

Research Article

The Association Between Stuttering Burden and Psychosocial Aspects of Life in Adults

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ABSTRACT

Purpose: Stuttering is a speech condition that can have a major impact on a person's quality of life. This descriptive study aimed to identify subgroups of people who stutter (PWS) based on stuttering burden and to investigate differences between these subgroups on psychosocial aspects of life.

Method: The study included 618 adult participants who stutter. They completed a detailed survey examining stuttering symptomatology, impact of stuttering on anxiety, education and employment, experience of stuttering, and levels of depression, anxiety, and stress. A two-step cluster analytic procedure was performed to identify subgroups of PWS, based on self-report of stuttering frequency, severity, affect, and anxiety, four measures that together inform about stuttering burden.

Results: We identified a high- ($n = 230$) and a low-burden subgroup ($n = 372$). The high-burden subgroup reported a significantly higher impact of stuttering on education and employment, and higher levels of general depression, anxiety, stress, and overall impact of stuttering. These participants also reported that they trialed more different stuttering therapies than those with lower burden.

Conclusions: Our results emphasize the need to be attentive to the diverse experiences and needs of PWS, rather than treating them as a homogeneous group. Our findings also stress the importance of personalized therapeutic strategies for individuals with stuttering, considering all aspects that could influence their stuttering burden. People with high-burden stuttering might, for example, have a higher need for psychological therapy to reduce stuttering-related anxiety. People with less emotional reactions but severe speech distortions may also have a moderate to high burden, but they may have a higher need for speech techniques to communicate with more ease. Future research should give more insights into the therapeutic needs of people highly burdened by their stuttering.

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Stuttering is an involuntary condition of speech fluency that can have a major impact on a person's physical, psychological, and social quality of life (Connery et al., 2020). The World Health Organization defines stuttering as a condition that occurs in speech rhythm due to involuntary repetitive prolongations and interruptions, in which

the individual knows precisely what they want to say (Williams et al., 2010). Approximately 1% of the world's population is reported to stutter (Yairi & Ambrose, 2013). Stuttering is about 4 times more common in men than women (Craig & Tran, 2009). The prevalence of stuttering changes throughout the life span: Up to 8% of children experience stuttering by the age of 4 years, reducing to an estimated overall prevalence of 0.72% for the adult population (Craig & Tran, 2009; Yairi & Seery, 2015). Previous studies reported a diverse range of individual characteristics to be associated with the persistence of stuttering including later age of onset, male sex, family history of stuttering, higher frequency and severity of stuttering-like disfluencies, lower speech sound accuracy, and lower expressive and receptive language skills (Singer et al., 2020).

The primary perceptual characteristic of stuttering is dysfluent speech. However, people who stutter (PWS) experience stuttering as beyond the observable speech disfluency. They report that the moment of stuttering often begins with a sensation of anticipation, feeling stuck, or losing control (Tichenor & Yaruss, 2019b). This can lead to secondary affective, behavioral, and/or cognitive reactions such as tics, bodily tension, anxiety, and avoiding words or situations (Teesson et al., 2003; Tichenor & Yaruss, 2019b). Stuttering is often accompanied by a variety of speaker perceived thoughts, feelings, and behaviors, such as shame, annoyance, guilt, sadness, helplessness, and avoidance (Bernard et al., 2022; Gerlach-Houck et al., 2023; Tichenor & Yaruss, 2020). Few large-scale studies have examined the interaction between stuttering severity or persistence in relation to psychosocial outcomes. Recently, the Australian Genetics of Stuttering study reported on self-reported phenotypic data in a cohort of 987 individuals. Blocking was the most frequent speech symptom (73.2%), and syllable repetition was the least frequent (38.5%; Boyce et al., 2022). A large proportion of the group (75.9%) had sought stuttering therapy, yet only 15.5% reported stuttering recovery. A significant negative correlation with age was found for both stuttering frequency and severity. Stuttering frequency was also positively correlated with experienced severity. The majority of the participants in that study was anxious due to stuttering (90.4%) and perceived stuttering as a barrier to education and employment outcome (80.7%; Boyce et al., 2022).

Secondary thoughts, feelings, and behaviors can elicit, maintain, or worsen stuttering (Tichenor & Yaruss, 2019b), and mental problems are also associated with stuttering severity and impact. Associations have been found with neuroticism (Bleek et al., 2012; Brocklehurst et al., 2015), repetitive negative thinking (Tichenor & Yaruss, 2020), worrying about making mistakes (Ntourou et al., 2013), anxiety (Boyce et al., 2022), and mental health issues (Gunn et al., 2014). Furthermore, social anxiety

was higher in PWS compared to people who do not stutter, with at least one quarter of adults who stutter meeting criteria for social anxiety disorder (Chu et al., 2020; Iverach, O'Brian, et al., 2009; Kraaimaat et al., 2002). These relations between stuttering severity, stuttering impact and mental problems, and any causal links, have, however, not yet been explored thoroughly in large data sets.

Research into the impacts, consequences, and implications of stuttering have so far mostly focused on PWS as a single group. Classification systems to determine subtypes of stuttering have been offered, but it is a challenge to determine subgroups because of the heterogeneity of the group (Yairi, 2007). No large-scale studies have tried to develop subgroups based on own experiences of PWS. Two subtypes of persistent stuttering have been described since 1952: exteriorized ("overt") and interiorized ("covert") stuttering (Douglass & Quarrington, 1952; Sønsterud et al., 2022). Ajdacic-Gross and colleagues determined a further two stuttering subtypes by examining biological factors and psychosocial adversities in childhood: One subtype was associated with factors such as atopic diseases and psychosocial adversities in childhood, while the other showed only sporadic associations with other variables and had few comorbid disorders (Ajdacic-Gross et al., 2018). Furthermore, a study on group experiences and individual differences showed that PWS with more covert behaviors and more negative cognitive and affective states were more likely to participate in self-help groups focused on communicating freely, rather than focusing on reducing stuttering (Tichenor & Yaruss, 2019a).

