et al., 2002; van Borsel et al., 2006). In general, it has been recognized that the male-to-female gender ratio is the smallest in young children, increasing with age. Older age brackets, from pre-puberty and onwards, not only include fewer PWS altogether, but also mostly males. However, Craig and Tran (2005) report an interesting fluctuation of male-to-female ratio over the lifespan: 3:1 for a 2-10-year cohort, 4:1 for 11–20-year-olds, 2:1 for individuals



between 21 and 49 years of age, and almost balanced (1.4:1) for persons over 50 years of age. In a recent study by Gerlach et al. (2018), where data were obtained from the population survey National Longitudinal Study of Adolescent to Adult Health - Add Health (Harris et al., 2009), the stuttering prevalence was found to be 1.91% with a male-to-female ratio of 1.84:1. In the survey, a total of 13,564 respondents (longitudinally) answered questions about stuttering in four waves over 14 years, and in the estimation of prevalence only the number of those who had answered “yes” to the question whether they stutter in both waves 3 and 4 were included. It is of interest to note that both prevalence of stuttering and the ratio between females and males render slightly different numbers when the information is self-reported compared to when it is obtained from researchers and secondary informants.

Why the ratio in the oldest age group is more or less balanced is not yet clear. Although the prevalence of stuttering has been found to differ substantially between the sexes (Yairi & Ambrose, 2013), with a greater proportion of males than females, further studies are needed to provide a more detailed understanding of the developmental trajectory of stuttering for each sex, and at what approximate age an increase in the male to female ratio occurs (Briley, Merlo, & Ellis, 2021).

Again, an explanation as to why the distribution fluctuates between different surveys can be attributed to research methodology issues, as discussed above. Research findings also need to be viewed within the context of the time the research was performed. An interesting example of this is a study from the 1970's (Feldman, 1977), where it was reported that the sex ratio for stuttering in adults seemed to decrease, implicitly indicating that the proportion of stuttering women had increased. However, another plausible explanation for the change in sex distribution could be attributed to the changing role of women in society and in the workplace in the 1970s, which may have resulted in an interaction between health care becoming more accessible to women and women being more likely to seek contact with speech and language pathologists (SLPs) (Nang et al., 2018).

### **3.5 MANIFEST SYMPTOMS OF STUTTERING**

The common features of stuttering have been described not only by researchers but also by parents of children who start to stutter as repetitions of syllables and parts of syllables, whole words, or parts of phrases, typically in the beginning of an utterance (Johnson, 1942). Other descriptions of stuttering include sound stoppages, blocks, and prolongations (Yairi & Ambrose, 1992). The availability of different methods for classifying dysfluencies has made it extremely difficult to find a common and comprehensive classification system, however, what listeners would likely perceive as overt stuttering characteristics in speech are repetitions, prolongations, broken words, and blocks (Yaruss, 1997).

### 3.6 ASSOCIATED SYMPTOMS OF STUTTERING

In the ICD-11 (International Classification of Diseases Eleventh Revision, 2022) definition of stuttering *word avoidances* or *substitutions* were added to the description of the disorder.

“Developmental speech fluency disorder is characterised by frequent or pervasive disruption of the normal rhythmic flow and rate of speech characterised by repetitions and prolongations in sounds, syllables, words, and phrases, as well as blocking and word avoidance or substitutions [...]” World Health Organization, 2022.

Stuttering symptoms sometimes called associated, or secondary, are more elusive as they are not directly apparent to the listener (Bothe et al., 2006). Instant word avoidances or word substitutions are example of actions or behaviours that are not perceived by the listener. Empirical studies have shown that a common phenomenon in stuttering is that the speaker perceives an anticipation to stutter. The anticipation can elicit a range of behaviours to forecome the stuttering to manifest, for example, word substitutions or word avoidances, paraphrasings, or avoidance of situations all together (Jackson et al., 2015; Tichenor & Yaruss, 2018). Other elements that exist ‘below the surface’ and which can also be attributed to the anticipation of stuttering include fear, anxiety and, by extension, a negative attitude to speaking and a discomfort to participate in social context (Beilby, 2014). O’Brian et al. (2022) concluded in their study on complexity of stuttering behaviour in PWS in relation to anxiety-related mental health and impact of stuttering, that listeners base their stuttering severity judgments on overall stuttering behaviour, while the speakers themselves seem not to. The PWS that participated in the O’Brian et al. (2022) study predominantly focused on how they experienced their stuttering and seemed barely aware of how their stuttering manifested behaviourally.

For many who stutter, the overall effect of associated symptoms is reduced quality of daily life including lower social and emotional functioning (Blomgren, 2010; Craig et al., 2009). Stuttering is for many perceived as a highly stressful and threatening experience, thus, involving much more than the surface disruptions in the speech. The depth and extent of the experience of stuttering often stands in stark contrast to the obvious speech behaviours, and the extent of manifest speech related symptoms is not always proportionate to associated symptoms (Manning & Beck, 2013). Although the variability in stuttering frequency is often substantial from day to day and from situation to situation for the same individual, the overall experience of stuttering has been found to be highly consistent from day to day (Constantino et al., 2016). Social and emotional functioning, quality of life, and mental health are examples of different areas in a person’s life that can be adversely affected due to negative experiences related to stuttering (Messenger et al., 2004). Results from several studies have demonstrated that PWS both have higher inherent levels of anxiety (trait anxiety) and condition- or situation-specific anxiety (state anxiety) compared to persons who do not stutter (Craig, 1990; Craig & Tran, 2014; Ezrati-Vinacour & Levin, 2004). Also, there seems to be an increased risk of developing social phobia in PWS, when compared to typically speaking persons (Blumgart et al., 2010; Craig et al., 2003). In terms of the development of anxiety across the

lifespan, having stuttering in childhood has been associated with an increased frequency of anxiety disorders (Iverach et al., 2017), and several studies have shown that adolescents who stutter describe increased anxiety, negative attitudes toward communication, negative peer experiences, and low self-esteem (Blood & Blood, 2004; Blood et al., 2001, 2011; Mulcahy et al., 2008; Smith et al., 2014). Thus, for many who stutter the daily experience of stuttering does not only involve surface speech disruptions but also negative reactions (from self and from others) with restricted autonomy as a consequence.

Researchers and clinicians have long argued that both overt speech behaviours and the psychosocial impact that stuttering has on a person's life should be a part of the concept of stuttering (Cooper & Cooper, 1996; Gabel, 2006; Yaruss & Quesal, 2004, 2006). In the fifth version of the diagnostic and statistical manual of mental disorders (American Psychiatric Association, 2013) an addition to the diagnostic criteria, up to then solely focusing on the overt speech symptoms, states that anxiety and avoidance also shall be considered a part of the disorder. Equally was done in the latest version of ICD-11 (2022), by expanding the text to note that stuttering leads to significant impairment in various important functional areas.

### **3.7 THE MULTIFACETED NATURE OF STUTTERING**

The importance of not only examining the manifest symptoms that a listener may observe in the speech of PWS but describing and conceptualizing stuttering from multiple perspectives has been stressed for decades. By considering all aspects of the speech fluency disorder and including the speaker's own assessment and experience, the understanding of stuttering will deepen and sharpen (Tichenor & Yaruss, 2018, 2019; Yaruss, 1998; Yaruss & Quesal, 2016).

The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO 2001), is a useful framework for understanding the experience of living with different health conditions. The framework has been adapted to stuttering to depict a disorder with multiple interdependent domains (Yaruss & Quesal, 2004). The most recently updated version (Tichenor & Yaruss, 2019) is based on extensive data collected from a large number of PWS (Figure 2).

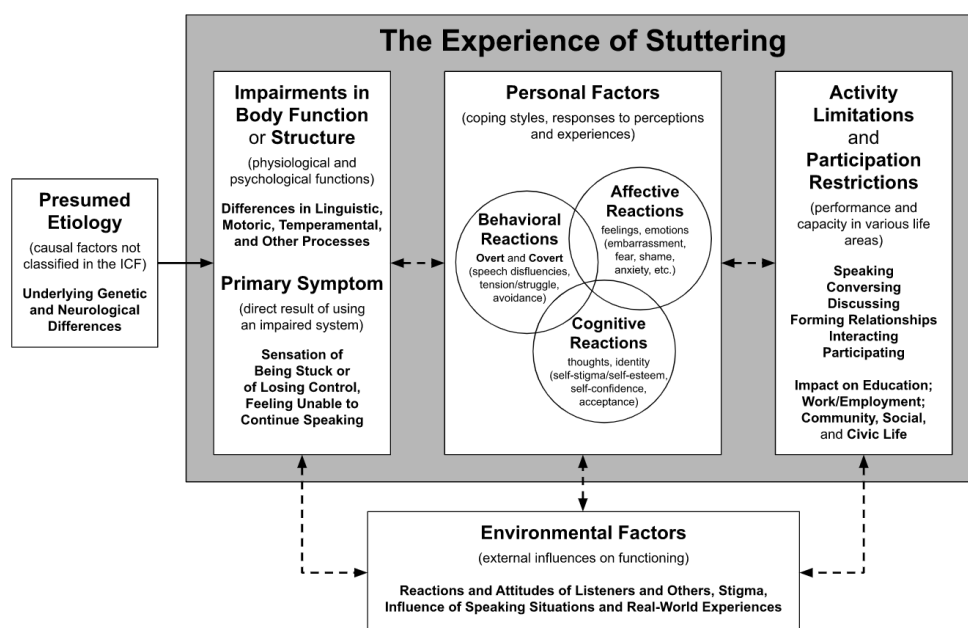


Figure 2. Tichenor and Yaruss (2019), an update of the Yaruss and Quesal (2004) representation of how the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) can be applied to stuttering. Reprinted from *Stuttering as defined by adults who stutter*, by S. Tichenor and S. Yaruss (2019). *Journal of Speech, Language, and Hearing Research*, 62(12), 4356–4369. Copyright © 2019 Seth E. Tichenor and J. Scott Yaruss. Reprinted with permission from the American Speech-Language Hearing Association, ASHA.

