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Essentials of Epidemiology and Phenomenology of Stuttering – Consequences for Clinical SLP Practice

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ABSTRACT

The Antwerp epidemiological and phenomenological study on stuttering focuses on the onset and development of stuttering. Descriptive data related to the onset of stuttering were obtained for a group of 1549 participants. The reported and observed variables were obtained in order to test several hypotheses concerning the age-related, gender-related and interrelated phenomena. The following aspects of stuttering and the related phenomena were studied: (a) stuttering-like disfluencies (type, frequency, duration, tension), (b) subtypes of stuttering and the role of temperament, (c) the onset of stuttering and the related variables, (d) precipitating factors post onset, (e) stuttering-associated behaviour (physical concomitants and avoidance), (f) awareness of stuttering, (g) speech attitude, (h) listeners' reactions. The findings provided a basis for the construction of a model of the onset of stuttering and a model of the development and consistency of stuttering characteristics and the related phenomena. The findings were used to establish directives relating to the clinical practice of speech-language pathologists dealing with stuttering, especially when it comes to the diagnosis and the treatment of stuttering.

Keywords:

stuttering ▪
stuttering-like
disfluencies ▪
subtypes of
stuttering ▪
behaviour ▪
awareness ▪
attitudes

INTRODUCTION

The key findings of the Antwerp epidemiological and phenomenological study of Boey (2008) are presented. Their consequences for the clinical practice of a speech-language pathologist are discussed. In fact, two major studies were conducted.

Study I is an epidemiological and phenomenological study on stuttering, carried out in the Centre of Stuttering Therapy (Antwerp, Belgium) between 1991 and 2006 on a large group of stuttering participants. The group consisted of 1549 individuals who were stuttering: 1048 young children and 501 children and adolescents with the average age of 6.4 years (range 1.9 – 17.8 years), 1191 males and 358 females (ratio 3.2:1). The findings of the multiple analyses of the observed and reported stuttering-related variables and the testing of multiple hypotheses led to several conclusions. By means of a structural equation analysis, a model of the onset of stuttering could be established. It was also possible to construct a model of the development of stuttering, explaining the determinants of the quantitative and qualitative characteristics of stuttering, stuttering behaviour and stuttering severity.

Study II analysed the effectiveness of a social cognitive behaviour therapy for stuttering in the long term, i.e. after approximately 10 years, with reference to pre-treatment data and no treatment conditions. Factually, the results of a group of participants who received the therapy were compared with those of the only-diagnosis group and the drop-out group. The therapy group was stratified at the intake according to their age, gender, stuttering severity, and temperament. The findings relating to the efficacy of clinical decision-making (treatment/no treatment) and the effectiveness of a long-term therapy were based on a between-group and within-group analysis, comparing the variables relating to stuttering, speech attitude, personality and social reactions. In addition, issues about the amount of recovery and persistence were clarified. Furthermore, the research was conducted with regard to the quality of life after the therapy, comparing the results of a group of adults that received a social cognitive behaviour therapy for stuttering with those for a group of adults that received a fluency shaping treatment. The conclusions of this study of therapy effectiveness had useful implications for the clinical SLP practice.

To summarise: in the present presentation four essential conclusions will be discussed, as well as their useful implications for the SLP practice and research. The conclusions concern:

- 1) the diagnosis of stuttering based on speech samples and characteristics of disfluencies,
- 2) the onset of stuttering and the related factors,
- 3) the development of stuttering and the related factors and
- 4) the effects of a social cognitive behaviour therapy in the long term.

KEY FINDINGS

Stuttering-like disfluencies (SLD)

Sensitivity and specificity of a SLD-based observation procedure

Two studies concerning the characteristics of SLD were conducted on native Dutch-speaking stuttering subjects and normally fluent speakers. A group of 693 stuttering children (aged 1-7) and 79 normally fluent children participated in the first study. In the second study, a group of 351 native Dutch-speaking older children and adults (aged 8-53) and a group of 80 people (aged 8-60) were examined. In general, the stuttering individuals had more frequent, longer and more tensed SLD than normally fluent speakers, and were significantly more likely to exhibit prolongations and blocks. Quantitatively, the use of a criterion of 3% SLD based on direct observation in a conversational speech sample is very helpful for distinguishing stuttering from non-stuttering individuals, resulting in high sensitivity and high specificity. Furthermore, the results suggest that frequency, duration and physical tension characteristics in native Dutch-speaking subjects are fairly similar to those of English-speaking children detected in the majority of published studies (Boey et al., 2007; Boey et al., 2009a)

Epidemiological and phenomenological findings

The findings of the epidemiological and phenomenological study revealed that all types of SLD had been reported (by parents) and observed (by a clinician) in the speech of both age groups of participants in the present study. The parents did not observe or associate repetitions with stuttering as frequently as the clinician did. Different kinds of SLD were reported in the same order of importance. Repetitions and vowel prolongation seemed to be more frequent among the younger children than among the older children and the adolescents. Blocks seem to be more frequent among the older children than among the younger. The frequency of SLD (percentage of total words) was about 15%. No significant relationship was found between the frequency of SLD and age or gender. However, the duration of SLD is significantly related to age, not to gender. The older participants had shorter duration than the younger ones. Perhaps the fact that they also showed more (shorter) blocks than (longer) repetitions and prolongations can explain this observation. A significant and clear relationship was found between the frequency and duration of SLD. A shorter duration is more often associated with a lower frequency of stuttering, a moderate duration with a moderate frequency and a longer duration with a higher frequency of stuttering. This relationship partially illustrates stuttering severity.