Identifying subgroups based on self-reported experiences of PWS could help to provide insight into distinctive characteristics, behaviors, etiological bases, and therapy needs. Burden refers to the total experienced impact of living with stuttering, which includes both the observable and nonobservable characteristics of stuttering. Observable characteristics include stuttering frequency and severity. Stuttering frequency has often been described as an aspect of stuttering that is reported different from stuttering severity and therefore should be asked separately (Brutten & Vanryckeghem, 2003; Riley, 2009). This may result from the variability in stuttering frequency (Tichenor & Yaruss, 2021) and from covert behaviors (Guntupalli et al., 2006). It is therefore important to take both self-reported frequency and severity into account. Burden cannot simply be described by observable factors such as frequency or severity of stuttering. Some PWS stutter frequently and are hardly affected by it, while others stutter very rarely and are affected severely (Brutten & Vanryckeghem, 2003; Riley, 2009). Internal, nonobservable factors, such as anxiety and being affected by stuttering, also influence the extent to which burden is experienced. Anxiety and stuttering severity or frequency are not always

related, even though PWS generally have more anxiety in social interactions than people who do not stutter socially (Ezrati-Vinacour & Levin, 2004; Messenger et al., 2004; Miller & Watson, 1992). A reduction in social anxiety does not in itself appear to result in significant improvement of speech fluency but can reduce stuttering burden (Alm, 2014). An individual's coping style can also influence the relationship between stuttering severity and quality of life (Koedoot, Bouwmans, et al., 2011). We therefore investigated a combination of observable (stuttering frequency and severity) and nonobservable (anxiety and affect) aspects of stuttering to gain a complete picture of stuttering burden.

The overall aim of the study is to investigate the psychological and social aspects of stuttering and its impacts on wellbeing and societal participation. Specifically, the first aim is to identify subgroups of PWS based on stuttering burden, as assessed via self-reported stuttering frequency, severity, affect, and anxiety while stuttering. The second aim is to examine the differences between these subgroups in terms of the consequences of stuttering across social (i.e., education, employment, social relationships) and psychological areas (i.e., quality of life, general anxiety, depression and stress).

Method

Participants

This study is nested within the Max Planck Institute Erasmus Genetics of Stuttering (MEGS) Study, part of an international Genetics of Stuttering consortium (<https://www.mpi.nl/genetica-van-stotteren>). Participants were recruited between December 2019 and December 2022. Inclusion criteria for the present study were (a) participants aged 18 years or older and (b) with self-reported stuttering. Participants were asked whether they had stuttered in the last 12 months to determine whether they experienced stuttering in the present. The medical ethics committee of the Erasmus Medical Center in Rotterdam approved this study (registration number: MEC-2019-0491). Participants were recruited through a number of ways including national media campaigns, promotion through articles in newspapers and television broadcasts, invitation through speech therapists, promotion through support organizations, and social media.

Procedure

The study was executed online. The participants first had to read an online information letter and provide informed consent. Subsequently, they filled out an online questionnaire about their stuttering (completion time approximately 15 min). Finally, participants were invited

through e-mail to fill out an additional questionnaire about the impacts of stuttering on their life: the Dutch translation of the Overall Assessment of the Speaker's Experience of Stuttering for Adults (OASES-A; Koedoot, Versteegh, & Yaruss, 2011; Yaruss & Quesal, 2006). The data from the two questionnaires were linked on an individual participant level. Besides these quantitative data, participants were also invited to record their speech and provide a saliva sample via mail. Speech recordings and biological samples were not used for the current article. Participation was voluntary and without any reward.

Measurements and Outcomes

The questionnaire was originally developed by Early Language in Victoria Study (Kefalianos et al., 2017; Reilly et al., 2009, 2013) and was then adapted for use by the researchers of the Australian Genetics of stuttering study (Boyce et al., 2022) and the MEGS study. The following self-reported demographic data were examined: age, sex, highest educational level, and employment. Educational level was categorized into low (elementary school, lower vocational education), intermediate (secondary [vocational] education), and higher education (higher vocational education, university). Employment was divided into work participation: part time, full time, and other. Additionally, participants reported whether stuttering had impacted their education attainment and employment (yes/no).

Participant's experience of their stuttering was measured with four variables: severity, frequency, anxiety, and affect. Participants rated their stuttering severity on a 10-point scale: "How severely do you stutter? Using the following scale, where 1 indicates no stuttering and 10 indicates extremely severe stuttering (can hardly get words out)." This question was translated from a validated English question on stuttering severity (Boyce et al., 2022; Horton et al., 2023). Frequency of stuttering was measured with one self-developed question: "How often do you stutter at the moment?", which was answered on a 5-point scale ranging from *variable, not every day* to *usually multiple times per sentence*. Self-report on frequency has been suggested to give a comprehensive view on this aspect of stuttering, as methods relying on observation are affected by variation in stuttering frequency (Guntupalli et al., 2006). Stuttering affect was rated on a 10-point scale: "How much are you affected by stuttering? Use the following scale, where 1 indicates not being affected by stuttering, and 10 indicates being severely affected by stuttering." This question is often used in clinical settings in the Netherlands. Anxiety while stuttering was measured with three questions: (a) Are you anxious while stuttering? (yes/no) and, if yes, (b) How anxious are you while stuttering? (a little, fairly, very, extremely); and (c) What

makes you anxious when stuttering? (letters or syllables, situations, people, telephoning, other).

Additional observable aspects of stuttering were measured as well. A question about types of stuttering (blocks, prolongations, repetitions, other) provided insight into the stuttering phenotype of participants. Physical reactions while stuttering were also described, by assessing seven types of reactions: sweating, trembling, or palpitations; blushing; freezing; making distracting sounds; facial grimaces; head movements; and bodily movements. Participants rated whether they had these reactions at stuttering onset and in the present when stuttering.

Participants were also asked whether they had attended a therapy for stuttering in the past and what type of therapy this was. Tried therapies were divided into four categories: speech therapy as a child, speech therapy as an adult, a specific Dutch stuttering program (BOMA-therapy [Bewust Omgan Met Adem en gedrag], Del Ferro, Hausdörfer, or McGuire), and other therapies.

Personality and emotional stress were assessed by the Depression Anxiety Stress Scales (DASS; P. F. Lovibond & Lovibond, 1995; S. H. Lovibond & Lovibond, 1995). The DASS contains 42 items on a 4-point Likert scale. The 42 items are divided into three subscales with a higher score indicating higher severity of the core symptoms of depression, anxiety, and stress, respectively. The DASS also has sufficient reliability and validity for the Dutch population (de Beurs et al., 2001).