One part of the framework defines the primary symptom of stuttering, described by PWS as a feeling of "loss of control" or of being "stuck" when trying to speak (Perkins, 1990; Tichenor & Yaruss, 2018, 2019). Feelings of loss of control or not being able to speak in the way expected can lead to a variety of reactions. These individual reactions are illustrated in the component of the framework entitled "Personal Factors". Examples of personal reactions include affective, behavioural and cognitive reactions that may arise as a result of the disorder. A person living with persistent stuttering often experience an interaction of affective, behavioural and cognitive reactions, which can cause both to an increase in observable stuttering behaviour and automatized coping strategies (Tichenor & Yaruss, 2018, 2019). The component "Environmental factors" in the framework reflect the impact that an environmental context can have on the speaker, e.g., via a conversation partner or, more generally, via society. A conversation can have negative consequences for a PWS by creating (real or perceived) pressure to speak and further reinforce personal reactions. Societal influences include public stigma against stuttering and negative perceptions of stuttering and PWS by people in general (Boyle, 2013, 2015, 2018; Boyle & Blood, 2015; St. Louis, 2020; St. Louis et al., 2016). Thus, environmental factors can have a major, and in many cases detrimental, impact on a person's overall experience of stuttering. Primary symptoms, Personal factors (reactions), and Environmental factors in combination, can affect a person's ability to live their life as they wish. This is described in the component of the ICF framework entitled "Activity and Participation." (Figure 2).

### **3.8 STUTTERING AND STIGMA**

“The view of others” and general attitudes often hold preconceptions and suppositions of derogatory traits linked to individuals with certain characteristics. The preconceptions may be fueled and fortified by how people of that context are portrayed in films, books and media, and thus, stereotypes and a public stigma is created. Stereotypes have a strong tendency to be internalized by the one who is the subject and may result in reduced societal participation and have a negative impact on quality of life (Corrigan et al., 2009). In the public eye, a person who stutters is often believed to be introverted, shy, nervous, anxious or fearful (Ham, 1990; Hughes et al., 2010; Schlagheck et al., 2009). Moreover, a common perception by people in general is that not all jobs are appropriate for those who stutter, and that stuttering is associated with less competence and intelligence (Gabel et al., 2004; Silverman & Paynter, 1990). Several studies have shown that individuals who stutter are afraid that others will view them as “mentally retarded” or “not normal” and that the internalization of negative attitudes leads to a negative view on self, even self-hate, with reduced social interaction and psychological well-being as a result for many (see for example Klompas & Ross, 2004; Plexico et al., 2009a, 2009b; Whaley & Parker, 2000).

### **3.9 COVERT STUTTERING**

In research investigating coping responses by adults who stutter, findings describe a great variety of emotions that are accompanying the stuttered moment, including fear, frustration, shame, embarrassment and helplessness. It has also been found that coping efforts are strongly influenced by a desire to protect both self and the listener from experiencing discomfort and emotional distress associated with stuttering (Plexico et al., 2009a, 2009b). Some PWS have developed such great skills when it comes to concealing the apparent stuttering symptoms that they pass as fluent speakers. In clinical experience, the main problems for those who stutter and yet pass as fluent consists of the anticipation of difficulty and fear of losing control, fear of ‘losing face’, and self-imposed curtailed freedom to participate in various social activities. Thus, concealing obvious stuttering symptoms, even successfully, may still be associated with severe negative impact of the person’s well-being. Although covert stuttering appears to be a well-recognized clinical phenomenon, research on covert stuttering is sparse. In a first report where covert, or interiorized, stuttering was recognised, it was rather negatively depicted with links to psychological components such as submissiveness and merely an “inauthentic” way of stuttering (Douglass & Quarrington, 1952). Constantino et al. (2017) have claimed the opposite, all forms of stuttering are authentic and passing as fluent is simply an active form of managing stuttering produced by the use of specific communication techniques rather than a passive form of repression. An observation made by Constantino et al. (2017) worth noting (with caution though, considering the small empirical base) is that the gender ratio of persons who pass as fluent include more women than men compared to PWS who stutter overtly, in general (Constantino et al., 2017). This is in line with my anecdotal, but long, clinical experience.

### **3.10 THE EXPERIENCE OF STUTTERING AS A FUNCTION OF SEX**

Research encompassing females who stutter and possible differences between females and males regarding the experience of stuttering is limited and the existing studies are rather heterogeneous from a methodological point of view and involve a relatively small number of participants. With fewer females who stutter, fewer women will be on the caseloads of clinicians and will be less likely to be included in research studies. Therefore, what is known about stuttering through research is likely based on findings from male informants who stutter (Nang et al., 2018).

Much of what has been conducted so far was mainly done in the 1970s and 1980s. Silverman and Zimmer (1979, 1982) compared interview data from a group of stuttering females and a group of stuttering males (10 participants in each group). It was concluded that there was a difference between men and women in stuttering symptomatology and also that the males were more likely to receive counselling and intervention for their fluency disorder, suggesting that males were more concerned about the speech impediment than were the females. In support of Silverman's and Zimmer's findings, it was found in a survey of more recent date, including 232 participants, that men who stutter were more likely than women to believe that their stuttering was a barrier to pursuing a desired occupation and that it would adversely affect their chances of promotion at work (Klein & Hood, 2004). In a study based on interviews with nine stuttering women, it was concluded that stuttering affected how the women viewed themselves, their relationships, their career potential, and their perceptions of how others viewed them (Nang et al., 2018). The authors found the quotes of the women over strategies to cope with stuttering and portrayal of self as a stuttering woman to be deeply gendered, provided we believe that what is referred to as an expression of femininity is through how we communicate, and how our communication is viewed by others is reflected in expectations of how women should behave (Nang et al., 2018).

Research examining the view of others and listeners' attitudes towards stuttering women and men separately is meager and the results ambiguous. Women who stutter were judged more negatively than men who stutter by observers in a study by Byrd et al. (2017), a finding that was confirmed in a later study by Croft and Byrd (2021). An intriguing finding is that the view of others seems to vary depending on who is asked. When judged by clinicians, stuttering was considered to have a stronger negative impact on females and children, whereas when university students were asked - their impression was that the negative impact of stuttering was stronger for males (Silverman, 1982). However, it should be noted that the study is of an older date and that gender norms likely have changed since then.

A few recent empirical studies have compared the impact of stuttering in females and males who stutter. Adriaenssens et al. (2015) and Iverach et al. (2017) found that adolescent females who stutter reported more negative communication attitudes and lower self-esteem, compared to age-matched males. Briley, Gerlach, and Jacobs (2021) conducted a longitudinal study and concluded that depressive symptoms in female PWS increased in severity with age, while those of male PWS remained stable. The Nang et al. study (2018) found that stuttering had a

pervasive impact on all areas of the women's lives, including relationships, career opportunities, and self-perception.

It is, however, difficult to determine why there is a difference in outcomes and how results should be interpreted and evaluated when the studies are so few in number. Furthermore, cultural, social and contextual prerequisites prove to change considerably over time which in turn may affect people's preconceptions and opinions and have an influence on how people make judgements. It is therefore hazardous to draw any general conclusions from a few research results, especially when these are spread over a large time interval, carried out in different contexts and with different methodological approaches.





## **4 RESEARCH AIMS**

### **4.1 GENERAL AIMS**

The overall aim of my project was to examine the experience of stuttering and coping strategies in young females and males who stutter. The aim was also to investigate whether subjectively perceived and externally assessed symptoms of manifest stuttering correspond, and if the correspondence is comparable between females and males, and, finally, whether the developmental profile of self-perceived impact of stuttering differs, as a function of sex and age.

### **4.2 SPECIFIC AIMS**

The specific aims of the thesis were to:

- Explore whether there are differences in the experience of stuttering and attitudes towards communication in adolescent girls and boys who stutter, compared to age-matched peers with typically fluent speech (Study I).
- Investigate whether sex has an impact on the experience of stuttering, and define the correspondence between subjective and objective stuttering severity assessments (Study II).
- Define the developmental profile of self-perceived symptoms of stuttering, by age (schoolchildren to young adults) and sex (Study III).
- Describe factors that have contributed to the development of covert stuttering in young women, and to examine the impact of stuttering on different aspects of life (Study IV).



## 5 MATERIALS AND METHODS

### 5.1 PARTICIPANTS

In all 211 PWS in ages between 7 and 30 years, and 233 teenage persons with no stuttering (PWNS), 13 – 17 years of age, were included in the thesis. In Studies I – III the sex distribution of the PWS was balanced, with a ratio of 1.1– 1.2:1 (males:females). Participants in Study IV were all females. Studies II and IV contained only new participants recruited specifically for this project, whereas Studies I and III pooled newly recruited participants with participants previously recruited in studies on adjacent topics. An overview of participants in each study is presented in Table 2.