Effect of temperament

Highly temperamental or emotionally highly reactive stuttering children differ to some extent from their less temperamental peers. Emotionally highly reactive children tend to have a more frequent sudden onset of stuttering, with more often reported (specific) factors near onset. Their tempo of speech/language development seems to be less often delayed and more often precocious. The observed stuttering is somewhat more severe. In other words, they produced more vowel prolongations and a higher frequency of consistency of stuttering was observed. The age of onset, the time since the onset and gender did not seem directly or

significantly related to temperament.

Model for the onset of stuttering

Age of onset

Stuttering typically begins at a young age i.e. at 3 years and 3 months on the average. The mean age of onset is 2 months later and is more variable for boys than for girls. The manner of onset (i.e., gradual or sudden) did not affect the age of onset. Within the group of younger children (aged 1-6 years), the reported stuttering in the family is associated with a 2-month earlier mean age of onset compared to the children without the reported stuttering in the family. This relationship between kinship and the age at the onset probably reflects the sensitivity and attitude of the parents previously exposed to stuttering, who do not usually wait to report it. The age of onset does not seem to differ with regard to stuttering severity. The age at the onset of stuttering is determined by the tempo of speech/language development. More often precocious speech/language development is associated with a younger age of onset of stuttering. On the contrary, a delayed tempo of speech/language development is associated with an older age of onset. The temperament does not seem to be related to the age of onset.

Manner of onset

Overall, almost two-thirds of the participants were reported with a gradual onset. More male than female have a gradual manner of onset and, conversely, more female than male have a sudden manner of onset. Kinship is not associated with the manner of onset. Children with a gradual onset stutter on the average less severely, compared to children with a sudden onset. Stuttering children with a delayed tempo of speech/language development were classified more often with a gradual onset than children with normal and precocious speech/language development. A reversed tendency can be observed within the group of children with a sudden onset. Far more children with precocious speech/language development than children with a normal or delayed tempo of speech/language development are represented in that group.

Conditions near onset

The parents reported specific events, activities of the child and circumstances to be associated with the onset of stuttering. For slightly more than half of the participants, the factors near onset were reported. The findings suggest that specific factors near onset have been reported more frequently in association with a sudden onset and a shorter time of onset, for younger males, and by parents classified as very concerned. Only the manner of onset remains significantly related to the known factors near onset, unlike gender, gender in interaction to the manner, parents' concern, the frequency of stuttering or the frequency of stuttering in interaction with the manner of onset. When

classified according to Johnson (1959), most of the factors near onset are emotional/behavioural and others are physical. When classified according to Yairi and Ambrose (2005), the principal category are emotional factors, followed by physical and developmental and, finally, by behavioural factors. Perhaps those factors are the precipitating factors in relation to the onset of stuttering. The fact that for highly temperamental children more such factors have been reported indicates this role.

Onset-determining variables and a model of onset

The onset of stuttering, i.e. the age of onset, the manner of onset and the time since the onset, seem to be significantly related to the tempo of speech/language development, temperament, gender, and stuttering severity. A structural equation model reveals that gender and temperament are exogenous variables (i.e., predictor variables) related to the onset of stuttering. See figure 1 added in the Appendix. Several indices of parsimony and fitness of the model indicate good to excellent. There is no bias of the amount of data used. Female gender influences the age of onset directly, but it exerts a major influence on the tempo of speech/language development, being more often precocious for girls. High temperament is associated with an increased stuttering severity, a sudden onset of stuttering, and with more frequent precocious speech/language development. Stuttering severity, the tempo of speech/language development, the age at the onset, the manner of onset and the time since the onset are endogenous variables (i.e., response variables). Geschwind and Galaburda (1985) can use those findings to support their bio-genetic model.

The development of stuttering: stuttering severity and the related variables

A model of the development of stuttering is illustrated by figure 2 in the Appendix. This complex model is based on significant and relevant relationships between the observed and/or the reported stuttering-related variables. Those variables partially explain the variability of the quantitative and qualitative characteristics of stuttering, stuttering behaviour and severity. It is important to stress that all the significant relationships found remain significant even in the context of other variables.

Stuttering-like disfluencies

The results suggest that the type of disfluency changes with age. Blocks were more often observed in the speech of older children while repetitions and vowel prolongations seem to be more frequent among younger children. The frequency of SLD seems not to be significantly associated with age groups, but it was reported that it increased in response to the precipitating factors post onset. However, the duration of SLD is significantly related to age. The older participants had shorter duration compared to the younger ones. Perhaps the fact that they also showed more (shorter) blocks than (longer) repetitions and prolongations can

explain this observation.

Precipitating factors post onset

Parents report emotion and fatigue as the most frequent precipitating factors after the onset of stuttering. Emotion is more often reported among older children than among the younger. Conversely, fatigue is more frequently mentioned in relation to younger than to older children. Moreover, among children with a longer time since the onset of stuttering, emotion is more often mentioned than among children with a shorter time since the onset. Fatigue as a stuttering-increasing factor, was more often observed among the children close to the onset of stuttering than among those with a longer time since the onset. Furthermore, emotion as a precipitating factor was more frequently registered among the children with a gradual onset of stuttering and more frequently among boys than among girls. No other significant relationships with precipitating factors were revealed.

Stuttering-associated behaviour – physical concomitants

Children with reported physical concomitants (e.g., facial movements, head and eye movements etc.) are more often younger and started stuttering at a younger age. More often physical concomitants were observed among the older children and children who started stuttering at a later age. The severity of physical concomitants seems to increase in proportion to the time since the onset. Furthermore, physical concomitants and their severity were found to be more frequently associated with a sudden onset of stuttering and temperamental children. Gender did not make any difference in relation to the amount or severity of the reported or observed physical concomitants. When controlled for all other variables, temperament remains significantly related to the amount and severity of physical concomitants.

