Title: Group Experiences and Individual Differences in Stuttering

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Abstract

Purpose: This study explored group experiences and individual differences in the behaviors, thoughts, and feelings perceived by adults who stutter. Respondents' goals when speaking and prior participation in self-help/support groups were used to predict individual differences in reported behaviors, thoughts, and feelings.

Method: 502 adults who stutter completed a survey examining their behaviors, thoughts, and feelings in and around moments of stuttering. Data were analyzed to determine distributions of group and individual experiences.

Results: Speakers reported experiencing a wide range of both overt behaviors (e.g., repetitions, blocks, tension) and covert behaviors (e.g., remaining silent, choosing not to speak). Having the goal of *not stuttering when speaking* was significantly associated with more covert behaviors and more negative cognitive and affective states, while a history of self-help/support participation was significantly associated with a decreased probability of these behaviors and states.

Conclusion: Data from this survey suggest that participating in self-help/support and having a goal of communicating freely (as opposed to trying to not stutter) are associated with less negative life outcomes due to stuttering. Results further indicate that the behaviors, thoughts, and experiences most commonly reported by speakers may not be those that are most readily observed by listeners.

1.1 LITERATURE REVIEW

A growing number of research papers and popular press books have highlighted and given voice to people's experience of living with stuttering (Ahlbach & Benson, 1994; Blood et al., 2011; Boyle, 2017, 2018; Constantino, 2018; De Nardo, Gabel, Tetnowski, & Swartz, 2016; Jackson, Yaruss, Quesal, Terranova, & Whalen, 2015; Plexico, Manning, & Levitt, 2009b, 2009a; Preston, 2013; St Louis, 2001; Tetnowski & Damico, 2001; Tichenor, Leslie, Shaiman, & Yaruss, 2017; Tichenor & Yaruss, 2018; Yaruss, Quesal, Reeves, et al., 2002; Yaruss & Quesal, 2004; Yaruss, Quesal, & Murphy, 2002). For example, research has shown that so-called ”covert” behaviors (Constantino, Manning, & Nordstrom, 2017; Douglass, Schwab, & Alvarado, 2018; Murphy, Quesal, & Gulker, 2007) and anticipation (Arenas & Zebrowski, 2017; Brocklehurst, Lickley, & Corley, 2012; Garcia-Barrera & Davidow, 2015; Jackson et al., 2015) are relatively common across the population of people who stutter. Recent research evidence has also increased awareness of the broader impact of stuttering, including societal stigma and self-stigma (Boyle, 2013; Boyle & Fearon, 2018), and occupational disadvantages (Bricker-Katz, Lincoln, & Cumming, 2013; Gabel, Blood, Tellis, & Althouse, 2004; Gerlach, Totty, Subramanian, & Zebrowski, 2018). These factors can have a notable impact on a person's life, so understanding them is vital for explaining why people experience stuttering in the way(s) they do—and why one person might experience stuttering differently from another person (Tichenor & Yaruss, 2019; Yaruss & Quesal, 2004).

Stuttering research as a whole has not sufficiently accounted for how *individual* differences in people who stutter might relate to or predict various aspects of the condition. Certainly, a vast body of literature exists comparing people who stutter *as a group* to groups of people who do not stutter. Such endeavors are fruitful for providing knowledge about factors such as the neurophysiological origins of stuttering (see for review, Etchell, Civier, Ballard, & Sowman, 2017). Still, it not yet known how individual factors (e.g., a history of treatment, participation in self-help/support organizations, etc.), might affect the manifestation of stuttering behaviors or the role that such behaviors play in a person's daily life experiences. Specifically, there are numerous types of therapy for people who stutter, some of which are focused more on enhancing fluency, and some of which are focused more on stuttering openly and freely, increasing communication effectiveness, or reducing negative behavioral or cognitive reactions (Bloodstein, 1993; Bloodstein & Bernstein Ratner, 2008). People's experience of stuttering might be affected by their differing therapy histories and treatment goals, their unique personal goals regarding speaking or communicating, or other prior experiences.

Likewise, research evidence suggests that participation in self-help and support groups affects speakers' communication attitudes (Bradberry, 1997; Herring, Millager, & Yaruss, 2018; McClure & Yaruss, 2003; Trichon & Tetnowski, 2011; Yaruss, Quesal, & Murphy, 2002; Yaruss, Quesal, & Reeves, 2007). The findings suggest that people who participate in self-help/support report better outcomes from therapy. Still, respondents in these studies came from highly selected and homogenous samples of people who participate in such groups/activities. As yet, studies have not specifically compared the experiences of people who have a history of participating in self-help/support and people who do not have such a history. The implications of such differences may be profound, for many studies in recent years have used samples that relied heavily on support group participants, in part due to the relative ease of recruiting (e.g., Boyle & Fearon, 2018; Constantino, Leslie, Quesal, & Yaruss, 2016; Howell & Bernstein Ratner, 2018; Sasisekaran, 2013). While not necessarily problematic due to the many types of people who participate in self-help/support (Yaruss, Quesal, Reeves, et al., 2002), relying on subject samples dominated by people who have participated in self-help/support or who have received treatment may yield data that is not representative of the broader population of people who stutter.

To better understand individual differences regarding how stuttering manifests itself and what speakers who stutter in their lives, it is necessary to differentiate between group aspects and individual differences. This can be accomplished by exploring how individual differences might be related to other aspects of respondents' experiences with stuttering. As outlined above, it is clear that prior participation in self-help/support and goals when speaking are two factors that affect individual experiences, so these should be further explored in order to improve diagnosis and treatment of stuttering. A person's goal when speaking should also be examined as a factor to differentiate between individuals within the population of people who stutter due to the varied natures of different treatment approaches. In addition to providing more information about the lives of those who stutter, this exploration of individual differences will help to reduce the gap between speaker-based and listener-based definitions of stuttering. Historically, most definitions of stuttering have been based on the observations of listeners (Conture, 1990; Cordes & Ingham, 1995; Gregory, 1986; Johnson, 1959; Teesson, Packman, & Onslow, 2003; Wingate, 1964; Yairi & Ambrose, 1992; see review in Yaruss, 1997). As such, they are focused on observable, surface behaviors (Jackson, Quesal, & Yaruss, 2012) that may not capture all of the aspects of stuttering experienced by those who actually live with the condition. Exploring individual differences in the experience of stuttering and stuttering behaviors will yield a better understanding of the myriad expressions of stuttering across the population of people who stutter.

Therefore, the purposes of this study were: 1) to explore what a large and heterogeneous sample of people who stutter perceive during the moment of stuttering, and 2) to examine how differences in respondents' personal goals when speaking, treatment history, and self-help/support participation might affect their perceptions, as well as their experiences, behaviors, thoughts, and feelings related to stuttering.

2.0 METHOD

2.1 Participants and Procedures

This study involved a detailed online survey distributed widely to adults who stutter. A total of 638 people started the survey and completed the consent form. Of those, 136 people were excluded from analysis: 3 because they indicated that they did not consider themselves to be people who stutter, 10 because they were under the age of 18, and 123 because they did not complete any meaningful portion of the survey other than the consent form. Final data for the study included the responses of 502 participants with usable data. Demographic data, including age at the time of the survey, age of stuttering onset, history of participation in self-help/support and speech therapy, and ethnicity, were collected from the majority of participants; some demographic data were missing for questions occurring at the end of the survey due to attrition (i.e., failure to complete the entire survey). Occupations reported by respondents were quite varied: some indicated they were students (12%), while others indicated they were Speech-Language Pathologists (9%) or retired from various occupations (7%). The remaining occupations reported represented various fields (e.g., law, healthcare, information technology, etc.), and 23 respondents (5%) elected not to specify an occupation. Table 1 summarizes the available demographic characteristics of the participants whose data were analyzed in this study.

Recruitment procedures were similar to those found in other recent surveys in stuttering research (see Boyle, 2013, 2017, 2018; Boyle, Beita-Ell, Milewski, & Fearon, 2018; Boyle & Fearon, 2018; Tichenor & Yaruss, 2019). Specifically, participants were recruited using a mix of snowball and convenience sampling, using research registries from previous studies, social media outlets, personal contacts of the authors, word-of-mouth, and national and international stuttering associations (e.g., the International Stuttering Association, the National Stuttering Association, and Friends: The National Organization of Young People Who Stutter) to encourage a broad sampling of people who stutter from different backgrounds and with different experiences. This survey was conducted via the Internet using Qualtrics (Qualtrics, 2018). All respondents were adults (ages 18 or older), who self-reported to be people who stutter and who completed an informed consent prior to receiving and completing the survey.