Table 2. Overview of participants in Studies I - IV

	nPWS (female/male)	nPWNS (female/male)	Mean age PWS female/male (min – max)	Mean age PWNS female/male (min – max)
Study I	56* (26/30)	233** (126/107)	15/15 (13 – 17)	15/15 (13 – 17)
Study II	38 (19/19)		17/17 (13 – 25)	
Study III	162*** (75/85) - Children (20/27) - Adolescents (38/42) - Adults (17/17)		16/15 (7 – 30) - Children 10/10 (7 – 12) - Adolescents 15/15 (13 – 17) - Adults 24/23 (18 – 30)	
Study IV	11 (11/0)			

\*29 PWS recruited for this project, remaining material collected in earlier studies

\*\*All 233 PWNS recruited for this project

\*\*\*59 PWS recruited for this project, remaining material collected in earlier studies

The participating PWS were recruited via different channels; by their SLP contact, through the national stuttering association (*Stamningsförbundet*), Facebook pages set up by the local stuttering association in Stockholm, and through social media outlets. In addition to being within the age range specified for each study, the inclusion criteria were; clinical diagnosis of stuttering (Study I), and/or self-identify as a PWS (Studies II, III, and IV), functional understanding of spoken/written Swedish (all studies). In Study IV, the inclusion criteria, in extension of self-identifying as a PWS, was to consciously attempt not to display any overt stuttering symptoms.

The recruitment of participants to the control group (PWNS) in Study I was conducted via schools in Sweden. Out of 43 schools that were initially contacted, eight agreed to participate. The only inclusion criteria for participants in the control group, apart from being a teenager in the age span 13 – 17 years, was to have functional understanding of spoken and written

Swedish. Otherwise, there were no specific limitations to participation, such as not having a stuttering diagnosis or other type of speech disorder.

## 5.2 MEASURES

The quantitative measures that were used in the studies consisted largely of self-report questionnaires. Study II also used a standardised tool assessing stuttering severity which complemented the set of self-reports. Study IV had a qualitative approach, thus, data were collected through semi-structured qualitative interviews and analysed through content analysis, but self-report of stuttering impact and a questionnaire for assessment of social anxiety were also included to provide background information. An overview of the measures included in each study is shown in Table 3.

Table 3. Overview of measures included in study I – IV.

*Note: OASES = The Overall Assessment of the Speaker's Experience of Stuttering, ASC = Attitude to Speech and Communication, SSI-3 = The Stuttering Severity Instrument Third Edition, LSAS-SR = Liebowitz' Social Anxiety Scale-Self-report, SLP = Speech and language pathologist*

MEASURE	Purpose	Study I	Study II	Study III	Study IV
<b>OASES-A-S</b> (Adults, >18 years)	Self-reported experience of stuttering impact		x	x	x
<b>OASES-T-S</b> (Teenagers, 13 – 17 years)	Self-reported experience of stuttering impact	x	x	x	
<b>OASES-S-S</b> (School-children, 7 – 12 years)	Self-reported experience of stuttering impact			x	
<b>ASC</b>	Self-reported attitude to speech and communication	x			
<b>Self-reported stuttering severity</b>	Self-reported stuttering severity in different speaking situations		x		
<b>SSI-3</b> (adapted version)	SLP-rated stuttering severity		x		
<b>LSAS-SR</b>	Self-reported experience of social anxiety				x
<b>Interview guide</b>	Topic guide for semistructured in-depth interviews				x

### 5.2.1 Assessments of stuttering impact and stuttering severity

#### 5.2.1.1 Stuttering impact

Common to all four studies in the thesis was the use of the instrument The Overall Assessment of the Speaker's Experience of Stuttering; the OASES (Yaruss & Quesal, 2004, 2016). The instrument aims at assessing and quantifying the impact of stuttering on different aspects of the speaker's life, as reported by the speakers themselves. The instrument is based on the International Classification of Functioning, Disability and Health, known as the ICF framework (World Health Organization, 2001). The ICF framework defines not only the symptoms of an impaired function – in this case, dysfluent speech – but also what difficulties an impaired bodily function are associated with, in terms of ability to perform daily activities

and participate fully in life. The framework also includes how personal and environmental factors interact with the other domains.

In the OASES, four sections are included, i) General Information, ii) Speaker's Reactions, iii) Daily Communication and iv) Quality of Life, which taken together give a measure of Overall Impact of stuttering. The instrument is adapted for three age groups; schoolchildren from 7 to 12 years (OASES-S; 60 items), teenagers from 13 to 17 years (OASES-T; 80 items), and adults from 18 years and above (OASES-A; 100 items). The items are scored by the respondent on a 5-point scale, with higher points indicating more negative impact or experience. For each individual section and for all four sections collectively, raw points are calculated and converted into impact scores, ranging from 1 – 5. The impact scores that are obtained correspond to impact ratings ranging from *mild* to *severe* (Table 4) (Yaruss & Quesal, 2016).

Table 4. Impact scores in OASES and corresponding impact ratings

<b>Impact score</b>	<b>Impact rating</b>
1.00 – 1.49	Mild
1.50 – 2.24	Mild/Moderate
2.25 – 2.99	Moderate
3.00 – 3.74	Moderate/Severe
3.75 – 5.00	Severe

Impact scores, impacts ratings, and interpretive descriptions for the three versions of the OASES (i.e., Schoolchildren, Teenagers, and Adults) are the same, which allows for following the development of the impact of stuttering from young years to older ages.

The response form of the three versions of the OASES have been translated into Swedish and tested for reliability and validity (Lindström et al., 2020). The reliability was found to be strong, with Cronbach's  $\alpha$  coefficients for impact scores higher than .80 for all sections in all age-versions, except for Section 1 in the version for adolescent ( $\alpha=.54$ ) and schoolchildren ( $\alpha=.29$ ). Internal consistency reliabilities of the scores for each section were higher than the correlation between sections, supporting construct validity (Lindström et al., 2020).

#### 5.2.1.2 Self-reported stuttering severity

A subjective rating of stuttering severity in everyday situations was performed in Study II. To get a measure of stuttering severity as perceived by the speaker themselves, a protocol was constructed with inspiration from protocols referred to in research where subjective stuttering severity is investigated (see for example Huinck & Rietveld, 2007; Karimi et al., 2014; O'Brian et al., 2004).

The protocol consists of seven aspects of everyday communicative situations: (1) Talking to family, (2) Talking to friends, (3) Talking at work/school, (4) Talking with unfamiliar people, (5) Talking under pressure, (6) Introducing oneself, and (7) Talking in general. The protocol uses a six-point rating scale where 0 corresponds to "No stuttering" and 5 to "Very severe

stuttering” (Table 5). The average score of the seven scales constituted the measure of self-rated stuttering severity.

Table 5. Self-reported stuttering severity; points and corresponding ratings.

Points	Severity rating
0	No stuttering
1	Very mild
2	Mild
3	Moderate
4	Severe
5	Very severe

One of the aims in Study II was to investigate the correspondence between the speaker’s self-perception of stuttering severity in a speech sample (a video recorded conversation) with an assessment of stuttering severity made by SLPs. To allow for this, an additional scale was included in the protocol: “How much stuttering took place in your speech during the video recording?”. Responses were rated on the same six-point scale as described above (Table 5).

#### 5.2.1.3 SLPs assessment of stuttering severity

The SLPs’ assessment of overt stuttering severity in Study II was based on components in the Stuttering Severity Instrument Third Edition (SSI-3, Riley, 1994; Swedish version by Carlsson & Åberg, 2015). SSI-3 is a clinical assessment tool used to obtain an objective measure of stuttering severity. The instrument measures stuttering severity in three areas: Stuttering frequency (percentage of stuttered syllables), duration of stuttered moments (the mean duration time of the three longest stuttering events), and concomitant physical movements (clinical judgments of e.g., distracting sounds, facial grimaces, head movements, using a scale of 0 = none to 5 = severe and painful looking). The three subscores are summed to provide a total score, and the total score is converted to severity ratings ranging from *no stuttering* to *very severe*.

A spontaneous speech sample and a text reading component are mandatory for assessment with the SSI-3. However, in order for the measurements to be consistent with Self-reported stuttering severity (“How much stuttering took place in your speech during the video recording?”, see 4.2.1.2.), the text reading part was omitted. Consequently, the total scores from the three subscores were not converted into a severity rating; instead, participants' relative severity of stuttering was ranked based on the raw total score.

### 5.2.2 Assessment of social anxiety

The Liebowitz’ social anxiety scale - Self Rating (LSAS-SR, Liebowitz, 1987) is a self-report questionnaire measuring fear and avoidance in 24 different presumptive social situations, of which 13 are performance situations and 11 are interaction situations. The response format is a 4-point scale, and the results can be derived both for the LSAS-SR as a whole and for the subscales fear and avoidance individually. LSAS-SR is a reliable measure of social phobia

with high internal consistency (Cronbach's  $\alpha = .95$ ) as well as high discriminant and convergent validity (Heimberg et al., 1999). The questionnaire has been translated into Swedish and is free of use (for information see <https://www.fbanken.se/form/34/liebowitz-social-anxiety-scale-self-report>). The LSAS-SR was used in Study IV.

### 5.2.3 Attitude to speech and communication

To allow for a comparison between teenage PWS and typically fluent peers (Study I), an adapted version of the Swedish version of the OASES-T was created; the Attitude to Speech and Communication, ASC (Dimitrakopoulos & Granlund, 2018). The ASC focuses on attitudes to speech and communication, with "speech" defined as the dynamics between phonation, articulation and (dis-)fluency. Items in the OASES-T-S that are related directly to the experience of stuttering are in the ASC substituted with items of a similar nature but targeting the experience of speech in general (the word "stuttering" substituted with "speaking ability"). The ASC consists of 67 items, thus 13 items less than in the original version. Most of the items in the OASES that do not have analogous items in the ASC come from the first section in the OASES and are items that focus on knowledge of stuttering and thus not adaptable for people who do not stutter (e.g., item no 7: *How much do you know about factors that make people stutter less or more often?*).

The items in the ASC are divided into four sections in accordance with the OASES-T: i) General Information, ii) Speaker's Reactions, iii) Daily Communication and iv) Quality of Life. ASC use the same scoring procedures, response scales, and Impact ratings as OASES-T (Table 5).