Stuttering-associated behaviour – avoidance behaviour

Overall, avoidance behaviour was less frequently reported (i.e., for 39% of the participants) than observed (for 59% to 70% of them). Clustering reported data on avoidance resulted in a cluster of behaviour leading to not speaking (keeping silent, saying less, asking someone else to say it etc.), a cluster with a language strategy to avoid speaking (use of other words, circumlocution etc.), and a cluster with a speech production strategy (distorting pronunciation, shouting, pitch rise, whispering etc.).

The children with reported avoidance behaviour were on average 8 months older than the children without reported avoidance behaviour. The older children were found to show a higher degree of severity of the observed avoidance behaviour. The reported data suggest a more frequent avoidance when the stuttering began at a later age. The time since the onset seems not to determine the frequency of the avoidance behaviour, but the degree of its severity. That increases in proportion to the time since the onset. Compared to a sudden onset, a gradual onset of

stuttering is more often associated with the reported avoidance behaviour. Neither gender nor temperament is significantly related to the amount of the reported or observed avoidance or its severity. When controlled for all other variables, age, manner and time since the onset all remain statistically significantly related to the observed and reported avoidance.

Awareness

Overall, about three quarters of the stuttering children were reported by their parents to be aware of their speech difficulty/stuttering. The reported signs of awareness were clustered as verbal reactions (remarks, asking for help, etc.), general non-verbal reactions (attitude, posture, staring etc.) and specific non-verbal reactions (crying, being cross, ticking, clownish behaviour etc.). Almost two-thirds of the younger children (< 3.8 years old) were reported to be aware of their speech difficulty/stuttering, a number that gradually increases with age to 98% for the older children (> 8.4 years old). More children who started stuttering at an older age show awareness, compared to the children who began stuttering at a younger age. Above all, children with a longer time since the onset were more often reported to be aware of their stuttering than the children evaluated sooner after their stuttering had begun. Gender does not seem to be related to awareness, but temperament does. There is a slightly higher number of highly temperamental children than those less temperamental that were reported to be aware of their speech. An interesting detail: the specific way of reaction towards their speech difficulty/stuttering was only significant for becoming cross because of the speech. There is a clear relationship between stuttering severity and awareness. As a group, the stuttering children classified as aware of their speech difficulty/stuttering, have a higher mean stuttering severity than those reported not to be aware of their speech difficulty/stuttering (Boey et al., 2009b).

Speech attitude and personality characteristics

The older stuttering children had developed a somewhat more negative speech attitude compared to the younger stuttering children. Stuttering girls as a group showed a more negative speech attitude than the stuttering boys, and a higher stuttering severity is associated with a more negative speech attitude. The increased frequency of stuttering and more severe physical concomitants both contribute to a more negative speech attitude. The amount or kind of parental reactions towards the speech of their stuttering child does not. Neuroticism and extraversion as personality characteristics both affect speech attitude. Higher neuroticism is associated with a more negative speech attitude and vice versa. Higher extraversion is associated with a less negative speech attitude and vice versa (Boey, 2008).

Social reactions

Parents nearly always react to the speech of their child. Parental reactions can be clustered into three groups. The

first: an instruction to calm down, to take it easy. The second: letting the child talk. The third: different kinds of instructions on how to speak, in an attempt to prevent the child from stuttering. The instructions as “stop it”, “breathe well, take a deep breath”, “say it, just say it”, “sing it”, “whisper” and completing the words are significantly related to a higher stuttering severity.

Besides parents, for most of the children their grandparents (88%) and teachers (86%) react to the stuttering. Less frequently mentioned were the siblings (40%) and other children outside the family (52%). The majority of the stuttering children (84%) meet between 2 and 4 different kinds of listeners reacting to their stuttering. The number of different sources of reaction is significantly related to stuttering severity, as is the number of total reactions. More specifically, the results suggest that the observed avoidance behaviour and physical concomitants seem significantly related to the number of listeners reacting to the speech of the child. The total number of listeners' reactions seems significantly related to the observed avoidance of words behaviour and to physical concomitants. The reactions of the parents to the speech of their child do not depend on the gender of the child nor on the fact whether the parents (father/mother) stutter themselves or have close family members who stutter. Highly temperamental stuttering children do not differ significantly from their less temperamental peers in relation to the amount of parental reactions they were reported to receive. The number of sources of different listeners and the number of parental reactions (≥ 3) to the speech of the child are both significantly related to the child's higher awareness of their speech difficulty. Moreover, the kind of parental reaction seems to be associated with the number of children aware or unaware of their disfluent speech. The results suggest that letting the child talk, or giving friendly remarks are associated with a lower awareness. Instructions on how to speak seem to be associated with a higher awareness. The number of different sources of listeners' reactions, the number of total reactions of the listeners and the kind of parental listeners' reactions are not significantly related to the speech attitude measured with the CATd.

Effectiveness of therapy

Between-group comparisons

In general, for almost three quarters of the stuttering children with mild stuttering severity at the intake, an estimated low impact of the precipitating factors, absence of listeners' reactions, an estimated low sensitivity of the child and emotional stability of the environment, it can be predicted that they will no longer stutter in 10 years on the average, when only counselling and no therapy is received. In contrast, 68% of the drop-out group is diagnosed as still stuttering on the average 10 years after the first assessment and 79% of them still complain of stuttering. It seems that there is a high risk of persistent stuttering for this group. About one-third (32%) of the therapy-group is diagnosed with post-therapy stuttering, on the average 10 years after the initial intake and about half of those participants (55%) still mention stuttering. Theoretically, part of that effect can

be attributed to recovery without a treatment and, in addition, a relapse can be expected for some of the participants of that group. When corrected on both accounts, the number of subjects with a treatment and no diagnosis of post-therapy stuttering remains about 50% (Boey, 2008).