The OASES-A was used to measure participants' experiences with stuttering in daily life (Koedoot, Versteegh, & Yaruss, 2011; Yaruss & Quesal, 2006). The OASES-A is a 100-item questionnaire with four sections: (a) general perspectives about stuttering; (b) affective, behavioral, and cognitive reactions to stuttering; (c) functional communication difficulties; and (d) impact of stuttering on the speaker's quality of life. Item responses are rated on a 5-point Likert scale, with higher scores indicating a greater impact. The Dutch translation of the OASES-A was shown to be a reliable and valid measure to assess the impact of stuttering on Dutch adults who stutter (Koedoot, Versteegh, & Yaruss, 2011).

Statistical Analysis

SPSS Statistics (Version 25; IBM Corporation) was used for hierarchical and k-means clustering and quantitative data analysis. Descriptive analyses were used to describe the population. R (Version 4.0.0 with packages stats, cluster, factoextra, ggplot2, cowplot, viridis, and grid) was used for inspecting clusters, principal component analysis, and plotting. R code for cluster inspection and principal component analysis (PCA) is provided in Supplemental Material S3. To create subgroups based on stuttering burden, we selected four variables that could influence how

people experience the burden of their stuttering: frequency, severity, affect, and anxiety while stuttering. We performed a correlation analysis (Pearson's chi-squared test) and PCA to explore the relation between the four variables.

A two-step cluster analytic procedure was performed to identify subgroups. Cluster analysis is a statistical technique that divides data into groups, such that participants within a cluster are very similar to each other and differ greatly from the other clusters (Clatworthy et al., 2005). A hierarchical cluster analysis (the Ward method) was performed on the four variables (frequency, severity, affect, and anxiety) to give insight into the number of clusters present in the data. The hierarchical structure of the dendrogram that visualizes the results of the clustering showed that two subgroups could best explain the data. This was confirmed by a scree plot of within-cluster distance and high silhouette values for most individuals when assigned to two clusters (see Supplemental Figure S1.1). Then, a k-means cluster analysis was carried out to define the cluster membership of each participant. First, differences between the two subgroups on the four variables used to identify the subgroups on stuttering impact were analyzed using a one-way analysis of variance for continuous variables. Second, other variables were analyzed (using one-way analysis of variance for continuous variables and Pearson chi-square tests for categorical variables) to provide further insight into the clusters. Descriptive analyses were conducted to provide insight into the differences between the clusters on variables such as age, sex, education level, employment, impact of stuttering, and different therapies trialed. A Bonferroni-adjusted α of .003 was used to account for the 16 variables (age, sex, education level, employment, country of birth, stuttering phenotype at onset, stuttering phenotype at present, physical reactions to stuttering at onset, physical reactions to stuttering at present, anxiety, therapy, DASS subscales, OASES subscales, impact on education, impact on career development, and impact on finding a job) that were compared between the subgroups ($.05/16 = .003$).

A sensitivity analysis was performed to determine the effects of age on the differences between the two subgroups. For this purpose, the participants were stratified into five age groups: 18–24 years, 25–39 years, 40–54 years, 55–69 years, and 70 years and older, based on prior findings of Boyce et al. (2022). The same tests and analyses were used as described in the previous paragraph.

Results

Participants

The characteristics of the total group of 618 participants who stutter are summarized in Table 1. The study

Table 1. Participant characteristics.

Characteristics	Total <i>n</i>	<i>n</i>	%	<i>M</i>	<i>SD</i>
Age	618			44.57	16.47
Sex, male	605	383	63.3		
Highest level of education					
Low	613	28	4.6		
Intermediate	613	220	35.6		
High	613	365	59.5		
Employment					
Work participation (full time)	609	311	51.1		
Work participation (part time)	609	85	14.0		
Other	609	203	33.3		
Country of birth (the Netherlands)	609	550	90.3		
Frequency of stuttering (1–5)	613			2.49	1.35
Stuttering severity (1–10)	604			4.13	1.84
Affected by stuttering (1–10)	613			4.32	2.36
Stuttering phenotype					
Blocks	618	443	71.7		
Prolongations	618	253	40.9		
Repetitions	618	449	72.7		
Anxiety while stuttering (1–5)	612			2.15	1.01
Anxiety for letters or sounds	439	183	41.7		
Anxiety for situations	442	339	77.7		
Anxiety for people	442	231	52.2		
Anxiety for telephoning	442	209	47.2		
Tried therapies					
No therapy	618	52	8.4		
Speech therapy as a child	618	454	73.5		
Speech therapy as an adult	618	380	61.5		
Stuttering program	618	203	32.8		
Other	618	196	31.7		
DASS-questionnaire, sum score					
Depression (0–42)	590			5.29	7.09
Anxiety (0–42)	589			4.21	5.31
Stress (0–42)	588			8.06	7.38
OASES-A questionnaire (1–5)					
General information	384			2.66	0.51
Reaction of the speaker	384			2.51	0.69
Daily communication	384			2.18	0.68
Quality of life	384			1.90	0.73
Total score	384			2.31	0.59
Reported impact on educational level (yes)	612	196	32.0		
Reported impact on career development (yes)	612	267	43.6		
Reported impact on finding a job (yes)	610	349	57.2		

Note. Minimum and maximum scores on items and (sub)scales are provided between brackets. DASS = Depression Anxiety Stress Scales; OASES-A = Overall Assessment of the Speaker's Experience of Stuttering for Adults.

population had an average age of 44.6 years ($SD = 16.5$) and 62.0% were male. Participants showed different types of stuttering: mainly blocks (71.7%) and repetitions (72.7%) and, to a lesser extent, prolongations (40.9%). Severity of stuttering was scored as 4.1, on average, on a scale range from 1 (*no stuttering*) to 10 (*extremely severe stuttering*). The participants had a minimum score of 2

and a maximum score of 9. The score on affected by stuttering was 4.3, on average, ranging from 1 to 10. More than half of the participants indicated that stuttering had had a negative impact on their career development ($n = 349$, 56.5%). This proportion was lower than the experienced impact on educational level: 196 (31.7%) participants stated stuttering had had an impact. Lastly,

267 (43.2%) participants experienced that stuttering had made it more difficult to find work.

Scores on the DASS were highly variable, from a minimum score of zero to a maximum score of 42 on the depression scale, 40 on the anxiety scale, and 38 on the stress scale. The mean scores of the cohort are categorized as “normal” by the DASS-manual; however, maximum scores of several participants are categorized as “extremely severe” (S. H. Lovibond & Lovibond, 1995). In total, 83% of the participants scored within the normal range for depression, anxiety, and stress. Overall, the OASES-A questionnaire showed that the impact of stuttering was moderate. The section “quality of life” showed an *M* score of 1.90, which is considered as a mild-to-moderate impact.