### 5.2.4 Interview guide for in-depth interviews

The data collection in Study IV consisted of in-depth interviews conducted by the author. An interview guide was used in which areas of interest were grouped to meet the purpose of the study. The areas were: (1) Perception of stuttering, speech, and communication, (2) Reasons for covering stuttering, (3) Strategies to cover stuttering efficiently, and (4) Consequences on different aspects of life due to covering strategies. Data collected also included OASES-A and LSAS-SR.

The sets of questions in the interview guide were asked to all participants, however, they were given the opportunity to decide for themselves how to interpret the question. Thus, elaborations around the questions developed freely and dynamically. Where appropriate, follow-up questions were asked, e.g., "...could you elaborate more on...", "...give examples of..." and "...tell me more about...". During each interview, the interviewer repeatedly summarised the participants' statements to validate their account, and to give the participants the opportunity to elaborate, clarify and/or comment on their reasoning.

### 5.2.5 Speech samples and audio/video recordings

To enable an objective assessment of stuttering severity with an adapted version of SSI-3 (Riley, 1994, see section 4.2.1.3.) a 5-minutes video- and audio recorded sample of spontaneous speech was collected from all individuals participating in Study II. The speech sample was elicited in a semi-structured conversation with a test leader, where the instructions were to talk about a neutral topic, such as an interest, an activity, or a holiday memory. If necessary, the test leader prompted in the conversation with short, open-ended questions, i.e. "Can you tell me a little more about...?" or "How was it when you...?". The total number of syllables in all speech samples ranged from 357–1498.

The conversation was digitally recorded with a Canon Legria HFR806 camcorder for all participants but one, who was recorded with a Sony Handycam HDR-CX250E camcorder. An audio recording of the conversation was also made, using a Tascam DR-22WL, to ensure sufficient sound quality. The video recordings were shot from the front with the image showing a participant's face and torso.

In Study IV, six of the interviews were conducted and video recorded on location, digitally with a Canon Legria HFR806 video camera. Five interviews were conducted digitally via video conferencing and recorded with the software's recording functionalities. To ensure adequate sound quality, the interviews were recorded using a Tascam DR-22WL.

## 5.3 PROCEDURES

### 5.3.1 Study I

This study included two groups of teenagers in the age 13 – 17 years; (1) teenage females and males who stutter (TWS), and (2) teenagers with no stuttering (TWNS). Data consisted of response forms from the OASES-T that were filled out by the TWS, and of the ASC, filled out by TWNS.

TWS: Two samples of participants answering the OASES-T from previous studies were used. One sample been collected for the adaptation of OASES-T to Swedish conditions (Lindström et al., 2020), and the other in connection with a degree project in which the correlation between self-esteem and stuttering impact in TWS was explored (Kennedy & Malmfält, 2016). As the two datasets were unbalanced in regard to sex ratio, additional data was collected specifically for this study (29 participants), resulting in an overall sex ratio of 1.2:1.

Participants were recruited via SLP clinics in different parts of Sweden and via the national stuttering association (*Stanningsförbundet*). Inclusion criteria for participation was: (1) 13:0 – 17:11 years of age, (2) functional understanding of spoken/written Swedish, and (3) diagnosed with stuttering by an SLP. In total, 26 female (46%) and 30 male (30%) TWS



completed the OASES-T. All participants, including those recruited through the national stuttering association, reported having contact with an SLP.

TWNS: The distribution of ASC was performed via schools in Sweden. Of forty-three schools that were contacted with overall information of the study, eight agreed to participate. The schools were geographically spread over five counties in Sweden, representing various socio-economic strata.

Principals, teachers, students, and their caregivers received detailed information and on how to administer the questionnaire, and written instructions were also included on the cover page of the questionnaire. The participants completed the questionnaire independently during class in the presence of the teacher, in case any clarification was needed. The approximate time required to complete the questionnaire was 15 – 20 minutes.

ASC responses from 126 female and 107 male TWNS in the ages 13 – 17 years (8th to 12th grade) were included in the study. The original number of responding TWNS was 251, but eighteen participants were excluded, either because they had left more than two items per sub-scale unanswered or stated non-binary/other for sex (the latter being too few to analyse as a separate category).

There were no statistically significant differences in age or frequency of females and males between TWS and TWNS, as shown with a t-test ( $t_{77.48} = -0.63, p = .53$ ) and  $\chi^2$ -test ((df = 1, N = 289) = 0.77,  $p = .38$ ).

### 5.3.2 Study II

The participants in Study II were females and males who stutter, 13 – 25 years old. The participants were recruited via three different channels: (1) the national stuttering association (*Stamningsförbundet*) annual summer camp for young PWS, (2) SLPs at three different clinics in Stockholm, and (3) the local stuttering association in Stockholm (*Stockholms Stamningsförening*). The primary source of recruitment was the summer camp, where 22 participants, aged 13-25, expressed an interest in participating in the study. As the sample was relatively small it was decided to expand the recruitment (however before compiling or analysing the data). This resulted in 4 additional participants being recruited via Facebook pages created by the local stuttering association in Stockholm and 12 participants being recruited by SLPs at three different clinics in Stockholm.

The participants completed the age-appropriate version of the OASES and Self-reported stuttering severity (see section 4.2.1.2). Thereafter, a five-minute video and audio recording of each participant in conversation with a test leader was conducted. When the conversation was terminated, the participants were asked to rate stuttering severity using an additional scale in the Self-reported stuttering severity protocol that read: “How much stuttering took place in your speech during the video recording?”.

Data collection and recordings with participants recruited from channel (1), i.e., the summer camp, was held in a separate room on the site of the camp. Data collection and recordings of conversations with participants from channel (2) and (3) were carried out in an SLP clinic in a hospital setting.

Three SLPs with expertise in stuttering and with 20, 30 and 35 years of clinical experience of stuttering, conducted the assessment of stuttering severity in the speech samples, using parts of the SSI-3 (Riley, 1994). The assessments of each speech sample were made individually by the SLPs, and the assessment forms were returned to the first author of the study (myself). Prior to the SLPs assessments, a narrow orthographical transcription of the speech samples had been made by the first and second author of the study. The transcriptions were provided to the SLPs to facilitate the assessment of stuttering frequency.

There was a high agreement between the SLPs in their assessment of stuttering severity. The inter-rater reliability value obtained between the total scores in the SSI-3 was .94 (95% CI [.91, .96]), measured with ICC; 2,1 (Weir, 2005).

### **5.3.3 Study III**

Data in Study III consisted of age-appropriate response forms of the OASES, filled out by schoolchildren, teenagers, and adults (OASES-S, OASES-T, OASES-A; Lindström et al., 2020). Data was pooled from respondents recruited in previous projects (74 from Lindström et al., 2020; 29 from Samson et al., 2021) and new respondents recruited specifically for this project. The 59 new individuals were recruited via two channels: SLPs in clinics, and the national stuttering association (*Stamningsförbundet*). Participants recruited from SLP clinics came from cities with various population sizes, located in different parts of Sweden. The participants were given verbal and written information about the study by their SLP in connection to stuttering treatment and completed the OASES questionnaire at the clinic. The participants recruited by the national stuttering association also came from different areas of the country. They received an invitation to participate and written information together with the OASES questionnaire by post, completed the form at their leisure and returned it by post.

### **5.3.4 Study IV**

The participants in Study IV, which was a qualitative study, were recruited from SLPs in different clinics in Sweden, self-help groups and from the national stuttering association (*Stamningsförbundet*). Those who expressed an interest in participating in the study received an information letter with details of how the study would be conducted, how data would be handled and research ethics. Thereafter, agreement of date and time of the interview was arranged with the test leader. All communication to this point was undertaken by e-mail.

When date and time for the interview were set, the participant received the consent form and required questionnaires by mail, together with a stamped envelope. Interviews were only conducted once all documents were returned to the test leader.

The interviews were conducted using an interview guide with topics based on the research aims of the study. The interviews ranged from 29 min to 69 min in duration, with a mean duration time of 45 min. Six of the eleven interviews were performed face to face in a venue that was convenient for the participant, and the remaining five via video conferencing. The change from on-site interviews to video conferencing was due to travel restrictions imposed by the Covid-19 pandemic.

## 5.4 ANALYSIS

### 5.4.1 Statistical analyses

In all four studies, demographic characteristics, such as age and sex, were summarized with descriptive statistics. In Study IV, descriptive variables consisted of a measure of impact of stuttering (OASES) and social anxiety (LSAS-SR), in addition to age and sex.

A summary of statistical methods used in Studies I – III is presented in Table 6.

Table 6. Overview of statistical methods used in the thesis.

		Study I	Study II	Study III
<b>Boxplot</b>	A visual representation of the quartiles in a sample, allowing the comparisons of quartiles, median, minimum, minimum, and maximum values	x	x	
<b>Common language effect size</b>	The probability that a randomly selected score from one sample is greater than a randomly selected score from another sample	x		
<b>Linear regression model</b>	A model that predicts the value of a variable (dependent variable) based on the value of another variable (independent variable) in a linear fashion.	x		
<b>Hedge's g</b>	Effect size, assessing how many standard deviations groups differ from each other		x	
<b>Spearman's rank-order correlations</b>	Measure of the strength of association (i.e., rank-order correlation) between two variables (nonparametric)		x	
<b>Polynomial regression model</b>	A model that predicts the value of a variable (dependent variable) based on the value of another variable (independent variable) in a polynomial fashion (e.g., curves).			x
<b>Mahalanobis Distance</b>	A multivariate distance metric between an individual and the central tendency of the multidimensional distribution, analogous to a multidimensional z-value.			x
<b>Akaike Information Criterion (AIC)</b>	An estimator of how well statistical models are at predicting future data and allows model comparisons that punishes unnecessary model complexity and overfitting.			x

Statistical analyses in Study I were performed using the Statistical Package for the Social Sciences (SPSS) (version 26.0, 2018). Figures were made in R (R Core Team, 2017). In Studies II and III, data analyses were carried out in R (R Core Team, 2017).