Furthermore, among the participants of the therapy group still stuttering after the therapy there seems to be a substantial reduction in the frequency and kind of stuttering-like disfluencies (i.e., less blocks and prolongations). Clearly, a large decrease of the number of subjects with avoidance behaviour and/or physical concomitants was observed. In addition, among those still exhibiting avoidance behaviour and/or physical concomitants, the severity of such behaviour lessened in the post-therapy period. Conversely, for the drop-out group the reduction of the secondary behaviour was observed among fewer participants and its post-condition severity remains higher compared to that of the therapy group. For the therapy group and the only diagnosis group, the amount of the reported precipitating factors was reduced by almost 50% in the post-condition compared to the pre-condition. This effect is lesser for the drop-out group. A significant difference relating to cognitive aspects of stuttering and speech attitude was observed between the three participating groups. Based on the self-report, the drop-out group had the smallest reduction when it comes to being preoccupied with stuttering. Between half and two thirds of that group continues to consciously think about stuttering, anticipating it and having cognitive reactions to it. On the contrary, an impressive portion of the therapy group reported to be no longer cognitively preoccupied with stuttering. The number of subjects in the therapy group that reported cognitive reactions relating to stuttering was between 80 and 90% before the therapy, compared to 13% and 33% after the therapy. Furthermore, the reactions became less intensive in the therapy group, an effect that is less frequently observed in the drop-out group. The therapy group obtained the best results on the speech attitude tests and the largest difference pre- versus post-therapy, better than both other groups. Overall, the average scores on the speech attitude tests approached the values for non-stuttering speakers.

Interestingly, the members of the therapy group that completed a personality inventory pre- and post-therapy showed a post-therapy decrease in neuroticism and neurosomatic reactions. Their extraversion scores increased and the social desirability score remained the same. That means they became less worried and more socially open after the therapy. Similar results were observed for the only diagnosis group. In contrast, the subjects of the drop-out group for whom the pre- and the post-therapy values could be compared, had an increase in neuroticism (with one exception), extraversion remained the same and the social desirability scores increased very much. Those findings suggest more worried people with more self-defensive mechanisms in the drop-out group. All the participants of all the groups were counselled on how to react to stuttering and the precipitating factors, and how to deal with peer reactions, reactions of the parents and teachers, etc. In addition, for the therapy group, the parents of the children younger than twelve followed a course for parents and attended the therapy or parts of it. In the post-therapy period, the drop-out group still reported to receive reactions

to stuttering in 25% of the cases from their parents and from other peers, and in more than a third of the cases from the teachers. The participants in the drop-out group did not receive any comment. Only a few subjects of the therapy group reported reactions to stuttering from the parents (6%), from peers (8%) and from the teachers (also 8%). A clear discrepancy emerges between the three groups regarding social reactions to their speech.

Within-group comparisons

The findings suggest that the pre-therapy age category in interaction with gender affected the outcome of the therapy with regard to the percentage of stuttering-like disfluencies and the overall stuttering severity. Initially, the age-category groups did not differ significantly concerning the percentage of stuttering-like disfluencies and the overall stuttering severity. However, the outcome after the therapy seems to be affected by the initial age group. When compared with each of the older age groups, the youngest age group (aged 1-6) stuttered significantly less in terms of % SLD, as well as in terms of stuttering severity. The group of children aged 7-12 stuttered significantly less frequently and less severely compared to the older group of children aged 13-18 and, as mentioned before, significantly more than the youngest group. However, no significant differences emerged when compared to the adult group. The group of older children (aged 13-18) had a significantly different higher percentage of SLD and a higher stuttering severity score compared to all other groups. In fact, the adult group (aged 18 years and older) is more like the group of children (aged 7-12) and did not significantly differ with regard to the post-treatment % SLD.

The outcome of the therapy also reveals a gender effect in favour of females. Initially, the %SLD and the overall stuttering severity did not differ significantly between males and females, but a statistically significant lower post-therapy %SLD and the overall stuttering severity were found for the females when compared to the males. As mentioned before, an interaction with the pre-therapy age category was noticed. As a group, the male teenagers (aged 13-18) obtained the worst results in terms of %SLD and the overall stuttering severity.

The pre-therapy stratification of temperament is limited to the two youngest groups of participants. Before the therapy, the highly temperamental children obtained a significantly higher %SLD and exhibited a significantly higher overall stuttering severity. However, after the therapy such a difference was no longer noticed. This means that highly temperamental children had a larger decrease in %SLD and stuttering severity than the less temperamental ones.

Overall, the initial stuttering severity was classified with reference to the median value of a stuttering severity instrument (SPI, SSI). The pre-therapy results were divided into two groups, one with the participants scoring below the median, and the other with those above the median. The outcome did not reveal significant differences between those two groups concerning the %SLD and stuttering severity. The group with the pre-therapy score for stuttering severity above the median had a significantly greater decrease than the other group.

Quality of Life

The quality of life for adults was studied after the treatment. Indications for the quality of life were suggested by the post-therapy effectiveness findings. Two other studies have been conducted focussing on the quality of life. The first study used measures with the OASIS and the second used an in-depth interview procedure.

Overall, the results of the OASES study revealed a mild to moderate impact of stuttering on the quality of life. The OASES measures seem to be related to the observed and self-reported post-therapy stuttering severity, improved extraversion, reduced anxiety and enhanced confidence after the therapy, which can be interpreted as an improved quality of life.