2.2 The Survey

In order to gather information about how people who stutter experience the moment of stuttering, a questionnaire was developed based on the findings from prior studies examining key aspects of the experience of stuttering, including anticipation (Brocklehurst, Lickley, & Corley, 2013; Garcia-Barrera & Davidow, 2015; Jackson et al., 2015), variability (Constantino et al., 2016), physical tension/other so-called secondary behaviors (Tichenor et al., 2017), the overall experience of stuttering (Tichenor & Yaruss, 2018; Yaruss, Quesal, Reeves, et al., 2002; Yaruss & Quesal, 2006), as well as behaviors exhibited during moments of both stuttered and fluent speech, and cognitive-affective experiences (e.g., Yaruss & Quesal, 2004). The larger survey addressed many topics related to the overall experience of stuttering; the present report focuses stuttering behaviors as well as related thoughts and feelings; other findings from the survey are not presented in this paper.

The survey gathered information about respondents' goals when speaking and prior participation in self-help/support organizations, so the potential relationships between these factors and speakers' stuttering behaviors and perceptions could be explored. In addition to asking about prior participation in self-help/support, items captured the respondents possible goals when speaking, such as speaking fluently, hiding stuttering, stuttering openly, not stuttering, stuttering in an easy/controlled way, saying what you want to say how you want to say it. The majority of items were frequency-based or agreement-based 5-point Likert scales (Dawes, 2008), while demographic items were generally coded as binary yes/no choices (e.g. history of self-help or therapy).

Prior to distribution, the questionnaire was piloted several times with small groups of people who stutter. Items were added, dropped, or reworded for readability and to ensure that the questionnaire captured a wide range of possible behaviors, thoughts, and feelings that would be relevant to a large group of people who stutter. This piloting process was iterative, beginning with a small number of adults who stutter (3-5), and growing to approximately 25 participants before the broader survey recruitment was undertaken. The survey items were reviewed and edited for readability, with a Flesch-Kincaid Grade Level of 8.6 (Kincaid, Fishburne, Rogers, & Chisson, 1975). The study was judged to be exempt from institutional review by the Michigan State University Human Subjects Research Protection Office under statute 45 CFR 46.101(b) 2.

2.3. Data Analysis

Data recorded in Qualtrics were exported to and analyzed in R-studio (Rstudio Team, 2018), a companion program to R (R Core Team, 2019). Various R packages were used for data analysis (likert, Bryer & Speerschneider, 2016; Boot, Canty & Ripley, 2017; ordinal, Christensen, 2018; polycor, Fox, 2016; ggplot2, Kassambara, 2018; sjPlot, Ludecke, 2018; AICmodavg, Mazerolle, 2017; Simpleboot, Peng, 2008; Brant, Schlegel & Steenbergen, 2018; dplyr, H. Wickham, François, Henry, & Müller, 2018; plyr, Hadley Wickham, 2016; knitr, Xie, 2018). All data were manually checked for data entry or coding errors. Since items were created to capture multidimensional constructs, exploratory factor analyses were completed to determine the underlying structure of the constructs. Though items were created around themes identified in previous qualitative work (see Jackson et al., 2015; Tichenor & Yaruss, 2018), confirmatory factor analyses were not conducted in order to reduce the likelihood that new structures or themes in the data might be overlooked. Oblique (Promax) rotation was used, because factors were assumed to correlate with one another. In order to estimate the number of factors though factor loadings, eigenvalues were estimated and plotted in a scree plot. Actual eigenvalues were created and plotted via parallel analysis. Lower and higher factor loadings were explored for parsimony and interpretability with scree plots as a guide.

Ordered logistic regression (ordered logit/proportional odds model) was performed to determine the likelihood of respondents answering a question in a certain way based on their answers to items related to their speaking goals or history of self-help/support participation (R. Williams, 2016). Ordered logistic regression was selected because it is useful for analyzing Likert data as a function of responses to other Likert data while accounting for the ordered nature of the data (R. Williams, 2006, 2016). Ordered logistic regression is also more powerful than multinomial regression for detecting underlying patterns of ordered data (Barry, 2017). Items representing goal when speaking and self-help/support participation were used to predict answers to other items (see section 3.1 for further details). The assumption of parallel lines (proportional odds assumption) was tested for each item's models using the likelihood ratio test of cumulative link models (Christensen, 2018). The assumption was considered to have been met for an item when there was no significant difference between models at p <. 01 (Allison, 1999). All items presented for interpretation in Section 3.3 met the assumption. Items that did not meet this assumption were removed from individual difference analyses. For this reason, some items are presented in group level analyses but not later when predicting individual differences. Hessian functions were used to obtain standard errors. Odds ratios were calculated from logits and transformed into probabilities for ease of visualization and interpretability. Missing data were treated as missing-at-random due to partial or incomplete survey completions; the number of observations per item is provided in each of the group-level analyses below.

3.0 RESULTS

3.1 Factor Analyses

Two factor structures were identified for each construct: *During the moment of stuttering*, *during a moment of not stuttering*, *goals when speaking*, and *cognitive-affective* *experiences*. The resulting underlying structures revealed some items with low factor loadings. Items with loadings less than .3 were considered not to significantly measure the construct (Hair, Tatham, Anderson, & Black, 1998), so they were removed from further analyses (Field, 2003). Items were also investigated to prevent cross-loading on factors; items that did not load significantly higher on one factor over another factor were excluded from both constructs (Matsunaga, 2010). Cronbach’s alpha was then calculated for each factor to establish reliability (Cronbach, 1951). Items with alpha scores lower than the cumulative factor alpha were removed from the factor. Tables 2 through 5 present the factors, items, factor loadings, and reliability coefficients from these analyses. The reliability of factors was judged to be acceptable to excellent. The individual factors within each construct were named as appropriate for ease of interpretation: *overt* vs. *covert* behavior during the moment of stuttering, and *not stuttering* vs. *openness* as a goal when speaking.

The highest-loading item on the factor of *Not Stuttering* as a goal when speaking was Q2, “My goal when speaking is to not stutter.” This item was used to predict other responses via ordered logistic regression. The highest loading item on the factor of *Open Stuttering* indicated the opposite pattern of prediction. Those data are not presented to limit redundancy. A history of self-help/support participation was determined in via an initial screening question, “Have you ever participated in self-help or a support group for stuttering?” Answers to these questions were used to predict answers to other survey items. This allowed the differentiation of respondents’ individual differences regarding their goals when speaking (see section 3.3.1) or history of participation in self-help/support (see section 3.3.2).

3.2 Common Experiences Across People Who Stutter

3.2.1 Behaviors and Experiences During the Moment of Stuttering

The vast majority of respondents reported experiencing a sensation of being stuck (96%) or a loss of control (93.9%) during the moment of stuttering. Within this group of respondents, a majority indicated that they experience this sensation of being stuck (59.4%) or a loss of control (50.4%) either often or always. In comparison, a slightly lower but still high portion of respondents (85.9%) reported at least some experience of "stuttering" or "stuttering-like" behaviors (e.g. repetitions, prolongations, or blocks) during moments of stuttering. Specifically, respondents indicated that they often or always produce prolongations (30.4%), repetitions (49.9%), or blocks (54.0%). Respondents also indicated that they often or always push or struggle during moments of stuttering (56.7%), experience increased physical tension (52.6%), use filler sounds or words (50.9%), close their eyes (45.6%), or move their arms or legs (23.6%). Figure 1 shows the full distribution of overt behaviors and experiences reported by respondents.

Although overt behaviors were frequently reported, many respondents also reported less-observable behaviors and experiences. For example, some respondents indicated that they often or always mentally "check out" (17.4%), choose not to speak (15.0%), remove themselves from a situation (10.3%), or let someone else speak for them (9.4%). The distributions of these experiences suggest that so-called *core* stuttering behaviors (e.g., repetitions, prolongations, and blocks, e.g. Conture, 1990; Gregory, 1986; Johnson, 1959, 1961; Van Riper, 1982; Wingate, 1964) describe some—but not all—of the behaviors experienced by people who stutter moments of during stuttering. See Figure 2 for a full distribution of less-overt experiences reported by respondents.

3.2.2 Experiences and Behaviors Exhibited When Not Stuttering

When asked about times when they are not stuttering, 61.5% of respondents reported that they often or always "feel fluent," and only 54.0% reported that they "speak effortlessly." Notably, 31.2% of respondents indicated that they only sometimes speak effortlessly and 26.3% indicated that they only sometimes feel fluent when not in a moment of stuttering. These data show that the opposite of stuttering is not fluent and effortless speech for a sizable percentage of people who stutter.