#### 5.4.1.1 *Study I*

To enable comparisons between female and male TWN and TWNS, the distribution of impact scores was presented in separate boxplots for the four groups. A boxplot is a visual representation of the quartiles in a sample and can, for example, be used to judge the distribution form of the sample. Superimposed on the boxplots were the sample means and 95% confidence intervals (CIs) for those means. Non-overlapping CIs around the means were interpreted as the means being statistically significantly different from each other (at  $\alpha = 5\%$  for a 95% CI). To statistically test if the sex difference was larger among TWS than among TWNS, we used a linear regression model in which TWN vs TWNS, and female vs male were entered as separately dummy coded factors and from which corresponding CIs around the two effects and the interaction effect were calculated.

The non-parametric Common language effect size (CL) was used to analyse the probability that a female or male speaker would report a more severe impact on a specific OASES item. Items for which the CL was greater than .70 was highlighted and reported - that is, items for which there was a 70% probability that a randomly selected female would report a higher value than a randomly selected male was highlighted, this was based on a CL greater than .67 corresponded to being statistically significant at an  $\alpha$  of .05.

#### 5.4.1.2 *Study II*

In this study, the distribution of median, minimum, and maximum OASES impact scores for females and males were illustrated in separate boxplots. The females' mean OASES impact score was compared to the males' mean OASES impact score by focusing on the CIs around the mean, and by calculating the effect size measure Hedge's  $g$ . Also, the relative risk that the participants were moderately or severely affected by their stuttering was calculated.

The correlation between the three measures of stuttering severity (self-rated stuttering severity in everyday situations, self-rated stuttering severity in the video recorded speech sample, and stuttering severity as assessed by the SPLs) was calculated using Spearman's rank-order correlations. Correlations were calculated and reported both for the group as a whole and for females and males separately.

The inferential statistics we focused on were the CIs. A CI should be interpreted as showing the range of parameter values most compatible with the data under the given statistical model.

#### 5.4.1.3 *Study III*

Study III focused on the relationship between OASES Impact scores, age, and gender, while controlling for speech fluency. It was hypothesized that the impact of stuttering would increase between childhood and young adulthood, to subsequently decrease. In addition, it was hypothesized that the impact of stuttering on females would be more severe than it was for males.

To test the first hypothesis, the relationship between OASES Impact score and age was modelled in a non-linear way using a polynomial of the second degree. We also tested other non-linear relationships such as a polynomial of the third degree or a logarithmic relationship, but the second-degree polynomial model clearly fitted the data best. However, to test the second hypothesis, an interaction term between age and sex was also required. This entailed fitting a relatively complex model to the data, which in turn implies a greater risk of overfitting the data. Therefore, the model fitting was made in a stepwise manner, beginning with a simple linear model, and progressively comparing more complex models. The model comparison was made using the Akaike Information Criterion (AIC) which allows for comparing fit across models while penalizing unnecessary model complexity. The polynomial model including an interaction term between age and sex, which allowed for potential differences between females' and males' age-related curves, turned out to be the best fit of the data and was selected. To control for speech fluency, an additional but similar model was applied, with speech fluency included as a predictor. This model made it possible to estimate how age and sex related to OASES Impact scores when adjusted for potential sex differences in self-reported speech fluency.

Outlier detection was made with the Mahalanobis Distance approach. This is analogous to detecting outliers using  $z$ -values but in a multi-dimensional context. When identifying outliers, we considered their Mahalanobis distance on OASES Impact score, age and sex.

## **5.4.2 Qualitative content analysis**

### *5.4.2.1 Study IV*

In Study IV, the approach was to interview young women who experience a problem with stuttering but where symptoms characteristic of stuttering are not perceived by others, due to their having developed skills in covering the symptoms (also known as covert stuttering).

Qualitative content analysis was used to structure, condense, and interpret data (Hsieh & Shannon, 2005; Lindgren et al., 2020). The first author verbatim transcribed the interviews. Three of the authors of the study participated in the data analysis. The analysis commenced with a read-through of the transcripts where notes were taken, individually, of key passages in the transcripts. This was followed by a discussion between the authors. The next step comprised identification and selection of meaning units of analysis. To ensure consistency of interpretation between the authors, meaning units were selected jointly from 30% of the interviews. In the remaining interviews, meaning units were selected by the first author alone. The three authors then discussed appropriate coding labels of the meaning units and the relationship between the different codes. Finally, similar codes were compiled into subcategories and themes, based on consensus.

## **5.5 ETHICAL CONSIDERATIONS**

In the initial phase of the doctoral studies, an ethical application, and two supplements, for the four studies in the research plan were submitted to the Regional Ethical Review Board in Stockholm. The application was approved in September 2016, project 2016/1527-31, and the two additional supplements in May 2017 (project 2017/854-32) and January 2018 (project 2017/2521-32).

A discussion with the examination board at the half-time seminar led to some changes in the research plan and consequently to the design of the studies not yet conducted, and thus, to a new ethical application. This was approved by the Swedish Ethical Review Authority in July 2019, project 2019-03258.

In all studies, written information was provided to all participants. In the information letter for Study IV, in which participants' personal experiences of stuttering were analysed through in-depth interviews, extra emphasis was placed on voluntariness and confidentiality.

Informed consent was obtained from the participants (all ages) and from the caregivers of participants younger than 16 years. No compensation for participation was offered.





## 6 RESULTS

The main findings of the four studies in this thesis are summarized in this section.

### 6.1 STUDY I

#### 6.1.1 Comparisons between TWS and TWNS

As a group, TWS held a more negative attitude towards communication than did TWNS, as can be seen in Figure 3. TWS had higher impact scores than TWNS; a standardised effect size difference of Hedges'  $g = 1.06$ . The means of the Overall impact score in OASES-T-S and in ASC differed statistically significantly at  $\alpha = 5\%$  (i.e., the 95% CIs around the means were non-overlapping between the groups). However, it is worth noting that teenagers in general tend to report some degree of negative reactions to speaking ability; 12% of the TWNS had impact scores that fell into the impact rating category moderate and 6% into the category moderate – severe.

Note that we focused our analyses on the impact scores in sections II - IV (sum of the scores of the items in sections II - IV divided by the number of items in sections II - IV). The reason for omitting section I from the analysis between TWS and TWNS was because this section concerns speakers' general information and knowledge about speaking and stuttering which the TWNS directed questionnaire did not include.

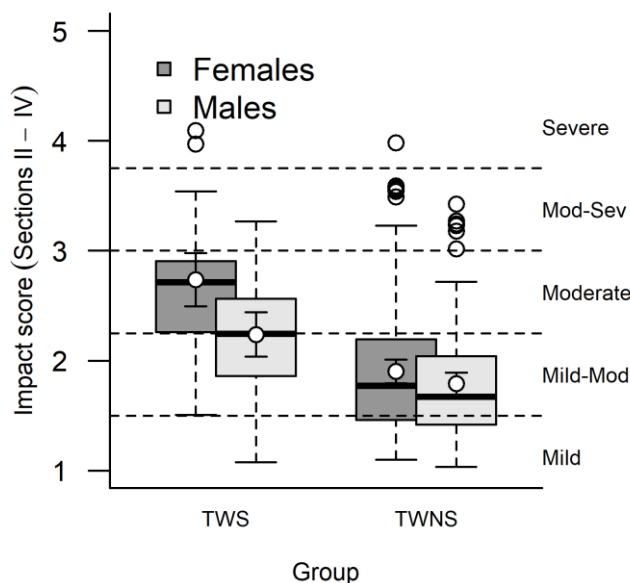


Figure 3. Boxplots over impact scores sections II - IV (the mean score of the items in sections II – IV) separated for female and male teenagers who stutter (TWS), and teenagers with no stutter (TWNS). Horizontal, dashed lines illustrate demarcations for the different impact ratings (mild to severe) in the OASES and the ASC. Point estimates of the means and corresponding 95% confidence intervals are superimposed on the boxplots in white. This figure was published in *Journal of Fluency Disorders*, 67; by Samson, I., Lindström, E., Sand, A., Herlitz, A., and Schalling, E. *Larger reported impact of stuttering in teenage females, compared to males – A comparison of teenagers' result on Overall Assessment of the Speaker's Experience of Stuttering (OASES)*, 105822–105822. Copyright © Elsevier (2021).

### **6.1.2 Comparisons between female and male TWS**

Female TWS reported a more negative experience of their speech impairment than male TWS, on an average 0.5 higher impact scores (Hedges'  $g = 0.87$ ). This was also reflected in the larger proportion of ratings in the "Moderate-Severe" and "Severe" impairment bands among female TWS (23%) than among male TWS (10% in the "Moderate-Severe" band). The sex difference among females and males in the group of TWNS was not as pronounced (Hedges'  $g = 0.19$ ).

### **6.1.3 Specific differences between female and male TWS**

The exploratory item analysis based on CL disclosed that females were more negatively impacted by their stuttering in situations involving communicating in school settings and social situations, than were males. Females were also emotionally more affected by their stuttering than males, as they scored higher, i.e., more negatively, on several items in the section Speaker's Reactions (feelings of shame, embarrassment, or isolation due to stuttering). Moreover, the females' ratings on items targeting communicative interaction revealed that they had a stronger tendency than males to withdraw from communication and let other people talk for them.

We also compared females' and males' responses to the item "How often can you speak fluently (without stuttering?)" to get an indication of whether the sex difference in impact scores was driven by a difference in severity/level of manifest stuttering symptoms. Here, the CL was 0.52, i.e., a 52% probability that a randomly selected woman reported more severe overt stuttering symptoms than a man (50% being the chance).