With regard to the in-depth-interview results, the findings for a group of adults who received a social cognitive behaviour therapy indicate that, approximately 10 years after the therapy, the quality of their life was substantially enhanced. The responses to the social cognitive behaviour therapy illustrate a substantial improvement of the quality of life, despite the fact that stuttering did not disappear. In contrast, the subjects of the Klompas and Ross study (2004) who received a speech therapy focussed on fluency shaping, seemed to have experienced a more restricted therapy outcome, and a less positive impact on the quality of life. Differences occurred with regard to diverse aspects of the quality of life such as education (i.e., academic performance, relationship with the teachers and classmates), social life (relationships in the family, at school, at work and elsewhere), and self-esteem (Boey, 2008).

IMPLICATIONS

Extending the knowledge about stuttering

Definition of stuttering

The definition of stuttering given by The International Classification of Diseases (ICD) of the World Health Organisation (WHO, 2006), or the DSM-IV-TR as the frequency of repetition or prolongation of sounds or syllables and of dysrhythmic hesitations is emphasised. DSM-IV-TR adds the accompanying emotional and behavioural phenomena. The findings of the present study support those parts of the definitions. However, it is possible to extend and refine the definition based on the findings of the present study. For example: "Stuttering is a speech disorder typically characterised by within-word disfluencies, such as repetitions or prolongations of sounds or syllables, blocks or longer repetitions of monosyllabic words. The frequency of such disfluencies in conversational speech is usually higher than 3% of total words. The disfluencies are typically longer in duration and the associated physical characteristics typically more tensioned. In addition, stuttering is often accompanied by behavioural phenomena, such as avoidance behaviour, physical concomitants or struggle behaviour, speech-related cognition (anticipation and reaction) and attitude, emotional stress, and social reactions. Stuttering puts children, adolescents and adults who stutter at risk of a reduced

quality of life, interfering with their health, education, and social and occupational conditions.”

Theory and a model of onset

Important findings of the epidemiological study concern the onset of stuttering. Given a very large sample size and the data set available, a well-fitted and parsimonious structural equation model was constructed, revealing the relationship between the onset characteristics (age, manner and time since the onset) and gender, speech/language development, temperament and stuttering severity. Some of the relationships between one variable (e.g., gender or speech/language development) and the onset of stuttering had been suggested by a few authors (e.g., Yairi and Ambrose, 2005). However, more complex relationships of multiple variables with the specific onset-related characteristics had never been found before. The role of gender was clarified. More female than male begin to stutter earlier, not only as a result of their gender, but also of the tempo of speech/language development, more precocious among females than among males. The tempo of speech/language development (i.e., delayed, normal, precocious) is a dominant factor in relation to the age of onset, the manner and the time since the onset. Furthermore, high temperament was found to be a factor related to the manner of onset. It also has an additional, indirect effect on other characteristics of the onset through the impact on stuttering severity and its association with a precocious tempo of speech/language development.

Because of the early age of the onset of stuttering and a gender effect, those phenomenological findings can reflect a biogenetic predisposition and/or early neurofunctional development processes. When combining those findings with other results of e.g. brain imaging studies, analysis of listeners' reactions not being causal for the onset of stuttering, and the knowledge of the bio-genetics of brain development, the model of the onset can support a model of the predisposition of stuttering as given by Geschwind and Galaburda (1985). They documented a hormonal gender-related effect on the brain development, leading to specific morphology, ectoplasm and less hemispheric dominance. Assuming that the discovered ectoplasm and a more developed neural network in the right hemisphere of people who stutter reflect a compensation for developmental growth problems of the left brain parts (De Ridder, 2006), it can be hypothesised that the incidence of functional extremes (i.e., talents and disabilities) should be more prevalent when stuttering. Phenomenological data concerning the gender ratio, the tempo of speech/language development and temperament relating to stuttering lend to some degree to the credence of such a biological model. At least the data do not contradict it. The model of the onset can be of use when constructing and testing other onset-related hypotheses.

Stuttering severity

The synthesis of literature given in chapter 1 showed that the relationship of a lot of factors related to stuttering severity has not been clarified. Even contradictions have

often been found. On the one hand, the present study extends our knowledge about stuttering severity owing to a detailed observation of stuttering-like disfluencies (kind, frequency, duration, physical tension) and stuttering-associated behaviour (avoidance, physical concomitants). On the other hand, a large number of participants and the availability of a large set of the reported data made it possible to conduct not only an univariate analysis of the variables related to stuttering severity, but also to apply a multivariate analysis or a structural equation modelling revealing more complex, more detailed and interrelated relationships with stuttering severity. This made it possible to clarify more precisely the relationship between the multiple variables and elements of stuttering severity. The study improved our knowledge about the relationship between the onset-related characteristics and stuttering severity, temperament and severity and other variables such as awareness, speech attitude, listeners' reactions, the precipitating factors and indirect personality factors. The present study made it possible to present an integrated model explaining stuttering severity.

The development of stuttering

Although it is not a longitudinal study, the comparison of age groups suggests developmental effects related to stuttering severity. Briefly, the characteristics of stuttering and stuttering severity seem to evolve in the direction of a more tensioned pattern of stuttering (more blocks, shorter duration, more physical tension) and more severe avoidance behaviour. Moreover, the variables and their interrelationships which contribute to this evolution were found. The impact of the environment and properties of an individual who stutters were explained. This extends our knowledge about a possible development of stuttering and it also informs us on the evolution of stuttering people as a group. A part of that group, children, adolescents as well as adults, risks a reduced quality of life with a negative impact on education, school performance, health, personal relationships, social life and occupation.