3.2.3 Cognitive-Affective Experiences

Respondents indicated that they often or always experience feelings of embarrassment (53.1%), being emotionally drained (49%), being exhausted (46.8%), and being ashamed (44.8%) when in moments of stuttering. Lower percentages of respondents indicated that they often or always feel like they are being who they really are (27.4%) or feel empowered (7.3%) during moments of stuttering. These data suggest that the majority of respondents reported experiencing more negative affective states than positive states during stuttering, though negative cognitive-affective experiences were not universal. Figure 3 provides detailed distributions of responses to these items.

3.3 Individual Differences in Stuttering

Factor analyses revealed two factors describing respondents' goals when speaking: *not stuttering* and *stuttering openly*. A majority of respondents (69.5%) indicated that they often or always have a goal of *not stuttering* when speaking (Q4). A smaller percentage (36.3%) indicated that they often or always have the goal of *stuttering openly and trying not to hide stuttering* (Q7). This indicates that, although the majority of respondents in this survey tended to have *not stuttering* as a goal, such a goal does not describe all individuals who stutter in the sample. To further evaluate this relationship, a polychoric correlation was conducted between the two highest loading factors on *Not Stuttering* and *Openness* as goals when speaking (specifically, Q2 “My goal when speaking is to not stutter” and Q7 “My goal when speaking is to stutter openly and not try to hide it”). Results indicated a moderate negative correlation between the two goals ($\rho = -.54$). This indicates that, although these goals are anti-correlated, they are not completely dissociable from one another.

To determine how distributed the dissociation was in respondents’ answers, the responses to these two factors were visualized in a scatterplot, as shown in Figure 4. Most participants indicated a preference for *not stuttering* as a goal when speaking. This is indicated by the larger concentrations in the bottom right of the figure (i.e., less open stuttering/more not stuttering as a goal). Still, many respondents indicated that they often, sometimes, or rarely have both goals, as reflected in the middle area of the scatterplot. This indicates that the goal(s) of a person who stutters when speaking may exist along a continuum of *not stuttering* to *open stuttering*. Self-help/support participation was associated with where an individual speaker might fall on this continuum. A negative history of self-help/support participation was associated with a higher tendency toward a goal of more fluency/less open stuttering. A positive history of self-help/support was associated with a tendency toward a goal of less fluency/more open stuttering.

To capture individual differences as predictors of aspects of the experience of stuttering, an ordered logistic regression analysis was conducted to gauge whether a person’s goals when speaking or participation in self-help/support differentiated other experiences reported in the survey. As noted above, goals when speaking fell clearly on a two-factor structure along a *not stuttering* and *openness* dichotomy. Therefore, the highest loading factor for not stuttering (Q4 "My goal is to not stutter") was selected as a predictor. This yielded four predictor categories following the 5-point Likert-based scale ("never" was the baseline). Because self-help/support participation was a binary yes-or-no question in the demographic data, there was one predictor categories for those analyses; a positive history of self/help support was the baseline. Unfortunately, the proportionally small sub-sample of people who had no history of treatment (n = 40) precluded valid exploration of history of treatment as a predictor for comparisons in this paper. (Note that the percentage of individuals reporting no prior history of treatment is almost identical to that found in prior research; see Yaruss, Quesal, Reeves, et al., 2002).

3.3.1 *Not Stuttering* as a Goal when Speaking as a Predictor of Experiences

A person's goal when speaking significantly predicted the likelihood that the person would report certain stuttering behaviors and cognitive-affective experiences. Table 6 shows the specific item odds ratios (ORs) and confidence intervals (CIs) for these analyses. The shaded cells indicate significant effects. Goal when speaking significantly predicted the likelihood of reporting to exhibit certain behaviors during the moment of stuttering, including remaining silent and choosing not to speak (Q13) and sensing a loss of control (Q17). For example, "rarely" having *not stuttering* as a goal (as opposed to "never" having *not stuttering* as a goal) increased the odds of remaining silent and choosing not to speak (Q13) by 3.56 (95% confidence interval ranging from 1.71 to 7.58; $p < .001$). "Always" having *not stuttering* as a goal (as opposed to “often” having *not stuttering* as a goal) increased the odds of remaining silent and choosing not to speak (Q13) by 13.48 at a 95% CI (range; 6.7 to 27.8; $p < .001$).

Because odds are difficult to interpret descriptively, these effects are presented visually through probability plots. Behaviors and experiences associated with stuttering can be predicted by how often someone has *not stuttering* as a goal (see Figures 5 to 7). For example, in Q13, the predicted probability of remaining silent and choosing not to speak increases the more often a person has *not stuttering* as a goal. This can be seen visually by the crossover effect of the five regression lines. The magnitude in the differences of the regression lines of the plotted graphs also represent the effect size of the differences with more divergent regression lines representing greater effect sizes. These effects can sometimes be relatively subtle (e.g. Q25, pushing or struggling) or they can be great (e.g. Q19, using filler sounds or words). An example of a non-significant prediction is Q12 (I repeat sounds or words). This non-significant prediction can be seen by how close together the regression lines are to one another. Note that the “always” regression line is still insignificant, even though it is slightly farther away from the others.

Overall, results indicate that the more likely person is to have *not stuttering* as a goal, the more likely they are to: remain silent (Q13), remove themselves from a situation (Q14), let someone else speak for them (Q26), use filler words (Q19), move body parts (Q24), and push or struggle (Q25). Having *not stuttering* as a goal also predicted other feelings, sensations, and perceptions. Specifically, people who had *not stuttering* as a goal were more likely to experience a loss of control (Q17), feel emotionally drained (Q47), feel exhausted (Q48), or feel ashamed (Q49). They were also less likely to feel empowered (Q50). Patterns in the data provide clear evidence that having *not stuttering* as a goal when speaking significantly increases the likelihood of experiencing negative cognitive/affective states and behaviors that people who stutter commonly report during moments of stuttering.

3.3.2 History of Self-help or Support Participation as a Predictor of Experiences

Participation in self-help/support also predicted the likelihood that the person would report exhibiting specific stuttering behaviors and cognitive-affective reactions. Having no history of self-help/support participation significantly *increased* the probability that someone would repeat sounds or words (Q12), feel like they are stuck (Q18), move their arms or legs (Q24), push or struggle (Q25), and let someone else speak for them (Q26). No history of self-help/support participation also increased the probability of feeling embarrassed (Q48) or ashamed (Q49) and decreased the probability of feeling empowered (Q50) and feeling like they are being who really are (Q51). Though significant, the effect sizes of these predictions were relatively small, as indicated by the changes in odds ratios between a negative and a positive history of self-help/support. Nonetheless, patterns in data support the interpretation that self-help/support participation is associated with less negative cognitive/affective constructs and experiences during moments of stuttering. Table 7 provides data concerning the odds ratios, confidence intervals, and the significance of predictions.

4.0 DISCUSSION

The experiences and behaviors reported by respondents in this survey support some widely held views about stuttering behaviors, while expanding the understanding of how people who stutter perceive their stuttering-related behaviors and experiences. Though respondents reported exhibiting common stuttering or stutter-like behaviors (e.g. repetitions, prolongations, and blocks), they also reported exhibiting other less-observable behaviors and experiences, such as feeling stuck or sensing a loss of control. Importantly, these experiences were reported to occur with an *even higher frequency* than the observable behaviors that are commonly used to define stuttering. Other covert stuttering behaviors, such as remaining silent, choosing not to speak, removing themselves from a situation, or letting someone else speak for them, were also reported to occur, though less frequently than the more-overt behaviors. These data suggest that there is a range of behaviors and experiences that people who stutter perceive during moments of stuttering. If clinicians and researchers only count or measure observable behaviors, they will miss key aspects of the moment of stuttering as perceived and experienced by people who stutter. Therefore, adopting a broader definition of stuttering would better capture the experiences of people who stutter (Perkins, 1990; Tichenor & Yaruss, 2018, 2019).

A broader view of stuttering would also help to decrease the discrepancies between speaker-based (Perkins, 1983, 1990) and listener-based definitions of stuttering (Wingate, 1964; Yairi, 2013; Yairi, Watkins, Ambrose, & Paden, 2001). The differentiation between speaker-defined and listener-defined stuttering is not merely semantic (Quesal, 2010), for the ways in which clinicians and researchers conceptualize stuttering dictates how they diagnose and treat the condition (Yairi & Ambrose, 2005). Overt behaviors, such as prolongations, repetitions, and blocks, provide seemingly concrete, measurable events that clinicians can be trained to observe (Bainbridge, Stavros, Ebrahimian, Wang, & Ingham, 2015; Cordes & Ingham, 1994; Curlee, 1981; Ham, 1989; Kully & Boberg, 1988; Martin, Haroldson, & Woessner, 1988; Yaruss, 1998; Young, 1975). Nevertheless, stuttering is something that is experienced by a *speaker*, not just a listener (Tichenor & Yaruss, 2019). Williams (1957) stated, “a person who stutters may learn to vary, or to control the ‘overt stuttering,’ but to him ‘his stuttering’ is a constant, an entity, a *something that still* remains” (pg. 393, emphasis added). Data in this study support a broader and more encompassing view of stuttering that gives voice to the experiences of a large group of adults who stutter.

