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Michael Boyle

Montclair State University, boylemi@mail.montclair.edu

Kathryn M. Milewski

Montclair State University

Carolina Beita-Ell

Montclair State University

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Disclosure of stuttering and quality of life in people who stutter

Michael P. Boyle*, Kathryn M. Milewski, Carolina Beita-Ell

Department of Communication Sciences and Disorders, Montclair State University, United States



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ABSTRACT

Purpose: This study investigated the disclosure practices of people who stutter, and the relationship between disclosure of stuttering and quality of life.

Method: Participants were 322 adults who stutter recruited from speech-language pathologists and support group leaders. Participants completed a survey that contained items measuring level of disclosure of stuttering, as well as a global measure of self-rated quality of life. Participants were grouped into low, average, and high quality of life subgroups. Analysis of variance tests compared disclosure levels among these subgroups.

Results: The low quality of life subgroup reported significantly lower levels of disclosure compared to both the average and high quality of life subgroups. Participants with self-help/support group experience for stuttering demonstrated significantly higher levels of disclosure of stuttering compared to individuals without such experience. In addition, a substantial number of participants in the overall sample reported that they more than rarely feel the need to conceal stuttering from others (40%), and that no one knows that they stutter in many areas of life (37%).
Conclusions: Attempts to conceal stuttering in at least some life situations are not uncommon among adults who stutter. However, being involved in self-help support groups may be a helpful way of increasing disclosure of stuttering. Speech-language pathologists should become aware of the positive relationship between disclosure of stuttering and quality of life and its relevance in assessment and treatment when working with people who stutter.

1. Introduction

Individuals with characteristics or conditions that are devalued by society often encounter stigma. Public stigma has been defined as “the prejudice and discrimination directed at a group by the population” (Corrigan & Rao, 2012, p. 464). Public stigma is associated with higher levels of depression in people with stigmatized identities and anticipation of public stigma is correlated with psychological distress (Quinn & Earnshaw, 2013). Encounters with public stigma can lead to self-stigma, or “internalizing stereotypes resulting in injury to one’s self-esteem and sense of self-efficacy” (Corrigan et al., 2009, p. 372). Self-stigma has been linked to detrimental effects including self-isolation, poor quality of life, lower health care service use, poorer health outcomes (Sirey, Bruce, Alexopoulos, Perlick, Friedman et al., 2001, 2001b), and not seizing opportunities for independent living and employment (Link, 1987). Self-stigma also has the consequence of creating the ‘why try’ effect, in which feelings of low self-worth lead people to undermine their efforts towards achieving life goals (Corrigan & Rao, 2012).

Decades of research demonstrate that people who stutter (PWS) are stigmatized publicly and are recipients of negative stereotypes, prejudiced emotional reactions, and discriminatory behavioral intentions (St. Louis, 2015). PWS have been shown to be acutely

* Corresponding author at: Department of Communication Sciences and Disorders, Montclair State University, 1515 Broad St. Building B – 2nd Floor, Bloomfield, NJ, United States.

E-mail address: boylemi@montclair.edu (M.P. Boyle).

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aware of public stigma, and many of those individuals internalize that stigma to the detriment of their physical and psychological well-being (Boyle & Blood, 2015; Boyle & Fearon, 2018; Boyle, 2013a, 2015a). It has been theorized that disclosing one's stigmatized identity may help to counteract the negative effects of stigma (Corrigan & Rao, 2012; Corrigan et al., 2009). In the area of stuttering, there has been a lack of investigation into the area of psychological correlates of disclosure among PWS, although there is research on this topic in other populations with stigmatized characteristics, including mental illness, LGBT status, and HIV/AIDS diagnoses. This introduction will review the costs and benefits of disclosing a stigmatized identity among individuals with a variety of conditions, then discuss the current status of the literature in stuttering and disclosure, and conclude with a statement of the purpose of the current study.

1.1. Benefits and costs of disclosure among individuals with stigmatized conditions

Before proceeding, it is worth clarifying some important terminology. The word disclosure has the connotation of revealing something private publicly, and typically this term is seen in research with concealable stigmas (e.g., HIV/AIDS, homosexuality, traumatic brain injury, etc.). For many PWS, stuttering cannot be consistently concealed from others during oral communication, and the act of speaking itself would therefore be a decision to disclose stuttering. Still, there are PWS who can conceal stuttering effectively most of the time during oral communication, or consistently minimize its visibility to others when speaking (Plexico, Manning, & Levitt, 2009; Boyle, 2018; Butler, 2013; Constantino, Manning, & Nordstrom, 2017; Plexico, Manning, & Levitt, 2009). Therefore, disclosure is not a simple issue as it relates to stuttering. However, in this paper we will be referring to disclosure generally as being open about one's stuttering, either behaviorally by stuttering visibly, by talking openly about one's stuttering, or doing both. In the following paragraphs, costs and benefits of disclosure related to several different stigmatized conditions are presented. Although stuttering should certainly not be equated with any of these conditions, it will be useful for the reader to review this research as a means of better understanding the phenomenon of disclosure in general and its correlates.