Subgroups of PWS

The four variables (stuttering frequency, severity, affect, and anxiety) included in the cluster analysis were highly correlated (see Supplemental Table S1.1). A PCA analysis identified two components that explain the majority of variance in the four variables (see Supplemental Figure S1.2). The first component is loading positively on all input measures. The second component is loading positively onto stuttering anxiety and affect, while loading negatively onto stuttering frequency and severity. Since there is more than one independent component that explains a major part of the variation in the four correlated variables, we proceeded to use the four variables in a clustering approach to identify subgroups of PWS.

Two clusters of participants were identified in the data. The first cluster contained 230 (38% of total) PWS and is characterized by higher scores on frequency ($M = 3.47$, $SD = 1.13$), severity ($M = 5.89$, $SD = 1.53$), affect ($M = 6.71$, $SD = 1.60$), and anxiety ($M = 2.63$, $SD = 1.08$; see Figure 1). This subgroup was therefore identified as “high burden.” The mean age in this subgroup is 39.01 years ($SD = 14.53$), and 56.1% were male (see Table 2). The second cluster contained 372 (62% of total) PWS and was characterized by lower scores on frequency ($M = 1.88$, $SD = 1.08$), severity ($M = 3.05$, $SD = 0.99$), affect ($M = 2.81$, $SD = 1.17$), and anxiety ($M = 1.84$, $SD = 0.81$; see Figure 1). This subgroup was therefore identified as “low burden.” The mean age in this subgroup was 48.36 years ($SD = 16.56$), and 66.4% were male. Stuttering frequency did not fully account for the differences between the two subgroups. Even when reported stuttering frequency was the same, the high-burden subgroup showed higher levels of stuttering severity, affect, and anxiety during stuttering (see Supplemental Figure S1.3).

When comparing the high-burden and low-burden subgroups, differences were found in trialed therapies (see

Table 2): More participants in the high-burden subgroup reported to have trialed speech therapy as a child ($p = .003$) and stuttering programs as an adult ($p < .001$) compared to the low-burden subgroup. Similarly, the high-burden subgroup showed higher percentages of persons who had trialed speech therapies as an adult ($p = .36$) and other therapies ($p = .07$).

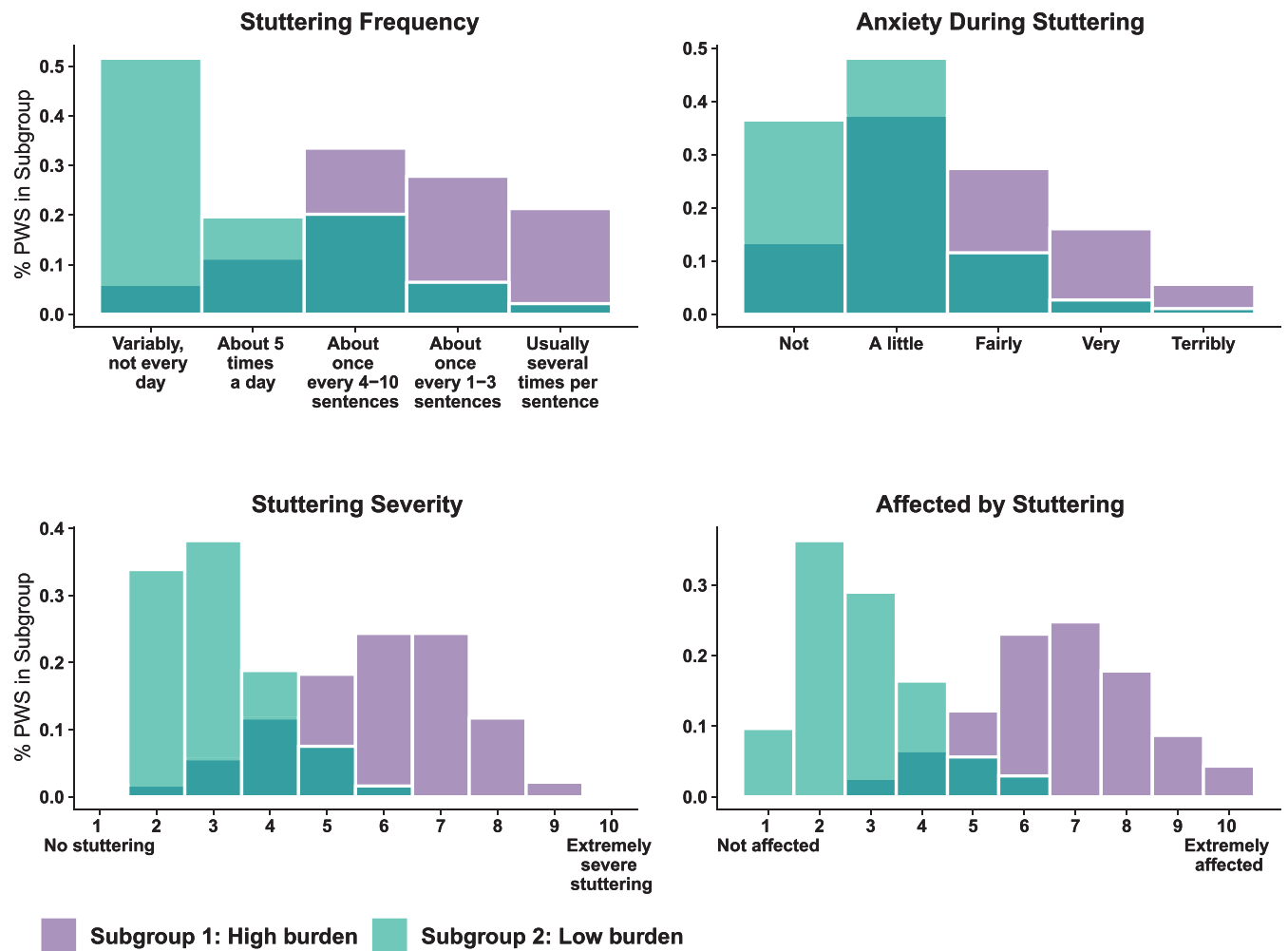
The Impact of Stuttering on Education and Employment

A significant difference between the two subgroups was found for the impact of stuttering on both career development ($p < .001$) and finding employment ($p < .001$; see Table 2). In the high-burden subgroup, 59.1% of participants reported that stuttering had negatively impacted their career development and 71.7% reported that stuttering had made it harder to find a job, compared to 33.1% and 47.3%, respectively, in the low-burden subgroup. No significant difference was identified between the two subgroups regarding impact on educational level ($p = .07$), in which 35.7% of the high-burden subgroup and 29.0% of the low-burden subgroup reported an impact.