Data from this study also address a critical open question in stuttering research: a relative lack of heterogeneity in research samples as compared to the population of people who stutter as a whole. Results show that several key aspects of a speaker’s prior experiences and beliefs directly affect their perceptions of stuttering—and their overt behaviors. Specifically, speakers’ goals when speaking (*not stuttering* vs. *stuttering openly*) were moderately negatively correlated. A history of self-help/support participation disambiguated this relationship to some extent: respondents who had a history of self-help/support participation also indicated a preference for more open stuttering as a goal. The reverse was also true. Respondents who had no history of self-help/support participation were more likely to indicate a preference for “not stuttering” as a goal. Future research should further evaluate this relationship to determine whether self-help/support leads people to have more open stuttering as a goal or if self-help/support organizations attract people who already have this goal.

Having the goal of *not stuttering* when speaking significantly predicted both more-overt behaviors (e.g., using filler words, struggling, moving arms/legs) and more-covert behaviors (e.g., remaining silent and choosing not to speak, removing myself from a situation, and letting someone else speak for me). Having the goal of *not stuttering* when speaking also significantly predicted an increase in negative feelings (e.g., feeling emotionally drained, exhausted, ashamed, and embarrassed) and a decrease in positive feelings (e.g., feeling like I'm being who I really am). Having a history of self-help/support participation significantly predicted a lower probability of certain behaviors (e.g., repeating sounds and words, feeling stuck, moving arms and legs) and negative feelings (e.g., feeling embarrassed, ashamed, empowered, or like you are being your true self). It was also associated with increased reports of positive feelings (e.g., feeling like I'm being who I really am, feeling empowered). These data provide strong evidence that individual differences in what makes a person *who they are* must be considered when attempting to understand each person's unique experiences associated with stuttering.

4.1 Clinical Implications: Goals of Therapy

A broader view of the behaviors and experiences perceived by speakers who stutter will allow for improved diagnosis and treatment. Typical assessments of stuttering behaviors, such as those included in the Stuttering Severity Instrument (SSI-4, Riley, 2009), include clinician observations of the percent of syllables stuttered, the duration of the longest stuttering events, and the presence of physical concomitants (e.g., tension and struggle). Research has already shown that speakers experience—and are aware of—physical tension that even expert clinicians cannot observe (Tichenor et al., 2017). Data from the present study further highlight the importance of self-reports of less-observable aspects of the experience of stuttering, such as remaining silent, removing themselves from a situation, or letting someone else speak for them. Using diagnostic criteria that focus only on observable behaviors increases the likelihood that clinicians will (a) fail to qualify someone for treatment when they should or (b) discharge someone from treatment when they should not.

These data highlight a potential negative outcome of treatment that is focused primarily on increasing fluency: Having the goal of *not stuttering* makes a person significantly more likely to demonstrate more-covert stuttering behaviors. Therefore, therapy that focuses on fluency may create a tendency toward more covert aspects of the stuttering behavior. This is not to say that covert behaviors are necessarily bad or negative. Previous research has shown that people who stutter covertly do so for several reasons, including attempting to "pass" as someone who does not stutter, to fit in with others, to control their speaking environment, or to be accepted by others (Constantino et al., 2017, p. 36). While stuttering covertly should be viewed as a choice of the individual who stutters, data from this study help to explain how this tendency might develop: the more likely people are to have the goal of *not stuttering* when speaking, the more likely they are to engage in covert behaviors and experience more negative cognitive/affective reactions, such as feeling emotionally drained, ashamed, or embarrassed. Thus, clinicians should be mindful of their clients' goals and their personal traits—and the potential consequences of different approaches to therapy—when planning treatment. In particular clinicians should be aware of potential unintended effect(s), such as reduced agency or increased covert behaviors, that fluency-focused therapy might have on their clients.

4.2 Clinical Implications: Self-help and support

Although there was an initial tension between the stuttering self-help movement and formalized therapy (see Gregory, 1997), this has decreased in recent years. Self-help/support organizations provide value to many people who stutter; they have been shown to increase acceptance, understanding, and provide a platform to practice therapy techniques in a safe environment (Bradberry, 1997; Trichon & Tetnowski, 2011; Yaruss, Quesal, Reeves, et al., 2002). Data from this study show that self-help/support participation also is associated with the goals a person has when speaking—and, moreover, that participation is associated with more positive perceptions of behaviors and experiences associated with moments of stuttering. It is unclear if self-help/support participation causes *changes* in goals when speaking (e.g., more open stuttering or more not stuttering) or if self-help/support naturally attracts people who already have those goals. Still, data from this study support the importance of documenting self-help/support participation in classifying the experiences of people who stutter.

4.3 Limitations and Future Directions

The main strengths of this study also highlight weaknesses that should be addressed in future research. Strengths include the large sample size and varied background of participants, in terms of self-help/support participation, goals when speaking, age, and sex. At the same time, recruitment of people who stutter who do not have any history of therapy was difficult. Future research should attempt to address this challenge, because it is reasonable to assume that a history of therapy (and, in particular, a history of different approaches to therapy) might alter how a person perceives and experiences stuttering. A related limitation of this study was that the type of therapy (e.g., more fluency-focused, more stuttering modification-focused, more counseling-focused, or a hybrid approach) was not accounted for in the responses of subjects. This was mainly due to the fact that people who stutter have generally experienced many types of therapy throughout their lives (see also Yaruss, Quesal, Reeves, et al., 2002). Future research should examine the effects of different types of therapy on the experience of stuttering, for it is possible that people who have had different types of therapy may be predisposed to experience stuttering in different. (Likewise, the same person might have different perceptions after experiencing different therapies or at different times in life.)

Next, the present study only addressed the experiences of adults, that is, people who have been living with stuttering throughout their lives. Future research should also explore individual differences in children and adolescents who stutter. Exploration of differences across age groups will yield a better understanding of how relationships between personal goals and the experience of stuttering develop over time.

Finally, although data in this paper provide preliminary frequencies of behaviors and experiences that speakers perceive during moments of stuttering, it is, as yet, unclear how reliable these experiences are (see discussion in Ingham, 1990; Smith, 1990).

4.4 Summary

This study provides data on the frequency with which a large and representative sample of people who stutter report experiencing key behaviors, thoughts, and experiences associated with stuttering. As expected, more overt behaviors, such as repetitions or blocks, were commonly reported. Importantly, however, a clinically significant proportion of people who stutter also reported frequently experiencing more covert behaviors, such as choosing not to speak, letting someone else speak for them, or remaining silent rather than taking the risk that they might stutter. Participants reported experiencing more negative cognitive and affective states, such as being embarrassed or ashamed; positive states, such as being accepting of stuttering, were reported less frequently. Individual differences in people's goals when speaking, and participation in self-help/support groups significantly predicted whether they were likely to experience negative behaviors and cognitive/affective states. Accounting for these person-centered constructs holds significant promise for identifying and understanding the individual experiences of people who stutter. This knowledge should lead to the improved diagnosis and treatment of stuttering, as clinicians and researchers will be better able to recognize the factors that affect the lives of those who live with stuttering.

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Figure Captions

Figure 1. Figure 1 contains the distributions of more-overt behaviors experienced by respondents.

Figure 2. Figure 2 contains the distributions of more-covert behaviors experienced by respondents.

Figure 3. Figure 3 contains the distributions of positive and negative cognitive-affective experiences reported by respondents.

Figure 4. Figure 4 visualizes the distributions of the two highest loading items on the two respective factors of *Goal When Speaking* (Not Stuttering vs Stuttering Openly) colored by self-help/support participation.

Figure 5. Figure 5 visualizes the predicted probabilities of experiencing certain behaviors during stuttering as a function of how often respondents have *not stuttering* as a goal when speaking.

Figure 6. Figure 6 visualizes the predicted probabilities of more-covert or internal experiences during stuttering as a function of how often respondents have *not stuttering* as a goal when speaking.

Figure 7. Figure 7 visualizes the predicted probabilities of certain cognitive-affective states occurring during stuttering as a function of how often respondents have *not stuttering* as a goal when speaking.