Recovery, persistence and relapse

The study of literature showed a lot of conflicting data with regard to recovery and the persistence of stuttering. In addition, although the phenomenon of a relapse is known, no data are available on how many of those who stutter relapse after being classified as recovered or in the post-therapy period. The results of the present study might contribute to a solution and resolve the situation of the conflicting data. Firstly, it was found that the recovery or persistence seem to be dependent on the initial stuttering severity. Mild severity seems to lead to a recovery more frequently than moderate or severe stuttering. Secondly, a low estimated impact of the precipitating factors, low emotional sensitivity of the stuttering child and their environment could have contributed to that finding. Thirdly, it seems useful to observe the recovery or persistence in the long term, i.e. post puberty. Part of the stuttering children, far more males than females, is vulnerable to relapse between the ages of approximately 9 and 16.

Relationship with personality

Stuttering is not a personality disorder, although, unfortunately for some people, it can coincide with such disorders. The present study revealed more precisely the relationship of some personality characteristics with the stuttering-related variables e.g. speech attitude and, indirectly, with stuttering severity. Pre-therapy, neuroticism, neuro-somatic reactions, social desirability, and anxiety about failing to perform seem to be increased, while extraversion seems decreased compared to the post-therapy condition in the long term. The findings suggest a reciprocal relationship between the stuttering characteristics and personality.

Effect of social reactions

Another group of findings improves our knowledge about the relationship between social reactions and stuttering. In the 1930s, the epidemiological studies suggested that parental reactions, as reactions to normal disfluencies of a child, caused stuttering. This theory lasted for the following 60 years. The influence of social reactions on stuttering is made clear by the findings of the present study. It contributes to the awareness of a person's own speech and is associated with the elements of stuttering severity i.e. physical concomitants and avoidance behaviour. Furthermore, the findings suggest a reciprocal relationship. Social reactions can have an influence on stuttering severity, and vice versa, stuttering severity can have an influence on the number, kind and frequency of social reactions.

Quality of life

The findings of the epidemiological and phenomenological study suggest that stuttering is a risk for a reduced quality of life. As mentioned before, when discussing the knowledge about the development of stuttering, it can have a negative impact on education, school performance, health, personal relationships, social life and occupation.

Diagnostic implications*Clinical diagnostic procedure*

The results of the present research show the validity of a clinical procedure to diagnose stuttering and distinguish it from a normal disfluency. Firstly, using counting stuttering-like disfluencies in conversational speech and applying a criterion of 3% of stuttering-like disfluencies to total words leads to a very high sensitivity and specificity of the correct diagnosis of stuttering. Secondly, a standard procedure of direct observation of speech samples consisting of longer phrases within a 20 minute-sample for a total of 100 words within longer utterances is a reliable and valid procedure with clinical relevance and a high intra- and inter-judge agreement. In addition, semi-structural interviews and other tests contribute to the quantitative and qualitative aspects of

the assessment of stuttering in order to evaluate the dynamics and variables related to stuttering, they assess the severity of stuttering and the impact on the quality of life.

Client-clinician agreement relationship, diagnosis and complaint

The pre-treatment agreement between a client and a clinician concerning the diagnosis of stuttering is higher than the post-treatment one, when relying only on the observation of stuttering-like disfluencies in a conversation. The findings suggest an underestimation of post-treatment stuttering based upon direct observation of speech, when compared with the self-report of a client. This suggests that the frequency of stuttering, or so-called chronicity, is higher in the post-therapy condition assessment than at the first intake. This also suggests the importance of registering the complaint of a client and/or conducting a semi-structured interview.

Content of diagnosis

The epidemiological and phenomenological study suggests that, in order to get insights into the effectuating variables and their interrelationships with stuttering severity, it is necessary to gather data about such variables. Consequently, a clinical assessment procedure needs to gather the quantitative and qualitative characteristics of stuttering and stuttering behaviour, but the speech attitude also needs to be assessed, as well as the personality characteristics and the environmental reactions. Those data can make it possible to get the diagnostic picture necessary to justify conclusions regarding measures that have to be taken or not.

Prediction based upon the diagnostic results

The effect study showed that some long-term prediction seems to be possible when referring to the initial diagnostic results. Briefly, mild stuttering with a lesser impact of the precipitating factors, no high sensitivity of the child or the environment, in 73% of the cases leads to a recovery from stuttering 10 years later, in the post-puberty period. For only a quarter of people with the initial moderate or severe stuttering a recovery can be predicted, based upon the initial diagnostic information. The results improve when the therapy was applied.

Therapeutic implications*Indications for counselling about effectiveness*

The study on the effects of a social-cognitive behaviour therapy reveals that a negative development of stuttering can be prevented. The results showed that a therapy contributes substantially to a recovery from stuttering, more frequently among children, when compared to adolescents or adults. The results also showed prevention and limitations of a negative development of diverse speech behaviour

components related to stuttering. This means less negative cognition (e.g., anticipation, reaction, preoccupation) about speech, enhanced self-esteem, fewer negative emotions (e.g., no fear of talking, shame etc.), the existence of feelings of competence related to speech, improved motor responses (i.e., talking more openly, less avoidance, postponement and struggle behaviour in reaction to stuttering), and improved problem-solving behaviour. The vulnerability to the precipitating factors was reduced. In addition, social reactions changed when compared to the pre-treatment condition, even if the stuttering persisted. In contrast with the treated group, social reactions remained present in the drop-out group. That suggests that the parts of treatment aiming at the social environment of the stuttering person may be responsible for the modification. Those findings of the study on effectiveness can be of use when counselling individuals who stutter or parents of the children who stutter.

Prediction of the outcome related to age and gender

In general, 61% of the individuals with the initial moderate to severe stuttering who received a social cognitive behaviour therapy, recovered. Those with a similar profile who did not receive a therapy recovered only in 26% of the cases. Of course, some caution is needed here. All of the potential predictive variables could not be the subject of the study. In addition, the recovery rates are higher for children and lower for adolescents and adults. More specifically, as a group, the males who started the therapy between the age of 13 and 18 did worse with regard to the recovery from stuttering. During puberty, far more males than females seem to be represented in the clinical population; and they also seem more vulnerable to a relapse into stuttering.