Impact of Stuttering and Emotional States

Significant differences were found between the two subgroups on the DASS (see Figure 2A), on questions regarding anxiety while stuttering (see Table 2), and the OASES questionnaire (see Figure 2B). First, the high-burden subgroup scored higher than the low-burden subgroup on DASS subscales depression, $F(1, 556) = 15.14$, $p < .001$; anxiety, $F(1, 557) = 24.75$, $p < .001$; and stress, $F(1, 556) = 16.25$, $p < .001$. The high-burden subgroup scored higher on all DASS subscales even though the mean scores and interquartile range for all subscales of the DASS were within the normal range for both the high- and low-burden subgroup, and the range of scores were comparable. Second, 70% of participants in the high-burden subgroup experienced anxiety for situations compared to 45.7% in the low-burden subgroup ($p < .001$). Similar differences were found for anxiety for letters or sounds ($p < .001$), anxiety for people ($p < .001$), and anxiety for making a phone call ($p < .001$; see Table 2). Lastly, the high-burden subgroup scored higher on all sections of the OASES-A, as well as on the overall impact score (see Figure 2B and Supplemental Table S1.3). On average, the high-burden subgroup showed a “moderate” impact, and the low-burden subgroup showed a “mild-to-moderate” impact. The high-burden subgroup scored especially higher than the low-burden subgroup on OASES-A Section II “reaction of the speaker,” $F(1, 334) = 65.63$, $p < .001$, and OASES-A Section IV “quality of life,” $F(1, 334) = 82.99$, $p < .001$.

Figure 1. High- and low-burden stuttering subgroups were distinguished based on anxiety while stuttering and on stuttering frequency, severity and affect. Overlaying histograms for high-burden subgroup (in purple) and low-burden subgroup (in green) are shown for the four measures that were used to define the subgroups, with overlap between the subgroups shown in dark green). The histograms show higher scores on all four variables for people who stutter (PWS) in the high-burden subgroup.



Stuttering at Onset and at Present

Participants described their stuttering phenotypes (blocks, prolongations, repetitions) and physical reactions while stuttering for two time points: when they started stuttering (at onset) and at the time of completing the survey (at present). At stuttering onset, the high-burden and low-burden subgroups reported highly similar outcomes regarding the stuttering phenotypes and physical reactions. Only a trend for more prolongations was found for the high-burden subgroup compared to the low-burden subgroup (uncorrected $p = .042$). This effect was no longer significant after correction for multiple comparisons. Besides that, no significant differences nor trends were found between the two subgroups at stuttering onset. In other words, participants with high-burden stuttering did not report other stuttering

phenotypes nor (physical) reactions at stuttering onset than participants with low-burden stuttering. However, at the time that the survey data were collected, the high-burden subgroup reported significantly more prolongations and physical reactions on all aspects at present than the low-burden subgroup (see Figure 3 and Supplemental Table S1.2). Thereby, participants in the high-burden subgroup reported a higher percentage of the stuttering phenotype (blocks, prolongations, and repetitions) and reactions at present compared to stuttering at onset. For participants in the low-burden subgroup, this was lower. Most striking is the large increase ($p < .001$) on reporting “no physical reactions from stuttering” in the low-burden group from stuttering at onset (17.7%) to at present (41.1%). In contrast, the PWS in the high-burden subgroup did not report any differences in experiencing “no physical reactions” over time.

Table 2. Subgroup-participant characteristics.

Characteristics	Subgroup 1: High burden			Subgroup 2: Low burden			<i>p</i>
	Total <i>n</i>	<i>n</i>	%	Total <i>n</i>	<i>n</i>	%	
Sex (male)	230	129	56.1	372	247	66.4	.05
Highest level of education							
Low	230	13	5.7	372	15	4.0	.51
Intermediate	230	96	41.7	372	119	32.0	.02
High	230	121	52.6	372	238	63.9	.01
Employment							
Work participation (full time)	228	117	51.3	371	194	52.2	.83
Work participation (part time)	228	36	15.8	371	49	13.2	.38
Other	228	75	32.9	371	128	34.5	.69
Country of birth (the Netherlands)	229	203	88.6	369	338	91.6	.42
Anxiety							
Anxiety for letters or sounds	198	90	39.1	232	89	23.9	< .001*
Anxiety for situations	199	161	70.0	234	170	45.7	< .001*
Anxiety for people	199	131	57.0	234	94	25.3	< .001*
Anxiety for telephoning	199	119	51.7	234	84	22.6	< .001*
Therapy							
Speech therapy as a child	230	185	80.4	372	259	69.6	.003*
Speech therapy	230	151	65.7	372	222	59.7	.14
Stuttering program	230	101	43.9	372	99	26.6	< .001*
Other	230	86	37.4	372	106	28.5	.02
Reported impact on educational level	229	82	35.8	372	108	29.0	.07
Reported impact on career development	229	136	59.4	372	123	33.1	< .001*
Reported impact on finding a job	229	165	72.1	370	176	47.6	< .001*

Note. The total *n* describes the number of participants per subgroup that filled out the question.

*Significance corrected for multiple testing.

Sensitivity Analysis—Age Groups

A significant difference in age ($p < .001$) was found between the high-burden and low-burden subgroups with mean ages of 39.01 years ($SD = 14.53$) and 48.36 years ($SD = 16.56$), respectively (see Supplemental Figure S1.4). Therefore, sensitivity analyses were performed to study whether the phenotypic differences observed between subgroups could (not) be attributed to the differences in age. For this, the main comparisons between the subgroups were repeated within five subsets of the participants with narrow age ranges (see Supplemental Table S2.1). Differences on the four variables that determined burden (frequency, severity, affect, and anxiety during stuttering) were significant for all age subsets (Supplemental Table S2.2 and Supplemental Figure S2.1). The conducted analyses show the same trends for different age subsets as shown by the main analyses, confirming that the high-burden subgroup is significantly more impacted than the low-burden subgroup.