Table 1. Demographic Data

Demographic Variable	% or M (SD)
Age	38.5 (15.52)
Sex	
Female	25.8%
Male	53.7%
Prefer not to say/Missing Data	20.5%
Ethnicity	
American Indian or Alaskan Native	0.0%
Asian American	3.7%
Black or African American	4.1%
Native Hawaiian or other Pacific Islander	0.0%
Caucasian	59.9%
Other	3.9%
Prefer not to say/Missing Data	28.4%
History of stuttering therapy	
Yes	90.1%
No	7.7%
Prefer not to say/Missing Data	2.2%
History of self-help or support	
Yes	64.0%
No	33.8%
Prefer not to say/Missing Data	2.2%
High education experiences (having college or post-graduate degree)	
Yes	55.3%
No	17.4%
Prefer not to say/Missing Data	30.3%

Table 2. Goal When Speaking Items	Factors and Loadings	
My goal when I speak is to…	Not Stuttering	Openness
1. speak as fluency as possible.	**0.758**	< .1
2. not stutter.	**0.847**	< .1
3. say what I want to say regardless of how I say it.	-0.115	**0.548**
5. stutter openly and not try to hide it.	-0.274	**0.607**
6. hide my stuttering.	**0.608**	0.208
8. stutter in an easy, controlled way.	< .1	**0.568**
	α = .82	α = .0.67

Table 3. During a Moment of Stuttering Items	Factors and Loadings	
During a Moment of Stuttering, I…	Overt	Covert
12. repeat sounds or words.	**0.491**	-0.152
13. remain silent and choose not to speak.	< .1	**0.781**
14. remove myself from a situation.	< .1	**0.752**
15. block on a sound or word. That is I put my mouth, lips, tongue in the position for speech but	**0.549**	< .1
16. prolong a sound.	**0.520**	-0.135
17. sense a loss of control.	**0.518**	0.197
18. feel like I'm stuck.	**0.582**	0.154
19. use filler sounds or words such as um or uh.	**0.554**	0.104
22. close my eyes or look away from the person with whom I'm speaking.	**0.546**	0.107
23. tense my muscles, or experience physical tension.	**0.619**	< .1
24. move my arms, legs, or hands.	**0.477**	0.129
25. push or struggle through it.	**0.707**	-0.18
26. let someone else speak for me.	< .1	**0.550**
27. mentally checkout, that is I feel removed or like I'm watching from afar.	0.194	**0.403**
	α = .84	α = .0.77

Table 4. During a Moment of Not Stuttering Items	Factors and Loadings	
During a Moment of NOT Stuttering, I…	Overt	Covert
30. repeat sounds or words.	**0.633**	< .1
31. remain silent and choose not to speak.	< .1	**0.851**
32. remove myself from a situation.	< .1	**0.709**
33. block on a sound or word. That is I put my	**0.892**	-0.113
34. prolong a sound.	**0.689**	< .1
35. sense a loss of control.	**0.625**	0.214
36. feel like I'm stuck.	**0.793**	< .1
39. tense my muscles, or experience physical	**0.550**	0.263
41. push or struggle through it.	**0.691**	< .1
42. I let someone else speak for me.	< .1	**0.639**
43. I mentally checkout, that is I feel removed or	0.113	**0.558**
44. I feel fluent	**-0.449**	-0.107
45. speak effortlessly.	**-0.517**	< .1
	α = .89	α = .0.82

Table 5. Cognitive Affective States	Factor Loadings
During a Moment of Stuttering, I feel…	
46. emotionally drained.	**0.810**
47. exhausted.	**0.704**
48. embarrassed.	**0.851**
49. ashamed.	**0.882**
50. empowered.	**-0.426**
51. like I'm being who I really am.	**-0.523**
	α = 0.85

Table 6. Odds Ratio and Confidence Intervals (Predictor: *Not Stuttering* as a Goal when Speaking).

During a Moment of Stuttering	Rarely			Sometimes			Often			Always		
Items	OR	2.5%	97.5%	OR	2.5%	97.5%	OR	2.5%	97.5%	OR	2.5%	97.5%
Q12 I repeat sounds or words	1.11	0.53	2.34	1.11	0.56	2.22	1.27	0.63	2.55	1.96	0.99	3.89
Q13 I remain silent and choose not to speak	3.56	1.74	7.58	3.49	1.75	7.12	7.92	3.92	16.38	13.49	6.70	27.82
Q14 I remove myself from a situation	2.13	1.00	4.67	2.93	1.44	6.20	5.10	2.49	10.82	10.76	5.29	22.75
Q16 I prolong a sound	1.08	0.52	2.26	1.26	0.62	2.54	1.19	0.59	2.39	1.69	0.85	3.36
Q17 I sense a loss of control	2.99	1.46	6.17	2.97	1.51	5.87	5.69	2.86	11.42	6.13	3.11	12.19
Q19 I use filler words such as um or uh	1.99	0.97	4.16	2.99	1.49	6.00	5.75	2.86	11.67	5.97	3.01	11.98
Q24 I move my arms, legs, or hands	2.11	1.03	4.40	2.51	1.27	5.06	2.55	1.28	5.12	4.34	2.20	8.70
Q25 I push or struggle through it	1.24	0.58	2.66	2.29	1.11	4.72	2.34	1.15	4.77	2.74	1.36	5.52
Q26 I let someone else speak for me	2.34	1.11	5.07	3.06	1.51	6.37	4.54	2.23	9.51	10.04	4.92	21.16

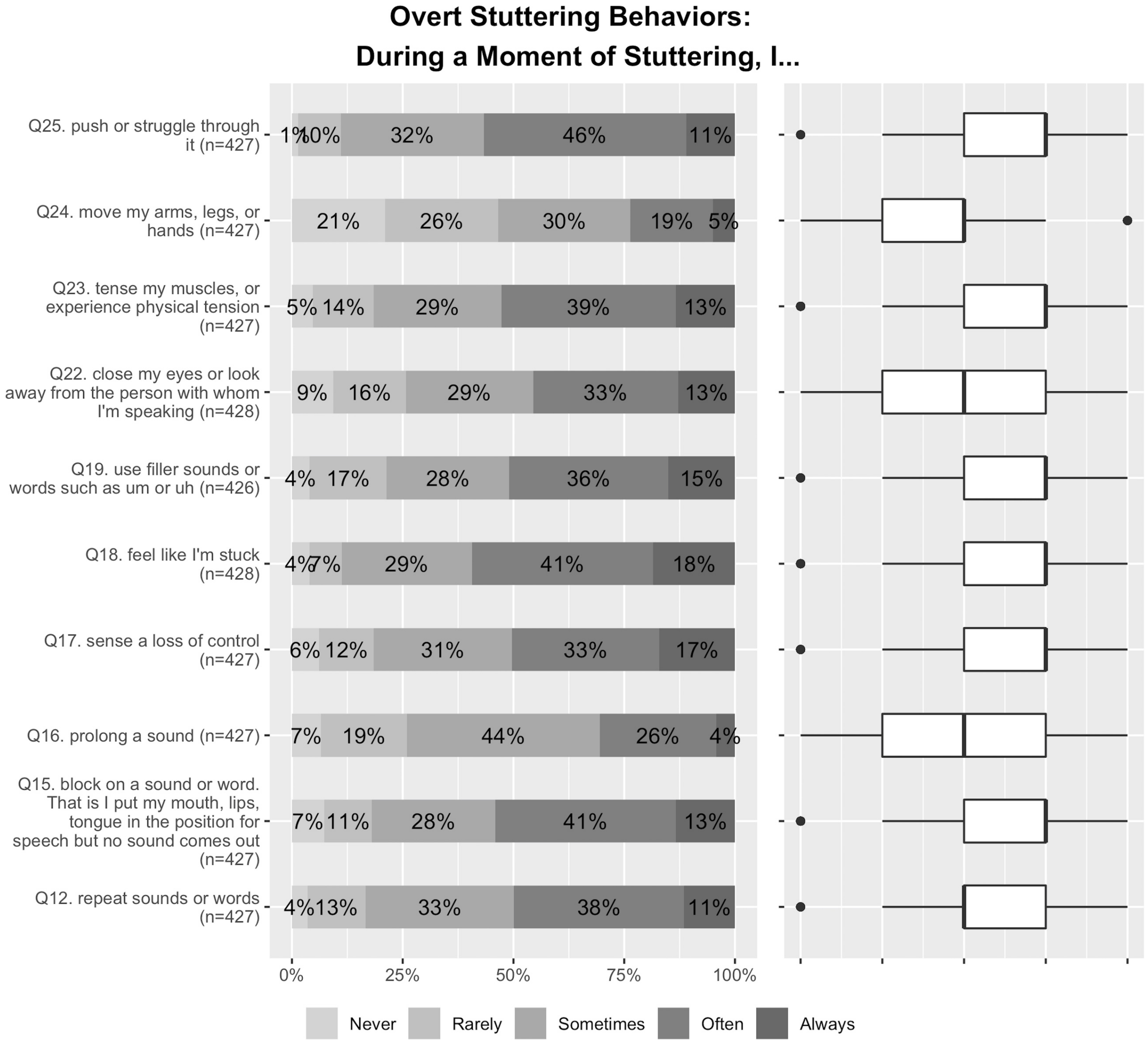
Feelings During Stuttering	Rarely			Sometimes			Often			Always		
Items	OR	2.5%	97.5%	OR	2.5%	97.5%	OR	2.5%	97.5%	OR	2.5%	97.5%
Q46. I feel emotionally drained	2.26	1.08	4.73	3.95	1.97	8.00	6.03	3.01	12.23	9.82	4.85	20.18
Q47. I feel exhausted	2.53	1.23	5.23	3.42	1.72	6.84	4.98	2.52	9.96	7.54	3.81	15.11
Q48. I feel embarrassed	2.73	1.32	5.69	10.63	5.25	21.89	10.63	5.25	21.89	27.46	13.25	57.95
Q49. I feel ashamed	2.06	1.01	4.24	3.34	1.68	6.73	7.30	3.66	14.77	21.71	10.55	45.46
Q50. I feel empowered	0.96	0.45	2.01	0.39	0.19	0.80	0.27	0.13	0.54	0.13	0.06	0.28
Q51. I feel like I'm being who I really am	0.62	0.29	1.33	0.31	0.15	0.63	0.20	0.10	0.40	0.07	0.03	0.15