## **6.2 STUDY II**

### **6.2.1 Sex differences in OASES impact scores**

In this study, 15 of the 19 females (79%) reported higher impact scores than the 50<sup>th</sup> percentile among the males. The standardised mean difference, Hedges  $g$ , was 0.33, however, the means of both groups were slightly skewed away from their respective median values (median score for females = 2.69, median score for males = 2.22) (see Figure 4).

Females in our sample were at somewhat greater risk of being more strongly impacted than were the males, as 79% of the 19 females fell in the "Moderate", and "Moderate-Severe" impairment band in the OASES, while 47% of the 19 males were found in the in "Moderate", "Moderate-Severe" and "Severe" impairment bands (a relative risk difference of 1.67 (95% CI [0.98, 2.83])).

Thus, the overall trend that could be discerned from the collected data was that females were more negatively affected by their stuttering than males, with a 1.67 higher risk of being in the moderate or more severe impact ratings than their male counterparts.

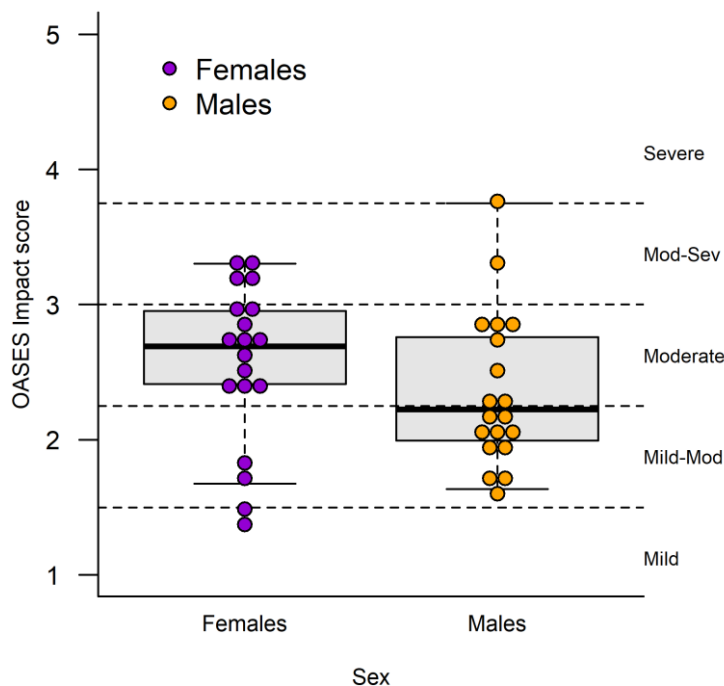


Figure 4. Boxplots of total impact scores separated for females (n = 19) and males (n = 19) who stutter. Superimposed on the boxplots are each individual female (violet) and male (orange). Horizontal dashed lines illustrate demarcations for the different impact ratings (mild to severe) in the OASES.

### 6.2.2 Relationship between ratings of stuttering severity

The participants' self-rating of stuttering severity in the video-recorded speech sample and the SLP's assessment of stuttering severity correlated quite highly, suggesting that the speaker and SLPs somewhat agree when rating the same speaking situation. However, the participants' self-rating of stuttering severity in everyday situations corresponded to a weaker degree with both their rating of stuttering severity in the video-recorded speech sample and the SLPs' assessment, suggesting that the rating of stuttering severity in everyday life may not be strongly related to stuttering in a brief conversation.

When analysed by sex, all correlations were weaker for females than for males. In particular, the females' perception of their stuttering was less consistent with SLP assessments than the correlation between the males' perceptions and the SLP assessments. Some females who were rated as having no stuttering by the SLPs rated themselves as having quite severe stuttering both in the video recording and in everyday situations. However, the disagreement between SLPs and females who stutter was not systematic as some females rated their stuttering as less severe than the SLPs did.

## 6.3 STUDY III

### 6.3.1 OASES and impact score as a function of age and sex

For both sexes, adolescents were more negatively impacted by their stuttering than children or young adults.

The sex-disaggregated analysis across ages showed that females were more negatively affected by their stuttering than males, with a mean difference in impact scores of Hedge's  $g$  of 0.57. The age-specific analysis of females and males showed that the sex difference was the largest among adolescents (a mean difference in impact scores of Hedge's  $g = 0.67$ ), whereas among children and young adults the difference was somewhat smaller (Hedge's  $g = 0.34$  and  $= 0.55$ , respectively). It also emerged that adolescent females were on average more impacted by their stuttering than younger and older female individuals, and more impacted by their stuttering than adolescent males (Figure 5).

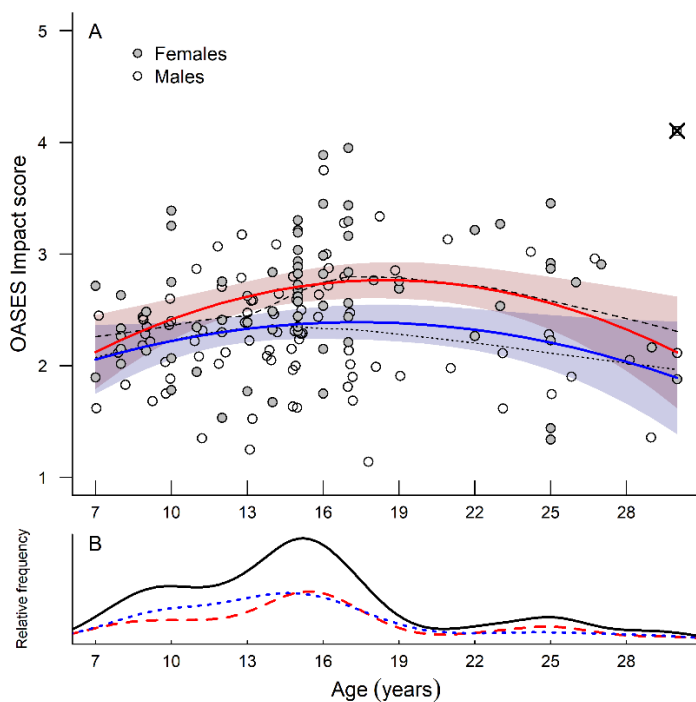


Figure 5. The top panel illustrates the relationship between OASES impact score (y-axis) and age (x-axis). Each individual is shown as a circle (gray background for females and white background for males). One outlier (a 30-year-old-man) is illustrated with a crossed over circle; this participant has been excluded from all results presented. The two solid curves are the average trends for females (red) and males (blue). The red and blue shaded areas are the 95% CIs around each curve. The dashed and dotted black lines are locally weighted smoothed lines of the data; note that the model closely matches the data.

The bottom panel are Kernel Density Plots illustrating the relative frequency of each year of age for the whole sample (black line), and for females (red) and males (blue). Note that females and males were similarly represented at each year of age.

When examining the relative frequency of total impact score and impact ratings in the OASES for each age and sex group it turned out that female adolescents had the highest risk of falling into the “Moderate”, “Moderate-Severe”, and “Severe” impairment band. The proportion of females falling in these bands was 84%, while the proportion of males falling in the corresponding bands was 59%. Expressed differently, the adolescent females had a 1.4 (95% CI [1.06, 1.88]) greater risk than age matched males of reporting difficulties in communicating in different situations, having negative affective reactions to stuttering and a negative impact on quality of life.

### 6.3.2 Accounting for self-reported speech fluency

To investigate the extent to which the amount of self-reported speech fluency affected the experience of stuttering, the first item in the OASES was used as an indicator: “How often can you speak fluently (without stuttering)?”. A relation was found between the responses of the item and total impact score, such that each increase in the response to the item implied in an increase in the OASES Impact score of 0.26 (95% CI [.15, .37]). However, the relationship between OASES Impact score, age and sex depicted in Figure 5 remained rather constant when accounting for self-reported speech fluency.

## 6.4 STUDY IV

Three main themes were identified in the analysis: (i) Personal aspects, (ii) Stuttering as a phenomenon, (iii) Managing stuttering. Nine subordinate thematic patterns were extracted, describing common elements in the women's accounts of their experience of stuttering (Table 7).

Table 7. Themes and sub-themes

Theme	Sub-theme
PERSONAL ASPECTS	Impact on personal development Emotions Perception of self Female perspective
STUTTERING AS A PHENOMENON	Beliefs about how others view stuttering Description of the act of stuttering
MANAGING STUTTERING	Coping strategies (Avoidance strategies) Reasons/motivations for covering Openness/Insights

Consistently for all women, a desire to fit in and not fall outside the boundaries of what might be perceived as "normal", was a clear motive for covering their stuttering. The women described that the coping strategy required constant observation and careful planning, which resulted in stuttering largely coming to control their everyday life and influencing their life choices. The development of the women's self-image and self-esteem had been strongly negatively affected, resulting in social anxiety, or generalized social anxiety, as was evident from the LSAS-SR results. Furthermore, the women expressed a particular vulnerability of being a woman who stutter, partly due to society's prevailing norms about the way women are expected to behave and communicate, and a lack of female role models who stutter openly.







## 7 DISCUSSION

This thesis examined stuttering in young females and males and sex differences in the impact of stuttering on different aspects of life. The impact of stuttering was also related to the age of the speaker. In addition, females' and males' strategy to cope with stuttering when communicating was examined, as well as the impact of the chosen strategy on quality of life. Attitudes towards communication in young PWS were compared with attitudes in young people with typically fluent speech. Moreover, the correspondence between a subjective estimate and an objective assessment of stuttering severity was examined, for females and males separately.

### 7.1 EXPERIENCE OF STUTTERING AS A FUNCTION OF SEX

The most important finding from the first three studies was that young females who stutter report that stuttering has a more negative overall impact on them, compared to young males. Using the OASES self-assessment questionnaire as the primary data source, which encompasses the entire experience of stuttering from the speaker's perspective, it was possible to gain an understanding of how, and in which areas, the experience of stuttering impact differed between the sexes. The results of the cross-sectional studies (Studies I – III) were based on a relatively large dataset, evenly distributed between females and males in all three studies.