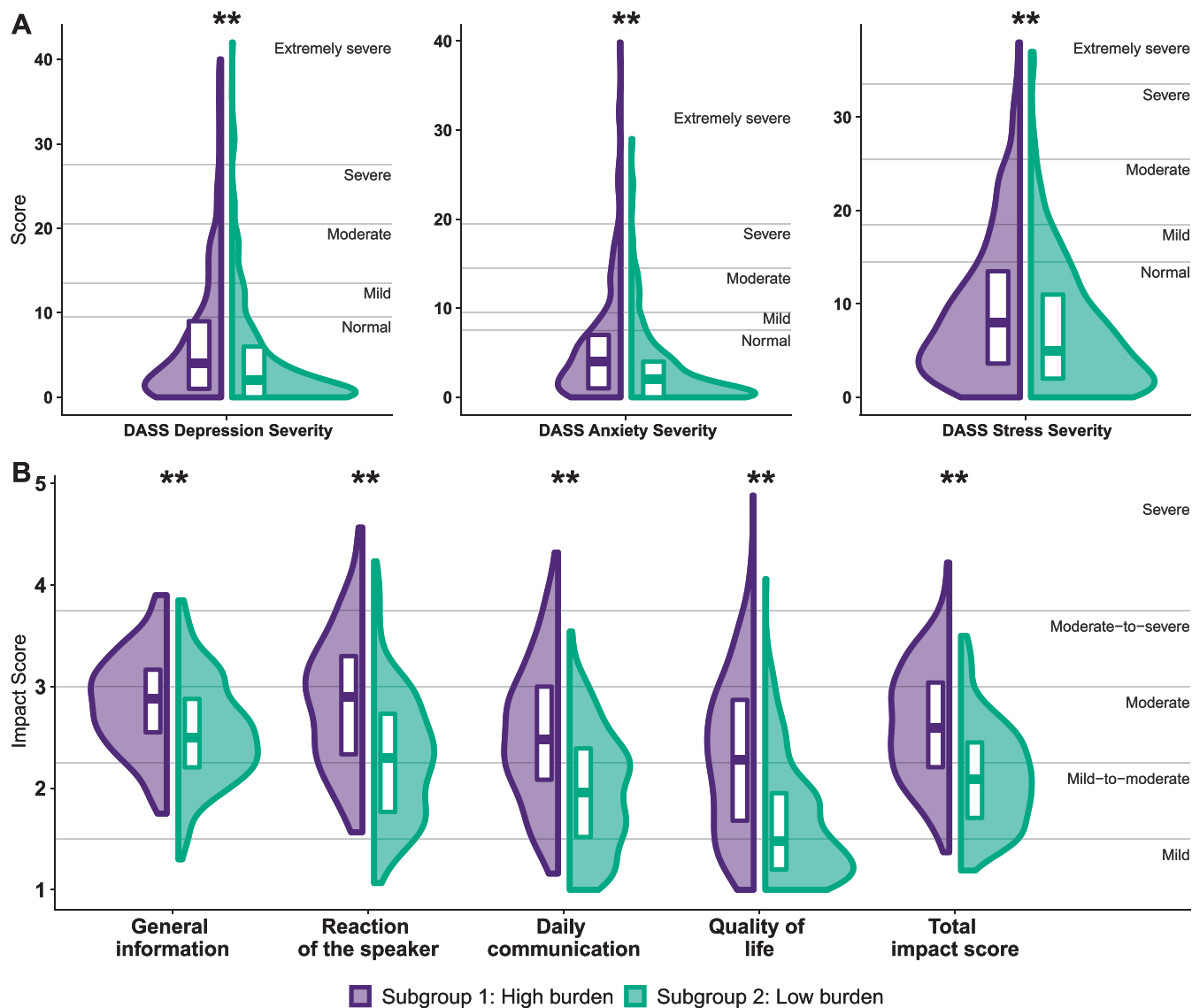
In summary, a similar pattern was seen for all results inspected over the five age groups: The high-burden subgroup showed higher anxiety for letters and sounds, people, situations, and making phone calls; more

participants attended therapy as a child; and more participants attended stuttering programs on top of regular speech therapy as an adult, reported more frequently an impact on career development, education level, and finding a job; and scored higher on depression, anxiety, and stress subscales, and on the OASES total impact score (see Supplemental Tables S2.3–S2.6 and Supplemental Figures S2.2–S2.5). For some variables, a relationship with age was observed. For example, stuttering frequency, depression, anxiety, and stress at present decreased with age in both the high- and low-burden group. For stuttering anxiety during stuttering at present related to situations, telephoning, people, and letters/sounds the relationship with age was only found in the high-burden subgroup. More specifically, for the age group of 25–39 years, the percentage of male participants was higher in the low-burden subgroup than in the high-burden subgroup (69.3% and 52.4%, respectively).

Discussion

This descriptive study aimed to identify differences in psychosocial aspects of life between burden subgroups