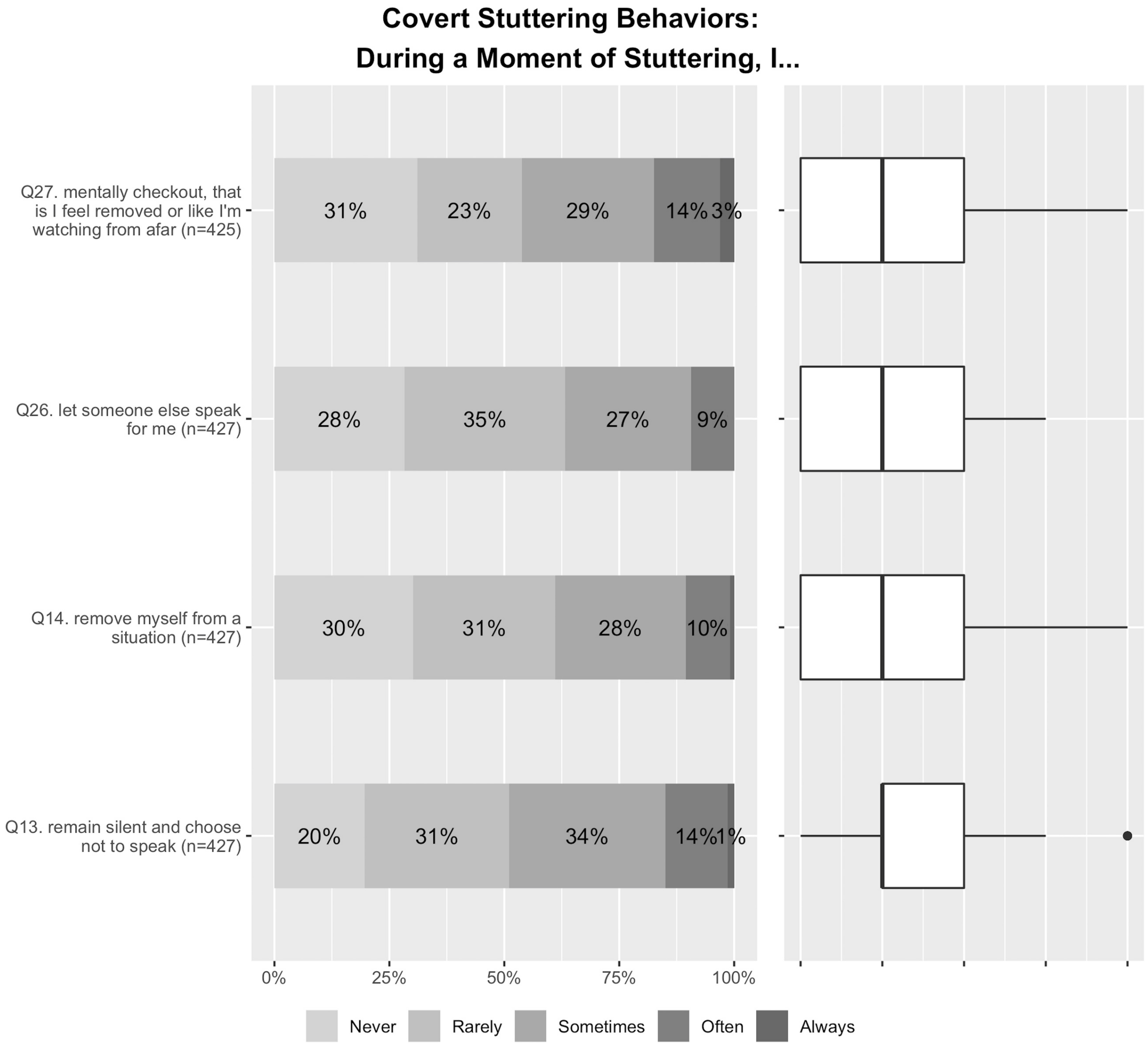
*Shaded cells indicate significant effects

Table 7. Odds Ratio and Confidence Intervals (Predictor: Self-Help/Support Participation)

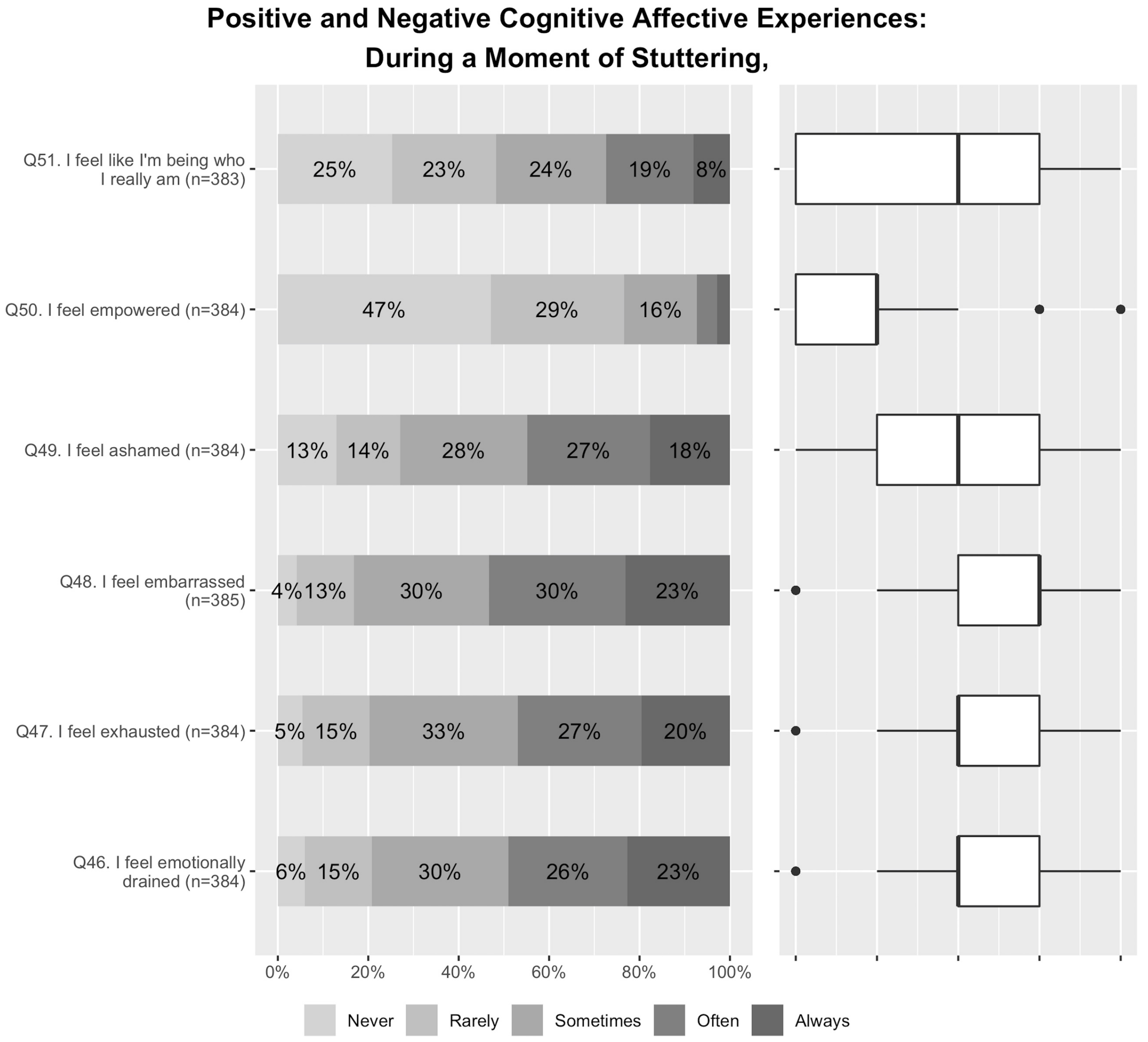
During a Moment of Stuttering Items	No Self-Help		
	OR	2.5%	97.5%
Q12 I repeat sounds or words	1.46	1.01	2.13
Q16 I prolong a sound	1.18	0.81	1.72
Q17 I sense a loss of control	1.30	0.90	1.89
Q18 I feel like I'm stuck	2.33	1.60	3.39
Q24 I move my arms, legs, or hands	1.56	1.08	2.25
Q25 I push or struggle through it	1.50	1.03	2.19
Q26 I let someone else speak for me	1.97	1.35	2.87
Q46. I feel emotionally drained	1.15	0.78	1.70
Q47. I feel exhausted	1.30	0.88	1.91
Q48. I feel embarrassed	2.23	1.49	3.33
Q49. I feel ashamed	1.88	1.27	2.80
Q50. I feel empowered	0.28	0.18	0.43
Q51. I feel like I'm being who I really am	0.35	0.23	0.52