Contribution to the quality of life

Clearly, social cognitive behaviour therapy contributes to the quality of life with regard to educational and scholar life, social relationships, occupation and family life. Moreover, the results suggest that the individuals who followed a social cognitive therapy significantly improved their quality of life when compared to the individuals who received the speech fluency training. As mentioned before, the social reactions to stuttering diminished after the social cognitive behaviour therapy and the coping strategies to deal with such reactions improved.

Social implications

Quality of life

People suffering from speech and communication disorders, experiencing a reduced quality of life can, although talented, contribute less to their family life and occupational and social environment. Their participation may be reduced, partners may become involved in the avoidance strategies or experience stress or negative feelings. Parents, grandparents and siblings may become unhappy when confronted with the stuttering of a child and perceiving the reduced quality of life. Typically, this a part of

the problem described at the initial intake. Conversely, when the therapy improves the quality of life for an individual who stutters, the disadvantages of stuttering disappear or become substantially reduced for the close relatives.

In specific cases, the incompetence to communicate and express thoughts and feelings can interfere with finding an appropriate school career, with job satisfactions and personal relationships. Exceptionally, it can even be an element of crime or aggressive behaviour (Vermassen, 2000, 2006). The study of the effectiveness of a therapy showed that the incompetence to communicate and express thoughts and feelings can be prevented, which means that, for some individual cases, the aforementioned problems with a school career, job satisfaction etc. might not arise.

Psycho-social health conditions

For some people who stutter, the coinciding long-term stress can contribute to the existence of psycho-somatic disorders, problems or complaints about their health in general (e.g., hyperventilation, depression, stomach problems, migraine, sleeping disorders etc.). It might be suggested that the prevalence of such problems and complaints could be reduced when the stress related to stuttering is decreased as a result of a therapy. Consequently, the medical costs are also annulated.

Medical costs

A reduced prevalence of the problems caused by the long-term stress related to stuttering contributes not only to the decrease of the medical costs. In fact, the study on the effectiveness of a therapy revealed that the average number of therapy sessions given to young children is half the number for adolescents/adults. So, in general, a therapy started at a younger age has positive consequences regarding the reimbursement of costs. This is of interest to the individual following a therapy and to the society that contributes to the reimbursement.

Limitations and future research

With regard to the diagnostic test procedure, that has been proven to be highly sensitive and specific when identifying stuttering, some remarks have been made. At the one hand, such a diagnostic procedure puts some demands on the skills of a clinician to multitask. They need to have the capacities and experience to trigger a speech sample, observe stuttering-like disfluencies and record them directly, and they need to be trained to reach an acceptable intra-judge and inter-judge reliability. On the other hand, the availability of a direct observational procedure contributing to an immediate and highly valid diagnosis is an important advantage for the clinician and the patient.

The epidemiological and phenomenological study contains one type of data and it is not a longitudinal study. From the ethical point of view, a longitudinal study cannot be recommended to patients. However, the comparison of age groups is another method to approach the evolution of stuttering with age. The relationship of the endogenous and the exogenous variables associated with stuttering was studied. Although the sample of participants was large and

the variables were numerous, perhaps a replication of the research elements can contribute to the conclusions made. The present study resulted in a model of the onset of stuttering, a model of the development and explanations of (interrelated) factors with an effect on stuttering severity. Of course, other variables that were not considered can have significant relationships with stuttering. It would be of interest to study the neuro-biological correlates of stuttering. The findings of the present epidemiological and phenomenological study can be of use in the research of such correlates, or to test specific neuro-biological hypotheses.

To study the therapy outcome, three groups were compared in the long term, according to the conditions of the therapy or no therapy taken. The groups were well-defined and stratified as much as possible with regard to the age at the intake, the initial stuttering severity, gender and temperament. Never before had such a study been conducted for such a relatively complex therapy, using the aforementioned methods and procedures. In addition, the effects for several elements of speech behaviour, stuttering and environmental reactions were studied. Nevertheless, it would be interesting to extend e.g. the number of participants, so that the statistical power of the analysis of the variables affecting the outcome could be increased. Also, a replication of the study could be of importance, as well as a comparison of the results with other therapy methods.

The quality of life study was restricted to a post-therapy situation. This study made it possible to construct a procedure to examine the quality of life and provided interesting insights. However, this kind of study can be taken as a start to refine the procedure of the examination of the quality of life. As in the case of the therapy outcome study, a replication can contribute to generalisation and precision of the findings. Also, a comparison with other methods of stuttering therapy can teach us about the effectiveness of the treatment. As suggested, future research can address those suggestions.

The findings of the epidemiological and phenomenological study extended the knowledge about important issues related to stuttering, such as the onset of stuttering, the development of stuttering and the explanation of stuttering severity and the interrelated variables. The results of the therapy effectiveness study and the quality of life study provided insights with regard to the improvement of speech and speech behaviour, recovery, persistence and relapse into stuttering. The present research solved the issues that remained unsolved after a review of the literature. Hopefully, the insights can be used by clinicians and researchers to improve the speech and the quality of life of people who stutter.