The picture that emerged from the item analysis was that females, to a greater extent than males, considered stuttering to have a negative impact in school settings or at work, and in social situations that require verbal communication. Moreover, the females reported that stuttering had a more negative affective impact than it did for the males. This was manifested in feelings of shame, loneliness, and isolation. Furthermore, the females showed a lower level of confidence in their speech as they, more often than the males, reported that they let someone else speak for them and that they avoided saying what they wanted to say, due to stuttering. The sex difference in attitudes to speech in teenagers in general was not pronounced, thus, the sex difference in the impact of stuttering should not be attributed to a presumption that teenage females in general are more apprehensive to communication than males. The results of Study IV showed that young women's experiences of the stereotypical social view of what characterizes a PWS had led them to use a range of strategies in order to be seen as 'normal', i.e., typically fluent. Their main incentives were to achieve the same privileges and maintain what they considered prestigious in a 'normal' social profile.

As stated in the introduction, stuttering is associated with stereotypical beliefs, prejudice, negative reactions from listeners, and public stigma. Self-stigma is what stigmatized people do to themselves by internalizing stereotypes, prejudices, and discrimination that they face from the public (Corrigan et al., 2009). Research examining stigma associated with stuttering and how it relates to sex, have concluded that female PWS are perceived more negatively by

listeners than male PWS (Byrd et al., 2017; Croft & Byrd, 2021). The explanation for the differences in listeners' attitudes is attributed to the double bias inherent in the identity of being both female and PWS (Croft & Byrd, 2021). The dual bias identity of being both a woman and a PWS (Croft & Byrd, 2021). The results of the interview study with nine women who stutter by Nang et al. (2018) can also be understood in terms of dual stigma identity. Here, stuttering was found to have a pervasive impact on the women's relationships, career opportunities and self-image, thus, the women's identity was intimately linked to their experience of stuttering. The women's experience of themselves as a person who stutters was interpreted as 'gendered', as the integration of identity and stuttering experiences was seen as a fusion of being a both woman and a person who stutters (Nang et al., 2018). In a similar way, the results of the present interview study with 11 women who stutter (Study IV), showed that the experience of stuttering had been integrated in a complex way into virtually all aspects of the women's lives; socially, emotionally, developmentally, and academically, and even implicated in areas such as finances (income) and physical health. Most apparent was the negative impact of stuttering on identity development and self-image. Like the reasoning in the Nang et al. (2018) study, stuttering appeared to be closely linked to gender, given that gender expression, in this case femininity, is largely manifested through the way in which women communicate and how they are expected to behave.

Feelings of shame, loneliness and isolation were reported to be more strongly experienced by females than males. Shame was also a recurring concept in the women's narratives in Study IV, and the emotion that emerged as most crucial for choice of coping strategy (covering their stuttering). Shame and guilt are self-conscious emotions that are more commonly found in women than in men (Else-Quest et al., 2012). Shame is also associated with greater susceptibility to becoming depressed or experiencing harmful levels of stress and anxiety (Matos et al., 2013). Numerous examples of how stuttering elicited high levels of anxiety were found in the data of Study IV. This was also reflected in the results of the measure of social phobia, LSAS-SR, suggesting generalized social phobia or social phobia in all participants except one.

Communication attitude, psychosocial health and self-esteem are variables that have been linked to the impact of stuttering (Adriaenssens et al., 2015; Carter et al., 2017; Iverach et al., 2017; Tichenor & Yaruss, 2020). These variables have been the subject of extensive empirical studies in the general population, and it has been concluded that sex and age have a moderating effect (Kling et al., 1999; Robins et al., 2002; Salk et al., 2017). For example, the development of depression is twice as common in females than in males, a difference that becomes apparent by age 12. Factors attributed to why this difference occur are biological (genetics), individual (e.g., early puberty with increased risk of both internalizing and externalizing problems, objectified body consciousness, ruminations), interpersonal (e.g., sexual harassment from peers), cultural and structural (gender norms) (Hyde & Mezulis, 2020). It is conceivable that analogous factors apply to the difference in females' and males' experience of stuttering.

Psychological research shows that self-esteem is at its lowest in adolescence and that females tend to have lower self-esteem than males (Bleidorn et al., 2016; Moksnes et al. 2010). The pronounced sex difference that we found specifically for TWS in our studies may be related to these findings. It has also been observed that adolescent females have considerably greater concerns and about achieving school assignments and demands at school than age-matched males (West & Sweeting, 2003). The results of our studies are concurrent: adolescent females with stuttering consider their speech impairment to be a greater barrier not only to daily communication but also to school performance, compared to males.

Sex and gender norms affect all individuals, not just females. A study by Butler (2014) detailed the experience of being a male PWS. It appeared that the males' experiences of 'speaking fluently' were linked to masculinity and gaining respect at work. The stereotypical view that stuttering is contrary to what is considered masculine verbal communication was suggested to be at the root of male's experiences (Butler, 2014). Research also shows that males are more likely than females to hide how they really feel, which again can be attributed to gender norms (Rose et al., 2012; Messenger et al., 2015). It may be that males may struggle with their stuttering as much as females but are less likely to report it.

## **7.2 EXPERIENCE OF STUTTERING AS A FUNCTION OF AGE**

In line with previous research (Bleek et al., 2012; Boyce et al., 2022; Briley et al., 2021; Carter et al., 2017; Freud et al., 2017), age was found to be an important factor in the experience of stuttering. Adolescents who stutter perceived the impact of stuttering to be more negative, compared to younger children and adults who stutter. However, what could further be concluded from our studies (Study III), was that adolescent females were particularly negatively affected by their stuttering, both in comparison to younger and older females, and to males of all ages. The data in Study III was comparatively large, spanning a wide age range, from early school years through adolescence and into young adulthood. Few studies in the field of stuttering have been conducted with a dataset of similar size, thus the analysis of the impact of age on OASES Impact score is based on a relatively robust sample, however future studies with larger and longitudinal samples are needed to test the generalizability of this finding. Moreover, the data derived from an equal number of female and male PWS, which is unique for research studies in the field of stuttering as it consistently reflects the prevalence of stuttering between the sexes (boys/men are approximately 2.5 - 3 times more likely to stutter than girls/women). Thus, the analysis of sex was carried out on a comparably large data set for both sexes.

## **7.3 TAKING SPEECH FLUENCY INTO ACCOUNT**

In Studies I and III, the measure of speech fluency consisted of the participants rating on a single item in the OASES ("How often are you able to speak fluently (without stuttering)?"),

whereas in Study II both a subjective and an objective measure of the severity of stuttering were included. The results in all three studies showed that the extent of manifest stuttering behaviour (or extent of speech fluency) seemed to be at a comparable level between the sexes and was therefore unlikely to be part of the explanation to why females and males experience stuttering differently. However, measures that can be used to assess the severity of stuttering have been discussed. One reason is that the frequency of stuttering varies from day to day and from situation to situation, making it difficult to obtain a stable baseline measure (Constantino et al., 2016). It is also common for listeners (e.g., the SLPs) and speakers (the PWS) to have different perceptions of the concept of stuttering severity. This difference in perception suggests that even very limited amounts of obvious stuttering symptoms can elicit very negative emotional responses (Riley et al., 2004). In parallel, O'Brian et al. (2022) found that when PWS self-report stuttering severity, they tend to primarily consider the experience of stuttering rather than its behavioural manifestations. The authors discuss the extent to which PWS are at all aware of how their stuttering manifests behaviourally (O'Brian et al., 2022). In line with this reasoning, and previous research (Constantino et al., 2016; Tichenor & Yaruss, 2018), the results of Study II showed that the severity of stuttering as perceived by listeners (SLPs) seem to miss important aspects of stuttering that only the speaker perceives, which was particularly true for the females. Thus, in order to obtain a more comprehensive description of stuttering severity that includes the behaviours and experiences that only the speaker can account for, assessment batteries need to include self-report instruments. Although the participant sample was small in Study II, there is reason to be vigilant that sex may be a factor of importance for the accuracy of stuttering behaviour assessment.

#### **7.4 SEX AND GENDER IN HEALTH CARE – RECOGNIZING DIFFERENCES IN MEDICAL CONDITIONS BETWEEN FEMALES AND MALES**

Slowly accumulating research from the 21<sup>st</sup> century shows a number of differences between health conditions in women and men. For example; eating disorders in young men are underdiagnosed and undertreated (Strother et al., 2012), and cardiovascular drugs are found to differ in effectiveness and safety depending on sex (Rosano et al., 2015). Different processes in the immune system are involved when female and male animals develop chronic pain; a finding that will have major consequences for pain research if the same differences between females and males exist in humans (Sorge et al., 2015). Moreover, gender stereotypes seem to matter in medical assessment: physicians tend to judge men's symptoms as somatic, whereas women's symptoms more often are regarded as being psychosocial (Hamberg, et al., 2002).

Better science is a prerequisite for better health care. Research dealing with human issues such as health and illness needs to take human diversity into account as it may add perspectives of values to all people. Sex, gender and age are factors of importance, and in an increasingly globalized world, so are socio-economical standing, cultural norms, and ethnicity. These factors may have implications for how people perceive, experience and cope

with a health condition. It is central to investigate if and why health care for men, women, and gender-diverse persons may differ, and, if so, what we can do to address these gaps. A systematic and consistent integration in research of possible differences between persons due to these factors can contribute to better understanding of etiologies, progression of diseases and medical intervention (Doyal, 2003).