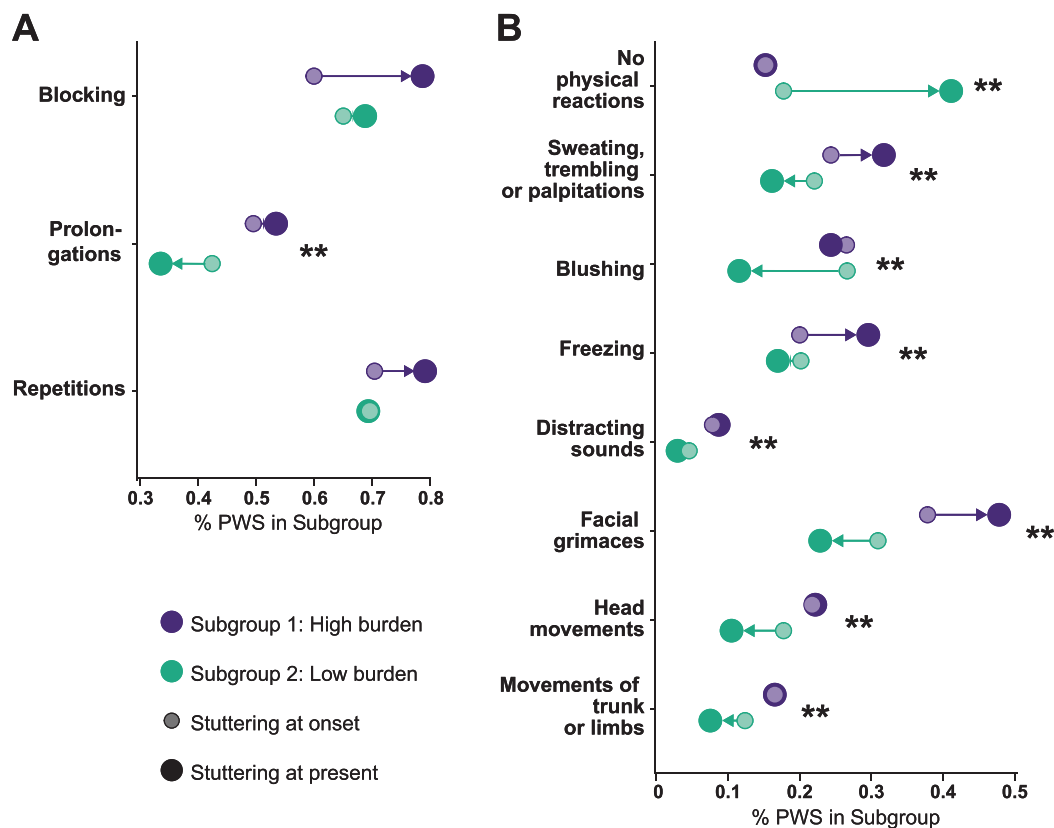
Figure 2. Subscores of the Depression Anxiety Stress Scales (DASS) and Overall Assessment of the Speaker's Experience of Stuttering for Adults (OASES-A) questionnaires for high-burden and low-burden subgroups. (A) Results of the three DASS subscales on depression severity, anxiety severity, and stress severity. (B) Results of the four OASES-A sections (general information, reaction of the speaker, daily communication and quality of life) and the OASES-A total score. Violin plots show the distributions of scores for the high-burden subgroup (in purple) and the low-burden subgroup (in green). Box plots show median and first and third quartiles. Score categories from normal to extremely severe and from mild to severe are provided according to the DASS (21) and OASES-A manual (25), respectively. **Significant difference between subgroups after correction for multiple testing.



of PWS. Two subgroups, high burden and low burden, were identified from a large study sample of volunteer participants. Around 38% of the participants were assigned to the high-burden subgroup (230 PWS), which showed higher scores on frequency, severity, affect, and anxiety. The low-burden subgroup contained 372 (62%) PWS and had lower scores on these four variables. The impact on educational levels did not differ significantly between the two subgroups; however, the high-burden group did experience higher impact on education and employment. The

high-burden subgroup also reported higher impact on overall depression, anxiety, and stress levels. The overall impact of stuttering was also higher for the high-burden subgroup. For present stuttering, there were differences between the subgroups on all (physical) reactions to stuttering, like blocking, sweating, facial grimaces, and freezing. The two subgroups differed significantly on age, but the sensitivity analysis showed that our findings could not be explained by the higher age of the low-burden group. Differences in social life, work experiences, and

Figure 3. Stuttering phenotype (A) and physical reactions (B) at onset and present. The arrows illustrate whether the subgroups reported an increase or decrease of the phenotype or reaction in time. **Significant difference between subgroups at present after correction for multiple testing. At onset, no significant differences were identified between the two subgroups. PWS = people who stutter.



psychological areas were still seen between the two subgroups when restricting analyses to more narrow age groups.

Stuttering can impact employment experiences, shape a person's self-identity, and adversely impact relationships (Connery et al., 2020). Our results quantitatively validated these qualitative findings. To our knowledge, this is the first study that developed self-reported data-driven subgroups in a sample of hundreds of PWS. Not only were stuttering severity and frequency used to determine subgroups based on burden, but also measures on being affected by and experiencing anxiety during stuttering were considered as influencing factors. It is important to take into account both the frequency and severity of the speech distortions (as measured by self-reported stuttering frequency and severity) and the emotional reactions to these (as measured by reported affect and anxiety), since these two aspects are not correlated for all PWS (Brutten & Vanryckeghem, 2003; Riley, 2009; Vanryckeghem et al., 2017). The two burden subgroups, determined via cluster analysis, highlighted that PWS can be affected very differently by their stuttering.

Stuttering and Anxiety

The large majority of participants reported experiencing anxiety during stuttering. In addition, differences between the two subgroups were seen in a general measure for anxiety. However, conflicting results exist about the relation between anxiety and stuttering. Several community cohort studies have provided evidence that anxiety is not associated with stuttering in young children who stutter (Kefalianos et al., 2014, 2017; Koenraads et al., 2021). However, higher levels of anxiety have been associated with stuttering in older children and teenagers with persistent stuttering (Blumgart et al., 2010; Iverach, O'Brian, et al., 2009). For adults, a heightened risk of social anxiety for PWS has been found (Blumgart et al., 2010; Iverach et al., 2018; Iverach & Rapee, 2014; Lowe et al., 2021; Smith et al., 2014). Social anxiety disorder is a chronic and disabling anxiety disorder that involves fear of negative evaluation in social situations (American Psychiatric Association, 2013). Conflicting evidence has also been found for the association between anxiety and stuttering severity. For some people, anxiety as a result of stuttering persistence can worsen stuttering (Bernard et al., 2022; Naz & Kausar,

2022; Sizer & Sizer, 2023; Smith et al., 2014). If stuttering severity and anxiety are correlated, this relation might create a vicious cycle: If a person is afraid to stutter, that person may stutter more as a result of classical conditioning (higher arousal level and higher tension elicit more stuttering). In addition, the person may increase the use of behaviors to escape or avoid stuttering (operant condition), causing the person to stutter more severely in the long term and experience higher levels of adverse impact (Brutten & Shoemaker, 1971; Tichenor & Yaruss, 2019a).

Around 38% of the PWS in our study were assigned to the high-burden subgroup. The differences between the low-burden and high-burden subgroups are similar to those found by a study of Iverach et al. (2018) comparing adults who stutter with and without social anxiety disorder. Stuttering adults with social anxiety are typically younger; more dissatisfied with their speech; report more avoidance of speaking situations; experience a greater negative impact of stuttering (OASES questionnaire); show a higher number of emotional, social, and behavioral problems; show more symptoms of depression; and show more negative thoughts and beliefs associated with social anxiety (Iverach et al., 2018). Part of the differences between the low-burden and high-burden groups may therefore be explained by the differences in experienced anxiety between the subgroups. However, it is fully understandable that PWS experience social anxiety. Current society is designed for fluent speakers; stuttering often leads to negative reactions or jokes about stuttering, and PWS are often perceived as not confident and shy (Boyle, 2017; Connery et al., 2020; Constantino et al., 2022). Reducing the stigma that PWS experience from society therefore has the potential to greatly reduce the impact of stuttering.