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APPENDIX

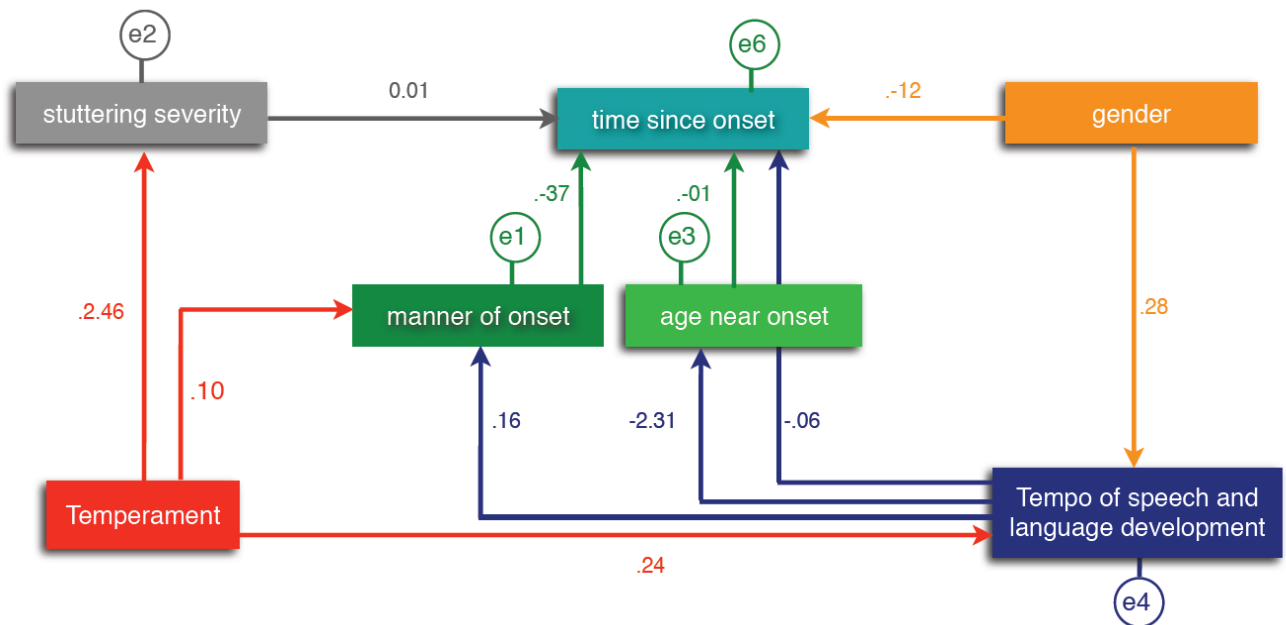


Figure 1. Onset of stuttering: related factors. Structural Equation Modeling Unstandardised regression weights.

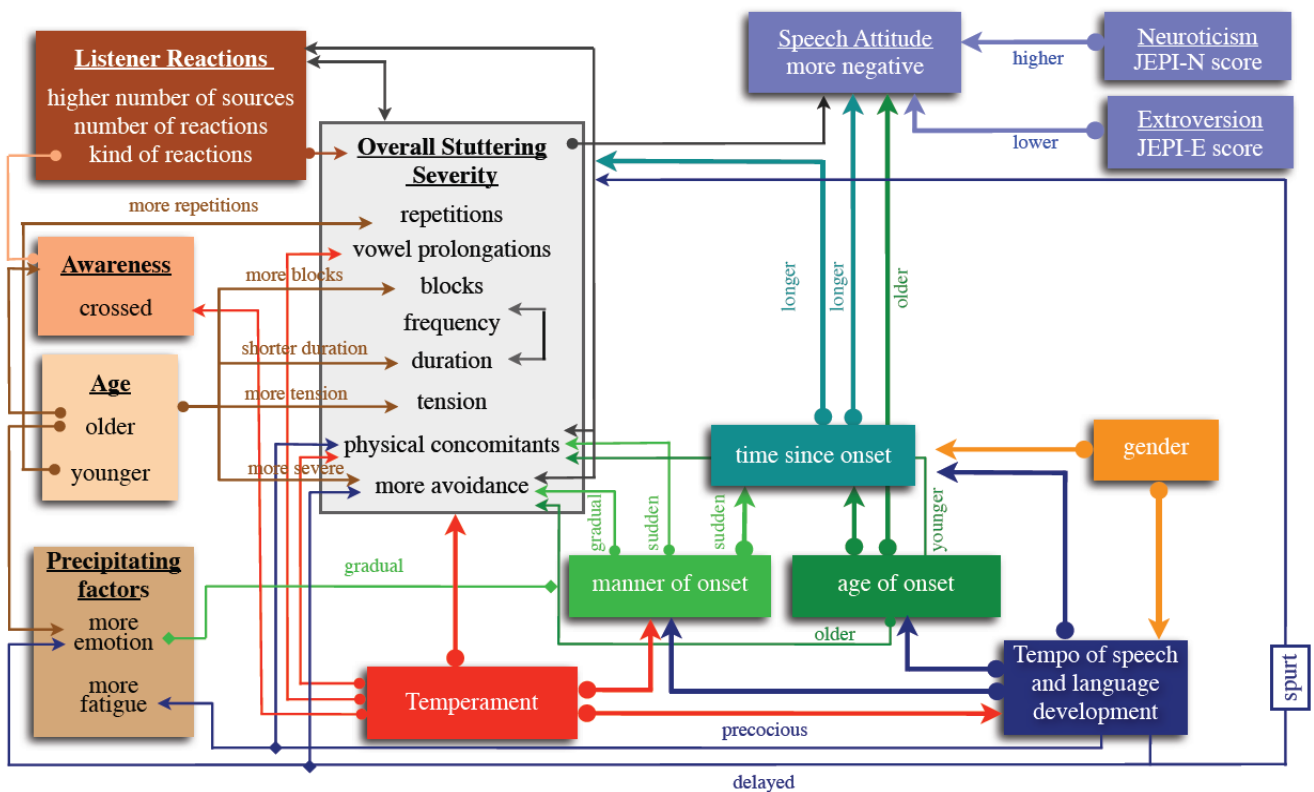


Figure 2. An integrated model of onset and development of stuttering and stuttering severity.