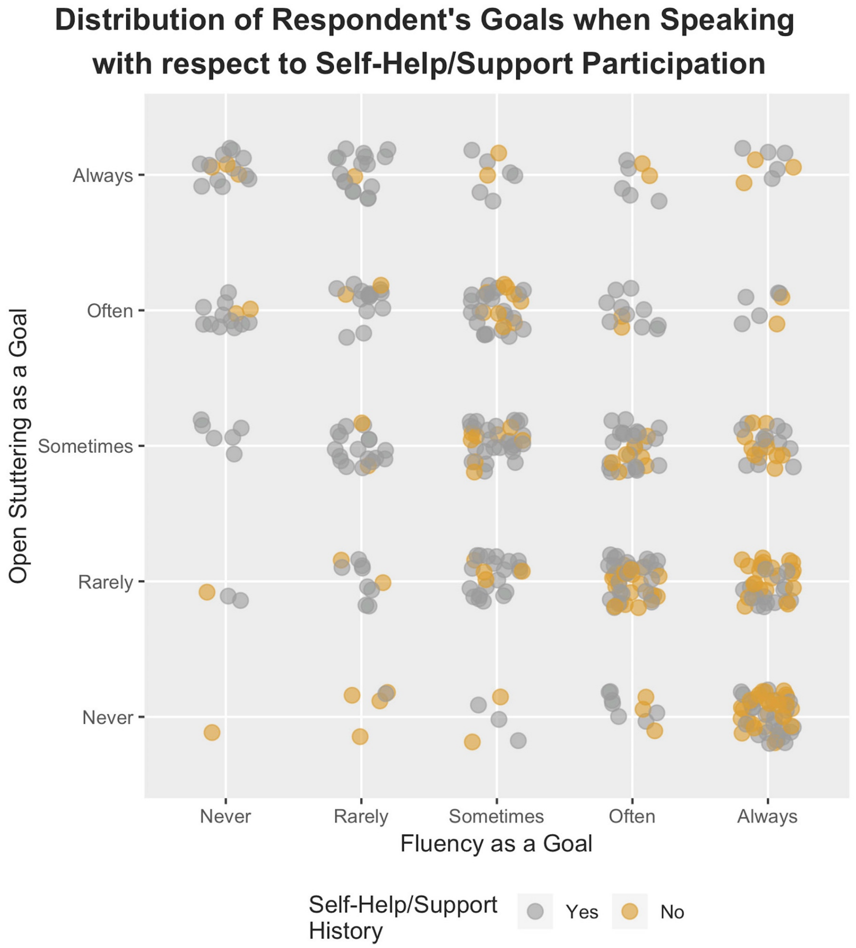
*Shaded cells indicate significant effects

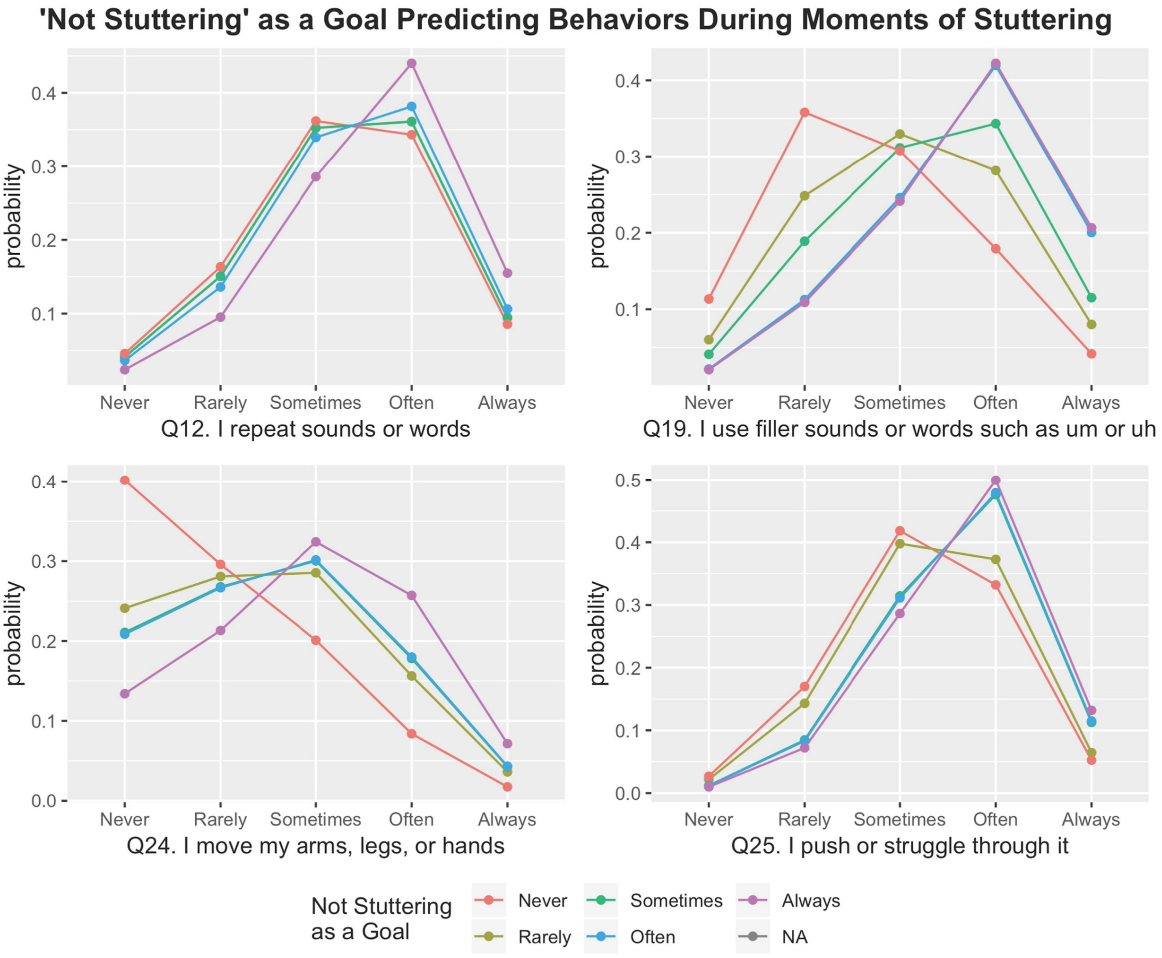

Overt Stuttering Behaviors:
During a Moment of Stuttering, I...
Q25. push or struggle through it (n=427)
1% 10% 32% 46% 11%
Q24. move my arms, legs, or hands (n=427)
21% 26% 30% 19% 5%
Q23. tense my muscles, or experience physical tension (n=427)
5% 14% 29% 39% 13%
Q22. close my eyes or look away from the person with whom I'm speaking (n=428)
9% 16% 29% 33% 13%
Q19. use filler sounds or words such as um or uh (n=426)
4% 17% 28% 36% 15%
Q18. feel like I'm stuck (n=428)
4% 7% 29% 41% 18%
Q17. sense a loss of control (n=427)
6% 12% 31% 33% 17%
Q16. prolong a sound (n=427)
7% 19% 44% 26% 4%
Q15. block on a sound or word. That is I put my mouth, lips, tongue in the position for speech but no sound comes out (n=427)
7% 11% 28% 41% 13%
Q12. repeat sounds or words (n=427)
4% 13% 33% 38% 11%
0%
25%
50%
75%
100%
Never
Rarely
Sometimes
Often
Always