Although the impact of sex and gender in health is increasingly recognized as an important aspect for an enriched understanding, there are challenges to be dealt with. The interpretation and description of the concepts sex and gender, data collection procedures and re-examination and adaption of measures are vital matters that must be addressed to avoid sources of error (Smith & Koehoorn, 2016). If health is regarded as a composite of biological constitution and socioeconomic circumstances, better health for everyone will likely be the result when the effects of social norms and expectations on the health of females, males and gender-diverse persons become an integral part of the discourse (Phillips, 2005). If differences in health between women and men are identified and recognized it may have a critical impact on the prevalence of health conditions, how symptoms are perceived, accessibility to health care and response to treatment. As suggested by Scaler Scott and Boyer (2015):

“...themes that would emerge from larger samples of women should be compared to those that emerge from a parallel sample of men. As in-depth qualitative information continues to be amassed from the perspective of people who stutter, interventions and stuttering support can continue to be improved accordingly.” (p 293)

## **7.5 METHODOLOGICAL CONSIDERATIONS**

Several variables may be involved in an individual's experience of stuttering and their negative impact of stuttering, e.g., communication attitude, emotional and social wellbeing, and self-esteem (Adriaenssens et al., 2015; Carter et al., 2017; Iverach et al., 2017; Tichenor & Yaruss, 2020). A large part of the data in the cross-sectional studies I and III were secondary; pooled from already existing data sets. This limited the number of variables that could be examined. The absence of any of these variables may have affected the studies' ability to answer the research questions. For example, certain personality traits or health conditions could have been found to predict levels of negative experience of stuttering. Not only in-depth health information was missing but also demographic data that may be relevant to the perception and experience of stuttering (socio-economic status, ethnicity, cultural background, etc.). Treatment history, involvement in self-help groups, access to intervention services are additional factors that may play a role. These topics could have been explored if data had not been pooled from other datasets, as it is possible that they could have had an impact on the results.

Thus, it is not fully ensured that the sample is representative of all aspects that may be important for the research question. The sample in the four studies may be representative of people from a specific cultural background or socio-economic group but not from another, or

representative of PWS who are willing to share their experiences of stuttering but not of those who have strong negative feelings towards their stuttering and therefore would avoid taking part in this type of research.

Self-report bias is another methodological issue. Empirical research suggest that self-report scales are not appropriate instruments for obtaining information from people who tend to repress unpleasant emotions, and particularly true for self-report scales that aim to measure and describe different aspects of the self (Saeedi et al., 2020). The in-depth interviews with women who stutter (Study IV) became an important complement to the self-report scales, but a similar study involving men who stutter was lacking in this thesis project and would have broadened the picture further.

In qualitative content analysis, there must be enough data to cover significant variation. The number of participants that should be included in a qualitative study in order to achieve data saturation is a methodological issue often discussed. However, the optimal amount of data depends more on the aim of the study and the quality of the data, and not on the number of participants per se (Graneheim et al., 2017). In Study IV, the data collected from the 11 participants were substantive and rich in content and variation, however, there was a broad consensus in the views and experiences expressed in the women's narratives that data was considered sufficient. The selection of participants is another important aspect to consider, for the transferability of the results. The participants in Study IV constituted a demographically homogeneous group, with striking social, educational and ethnic similarities. A possible reason for this may have been the recruitment process that was carried out via SLPs, through self-help groups and the national stuttering association (*Stamningsförbundet*). There may be potential differences in access to or knowledge of the services available among PWS, for example depending on where in Sweden one resides. A different approach to recruitment, such as advertising the study in public places where people spend time and interact, might have yielded a different set of participants.

In studies II and III, the representation of ages was not equally dispersed along the age span, the sample size for schoolchildren and adults was decidedly smaller than the sample size for teenagers (however, at each year of age females and males were similarly represented, and females in all age-groups consistently being the most negatively affected). Moreover, because the studies were cross-sectional in design, their results gave an indication of generational, rather than developmental, patterns. Longitudinal studies with a more evenly distributed representation of ages along the age span and with a broader age range (>30 years) would therefore be needed to determine the developmental impact of stuttering across the lifespan in females and males.

Another limitation was the procedure in Studies I – III. The SLPs who recruited participants asked clients involved in therapy to complete the OASES regardless of which phase of therapy they were in. It is possible that the results would have altered if assessments had been made at the same stage of the therapy process by all participants, although we have no reason to suspect that females and males systematically were in different phases of therapy.

A methodological issue in Studies I and III was the use of a single item in the OASES as a measure of “self-reported speech-fluency”. This is an ambiguous metric given that prior literature establishes stuttering as a variable condition. Also, there are several possible interpretations of the question “How often are you able to speak fluently (without stuttering)?”. A speaker could mark this question very low since they are able to cover their stuttering well, but still stutter frequently and intensely in the absence of covering. Or the participants may have interpreted the item as asking how often they can speak without noticeable disfluencies (but with for example avoidance strategies). However, according to the results in both studies on this specific item, females and males shared the same experience as they were strikingly consistent in their ratings, whereas they were clearly inconsistent in their experience in several other matters. In addition, in Study II, we used more measures to assess the degree and extent of stuttering more thoroughly and included both subjective ratings and objective assessments. Here too, the results did not reveal any difference between the sexes; females and males were assessed as having the same degree of stuttering.





## 8 CONCLUSIONS

Many men and women who stutter find that stuttering has a negative impact and limits various aspects of their lives. However, females, compared to males,

- report that stuttering has a more negative overall impact and a more negative affective impact, manifested in feelings of shame, loneliness, and isolation.
- consider stuttering to have a more negative impact in social situations that require verbal communication.
- show a lower level of confidence in their speech as they let someone else speak for them and avoid saying what they want to say.

Teenage females who stutter is a distinctively impacted group of PWS, more impacted than their male counterparts, and younger and older females. The differences seem not to be due to differences in the severity of manifest stuttering between females and males.

The female experience of the stereotypical view of what characterizes a person who stutters risks leading them to use avoidance strategies in order to be seen as 'normal' (i.e., typically fluent).

Female PWS experience a dual bias being a woman who stutters, due to prevailing norms of how women are expected to behave and communicate, and due to society's stereotypical beliefs about stuttering.



## **9 POINTS OF PERSPECTIVE**

### **9.1 FURTHER RESEARCH**

The results of the studies in this thesis indicate that a sex difference exists in the experience of stuttering. However, there are still a number of unknowns.

- Studies I – III are of cross-sectional design. Thus, it is not possible to determine how the experience of stuttering develops in females and males. It would therefore be of interest to carry out similar studies with a longitudinal approach.
- Age and gender are not sufficient descriptors of a person. Future studies should include more in-depth health and demographic information in order to explain differences between individuals' experience of stuttering.
- The studies are conducted in a Swedish context. Considering that there are cultural differences in attitudes towards PWS (St. Louis et al., 2016), as well as cultural differences in the value of self-expression and gender equality (Inglehart et al., 2014), future studies should cross-culturally explore stuttering as a function of age and sex.
- The data in Study IV suggested that women's access to stuttering treatment varied in extent, with some of the participants having no experience of stuttering treatment at all. Investigating potential differences between the sexes in services or service delivery for PWS is therefore warranted.
- Research has shown that men in general are reluctant to disclose difficulties and problems because they fear that they will be judged as inadequate or weak (Addis & Mahalik, 2003; Tyler & Williams, 2014). Therefore, research on men's incentives to use avoidance behaviours as a coping strategy for stuttering would be of value.
- The results in Study II was based on a fairly small sample. Future studies could relate objective assessment of stuttering severity and self-reported stuttering severity with impact of stuttering in larger groups, separately for females and males for more robust comparisons to be made.

### **9.2 CLINICAL AND GENERAL IMPLICATIONS**

The results of the studies in the present thesis suggest that females who stutter during adolescence are more negatively affected by their speech than their male counterparts and more likely to develop avoidance behaviours as a way of protecting themselves and others. Understanding sex differences is important for adequate support and early intervention for girls who stutter, preventing negative effects on quality of life, mental health problems, the development of self-stigma, and limitations in various areas of daily activities.

Clinicians being mindful that sex differences exist, can be better able to recognize and address factors that seem to affect females who stutter, and, by that, individualize treatment and target treatment goals with greater precision. Specifically, regular follow-ups of girls who stutter could be offered in health services as a way to promote positive self-esteem

development and prevent the person from developing avoidance behaviours, turning to silence or keeping their stuttering a secret.

Clinicians should also be vigilant that instruments available for assessing overt stuttering behaviour seem to present a representation of stuttering that is not fully agreed on by the person themselves, and more so for females than males. Moreover, the same degree and extent of stuttering, both from a subjective and objective perspective, appears to be perceived and experienced differently between the sexes, with the female experience more negative than the male. Knowing this, SLPs should make sure to include self-report instruments in the assessment battery and encourage self-assessment in various communicative situations where speech is involved, in order to gain a more accurate understanding of how the experience of stuttering and its manifestations relates to overt stuttering behaviour.

Research has shown that an important part of treating stuttering is for SLPs to provide educational information about stuttering to reduce self-blame and stigma (Boyle, 2020, Douglass et al., 2018). The results of Study IV showed that there appears to be a particular gap in this regard for women who stutter and may have occurred as a result of a course of events involving avoidant behaviours from one party (the PWS) and lack of knowledge and misinterpretation from the other party (people close to the PWS). This has resulted in inadequate or non-existent health care interventions and thus the opportunity to gain an understanding of the cause of the predicament has been lost. Clinicians should therefore aim to provide adequate and age-appropriate educational information on stuttering already at school age to girls (and boys) who stutter to prevent self-blame and negative self-esteem to develop. In addition, it is important for SLPs to raise awareness among health care providers, parents, teachers and in the workplace to ensure that negative attitudes and stigma affecting females who stutter are reduced.





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