Stuttering Burden and Therapy

The high-burden subgroup reported having attended significantly more diverse therapies than the low-burden subgroup. Possible explanations for this finding are the following. First, PWS with higher stuttering severity or higher anxiety might be more inclined to attend therapy. Second, children who stutter are more encouraged to follow speech therapy when their stuttering is more severe or worsens. We did not find any differences between how the two groups experienced their stuttering at onset (type of stuttering nor physical reactions) that could explain the differences in trialed therapy as a child. Still, these results might be due to a recall bias since participants needed to report on stuttering that occurred many years ago. Recall bias might occur for both reporting on trialed therapy as well as stuttering experiences as a child. High-burden PWS might recall their therapy as a child more adequately than low-burden PWS, who might more often have

forgotten about the therapy in their childhood. Third, PWS in the high-burden group may have experienced fewer positive effects of treatment. The presence of an anxiety-related disorder might be one potential contributing factor when a person does not respond to a therapy (Kraaimaat et al., 2002). Fourth, higher awareness due to—ineffective—therapy could increase feelings of concern and, as a result, increase stuttering severity and the burden of it (Lowe et al., 2021). It has been recognized that the ability to maintain the benefits of speech restructuring may only be achieved by around 30%–70% of PWS (Craig & Hancock, 2014; Craig & Tran, 2006; Franken et al., 1997; Iverach, Jones, et al., 2009; Langevin et al., 2006). Speech restructuring therapies can, for example, be effective in lowering the emotional reactions to stuttering (Franken et al., 1997). However, in some cases, speech therapies, such as speech restructuring procedures to control stuttering, even appear to be in conflict with psychological therapies for the therapy of anxiety (Lowe et al., 2021). This might especially be the case in people with high-burden stuttering. In contrast, nonavoidance speech therapies (Sisskin & Goldstein, 2022) target mental problems such as stuttering related anxiety. Further research is, however, required to investigate these—and other—explanations.

Participants with high-burden stuttering may not trial the appropriate (holistic) therapy to lower their burden. People with high-burden stuttering might have a higher need for psychological therapy to reduce secondary stuttering behaviors and feelings such as avoidance and anxiety. Iverach et al. (2019) described that PWS who trialed anxiety treatment reported lower stuttering severities than PWS who trialed speech treatment, yet the two groups did not differ on clinician-rated percentage of syllables stuttered (Iverach et al., 2019). This might suggest that people with higher burden stuttering are more likely to focus on speech therapy where people in the low-burden group are more likely to additionally focus on treatment for anxiety. Similar results were found in a study for PWS with more overt stuttering, who were more likely to participate in therapies focused on reducing stuttering instead of communicating freely (Tichenor & Yaruss, 2019a). Iverach and Rapee (2014) already pleaded for better collaboration between speech pathologists and psychologists, to develop and implement comprehensive assessment and treatment programs (Iverach & Rapee, 2014). Our results indicate that especially in high-burden individuals, therapy should target reducing the impacts, speech and stuttering related anxiety, and other psychosocial consequences of stuttering. Psychological therapies, such as cognitive-based therapy and acceptance and commitment therapy, are explicitly offered to PWS. Either way, more understanding of PWS's therapy satisfaction at both low and high burden is needed.

Strengths and Limitations

The large sample size and detail in both demographic data as well as psychosocial and stuttering-related data are strengths of this study. Still, our study had several limitations. First, recruitment bias could have occurred because participants were self-selected. It is likely that people who experience difficulties with their stuttering might be more eager to join a study about the problem. This may influence how well our results can be extrapolated to the broader population of PWS. Second, it should be noted that distinguishing two subgroups is not sufficient to describe the high variability in stuttering and experiences for individuals who stutter. Personalized treatments, tailored to the needs of the individual, are required (Connery et al., 2021). Stuttering not only varies between individuals, but PWS can also experience variability between situations and moments in both stuttering severity as well as in internal aspects (such as physical tension) and cognitive experiences (such as negative thoughts and feelings; Tichenor & Yaruss, 2021). Third, the sample size for the OASES questionnaire was lower than for the rest of the study, as participants were invited separately for this survey. Fourth, the low-burden subgroup in this study was, on average, 9 years older than the high-burden subgroup. A negative correlation between age and stuttering severity has been found in earlier literature (Boyce et al., 2022; O'Brian et al., 2022). In sensitivity analysis for age, the direction of effects was preserved but differences were less substantial. This might be due to smaller sample sizes when dividing the overall cohort into age groups, reducing the power. Our sensitivity analysis did highlight the age ranges for which our results are consistent; the majority of results could be replicated in all age groups, from 18 to 25 years old to the group of age 70 years and older. Yet, more subtle differences between the subgroups that did not reach significance after correction for multiple testing, for example, in sex and education level, were not addressed in these sensitivity analyses. Fifth, recall bias might have affected the data investigating the onset of stuttering. Sixth, anxiety during stuttering can vary between situations (Vanryckeghem et al., 2017); the single-item question used to measure anxiety during stuttering may have missed nuances regarding its variability.

Conclusions

The purpose of this study was to provide insight into the association between stuttering burden and psychological and social aspects of stuttering. We identified two subgroups (high and low burden) based on self-report of stuttering, and showed that the high-burden subgroup more frequently reported emotional and physical reactions to stuttering and impact on education and employment,

and scored higher on measures of anxiety, stress, depression, and impact of stuttering. These results emphasize the diversity in burden and impact of stuttering on individuals. Our results also stress to look beyond stuttering frequency as a measure of stuttering severity, as several PWS in the high-impact subgroup reported high levels of severity, affect, and/or anxiety despite reporting low stuttering frequency. We therefore suggest to enhance tailoring and personalization of therapies, to focus on those aspects of stuttering with the largest impact on stuttering burden. For example, people with high-burden stuttering might have a higher need for psychological therapy to reduce stuttering-related anxiety. Future research should give more insights into the therapeutic needs of PWS.

Data Availability Statement

The primary data have been deposited at the Psycholinguistics Archive (<https://archive.mpi.nl/mpi/>), a public data archive hosted by the Max Planck Institute for Psycholinguistics. Data are accessible to academic users under the persistent identifier <https://hdl.handle.net/1839/f2241467-b5eb-44de-af97-da550dd5b763>.

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