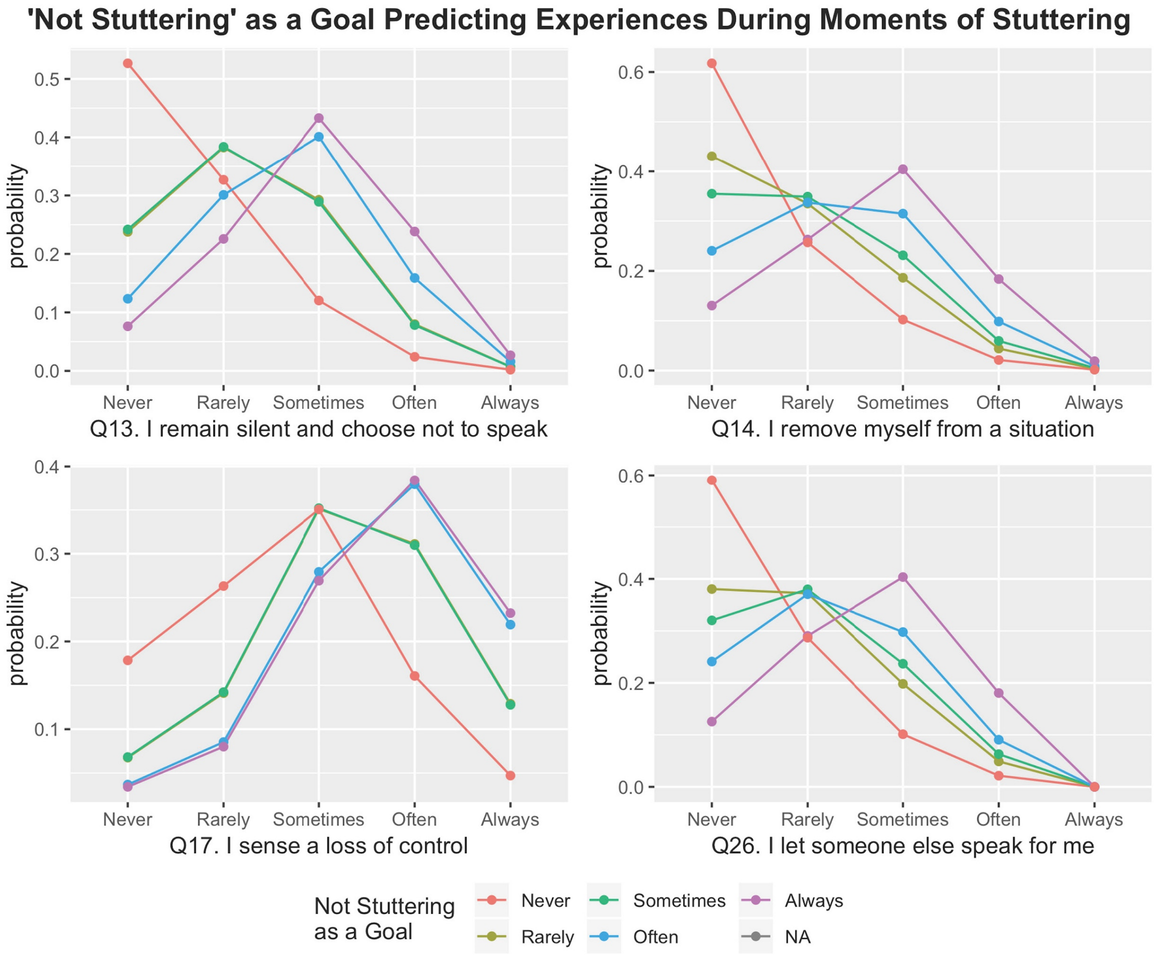


Covert Stuttering Behaviors:
During a Moment of Stuttering, I...

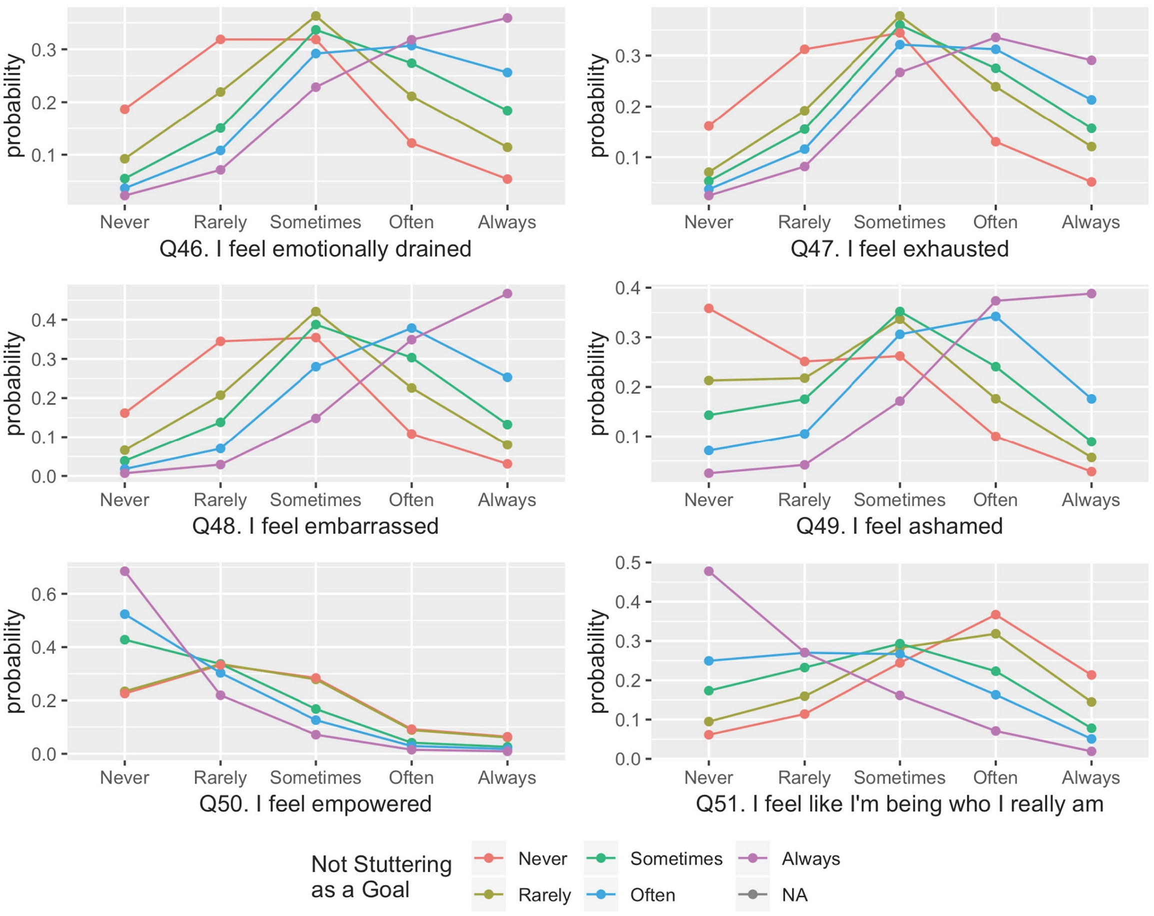

Positive and Negative Cognitive Affective Experiences:
During a Moment of Stuttering,
Q51. I feel like I'm being who I really am (n=383)
25%
23%
24%
19%
8%
Q50. I feel empowered (n=384)
47%
29%
16%
Q49. I feel ashamed (n=384)
13%
14%
28%
27%
18%
Q48. I feel embarrassed (n=385)
4%
13%
30%
30%
23%
Q47. I feel exhausted (n=384)
5%
15%
33%
27%
20%
Q46. I feel emotionally drained (n=384)
6%
15%
30%
26%
23%
0%
20%
40%
60%
80%
100%
Never
Rarely
Sometimes
Often
Always


Distribution of Respondent's Goals when Speaking with respect to Self-Help/Support Participation
Open Stuttering as a Goal
Always
Often
Sometimes
Rarely
Never
Fluency as a Goal
Never
Rarely
Sometimes
Often
Always
Self-Help/Support History
Yes
No


'Not Stuttering' as a Goal Predicting Behaviors During Moments of Stuttering
probability
0.0
0.1
0.2
0.3
0.4
0.5
Never
Rarely
Sometimes
Often
Always
Q12. I repeat sounds or words
Q19. I use filler sounds or words such as um or uh
Q24. I move my arms, legs, or hands
Q25. I push or struggle through it
Not Stuttering as a Goal
Never
Rarely
Sometimes
Often
Always
NA



'Not Stuttering' as a Goal Predicting Experiences During Moments of Stuttering


'Not Stuttering' as a Goal Predicting Feelings During Moments of Stuttering