Research suggests that disclosure of a stigmatized identity is a complicated phenomenon with both benefits and costs. Corrigan et al. (2010) studied disclosure and self-stigma in people with mental illness and found that those who were more open about their mental illnesses experienced a lessened impact of self-stigma on their quality of life (QOL). Disclosure was also related to increased empowerment and enhanced self-esteem. Disclosing mental illness can lessen worry and concern over secrecy, afford opportunities to find supportive peers and family members, and increase a sense of power and control (Corrigan, Roe, & Tsang, 2011). However, costs of disclosing include the potential for mandated treatment, job and housing discrimination, and avoidance by the general public (Corrigan, 2005). Halpin and Allen (2004) found that for gay men, disclosure initially correlated with social judgment, stigma, and less contact with other gay individuals, but later resulted in less stress arising from prejudice, better self-esteem, increased satisfaction with life, less loneliness, and greater happiness. Individuals in later stages of disclosure reported protesting against stigmatizing homophobic values in society and emergence of renewed and valued self-images. Kosciw, Palmer, and Kull (2015) found that in LGBT youth, disclosure was linked with greater risk for victimization, but also higher self-esteem and less depression. The positive effects of disclosure on well-being mitigated the negative effects of victimization and reflected greater resiliency in the face of stigma. Additionally, disclosure is related to reduced stress for LGBT individuals (Corrigan & Matthews, 2003), better relationships with partners (Caron & Ulin, 1997), greater support from families (Kadushin, 2000), and increased job satisfaction (Griffith & Hebl, 2002), but may have costs including employment discrimination (Lloren & Parini, 2017). LGBT individuals cite reasons to disclose including acceptance, community, comfort, happiness, and promotion of political action, while costs that diminish the likelihood of disclosure include shame, conformity, harm, and discrimination (Corrigan et al., 2009).

Zea, Reisen, Poppen, Bianchi, and Echeverry (2005) found that disclosure of HIV status led to greater social support, which had positive impacts on psychological well-being. Social support is especially important because it enables people with HIV to cope with health concerns and buffers the negative impacts of stigmatization including stress, anxiety, and depression (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). Disclosure has also been associated with greater social support in individuals with substance abuse (Weisz, Quinn, & Williams, 2016), suggesting they too may benefit from the coping skills individuals with HIV experience after disclosure. Although disclosing HIV status can reduce depression (Vyavaharkar et al., 2011; Zea et al., 2005), increased depression can result if disclosure is not well-received (Kalichman et al., 2003). Other costs include damage to current relationships (Okareh, Akpa, Okunlola, & Okoror, 2015) and stigma (Valle & Levy, 2009). As a result, people with HIV engage in selective disclosure to friends more often than family members, and only certain family members who are anticipated to be supportive (Kalichman et al., 2003).

Less research has been conducted on the benefits and costs of disclosure among populations that speech-language pathologists are responsible for working with clinically. Riley and Hagger (2015) found that individuals with traumatic brain injury (TBI) disclose to gain social support, which may buffer against the effects of stigma. Hagger and Riley (2017) found that concealment of brain injury was associated with low self-esteem. They theorized that disclosing may provide a gateway to identifying with other individuals with brain injuries, and that identification may reduce self-stigma, thereby enhancing self-esteem. Disclosure of brain injury also enhances the quality of friendships but risks exposure to discrimination and prejudicial responses from others (Hagger & Riley, 2017; Riley & Hagger, 2015; Shorland & Douglas, 2010). For individuals with multiple sclerosis (MS), fear of losing one's job or being denied a promotion sometimes prevent disclosure to employers, although responses of employers have been reported to be generally positive, including offering workplace accommodations and increased social support (Kirk-Brown, Van Dijk, Simmons, Bourne, & Cooper, 2014; Reed, Meade, Jarnecke, Rumrill, & Krause, 2017). Although most people with Parkinson's disease rate reactions of others as positive, fears about others questioning their competence or pitying them along with a fear of upsetting others sometimes prevents disclosure (Haines et al., 2006).

Previous research has found that although disclosure has both benefits and costs, concealment of one's identity is associated with a host of negative outcomes. Concealment causes what [Wegner and Lane \(1995\)](#) refer to as the secrecy cycle which involves a set of cognitive processes that lead to obsessive preoccupation with the secret, including constant fear that the secret may be leaked. [Pachankis \(2007\)](#) found that preoccupation with a secret can lead to affective consequences including self-consciousness, vigilance, guilt, and shame. Such affective states lead to behavioral consequences including self-monitoring, careful management of impressions, social isolation and avoidance, an increased impact of others' reactions on future interactions, and challenges in close relationships. Experiences with these behaviors can then lead to negative self-evaluative consequences, including low self-efficacy and identity ambivalence.

Recognizing the harm of concealment and potential benefits of disclosure, programs have been created to assist individuals in navigating the complex process of disclosure. The Coming Out Proud program ([Rüsch et al., 2014](#)) was developed as a peer-led group intervention aimed at empowering individuals to make a personal choice about whether to disclose their mental illness. A pilot trial found significant decreases in disclosure-related stress in participants who reported gaining necessary coping resources to handle stigma-related threats. A similar intervention for adolescents with mental illness called Honest, Open, Proud ([Mulfinger et al., 2018](#)) resulted in reduced stigma related stress and increased QOL. The intervention also had a positive effect on self-stigma, disclosure-related stress, help-related intentions, secrecy, attitudes to disclosure, and depressive symptoms. [Morrow \(1996\)](#) designed a Coming Out Issues Group meant to promote disclosure among lesbians. Results showed higher disclosure rates corresponding with identity development and increased personal empowerment.

1.2. Evidence regarding disclosure of stuttering

In the area of stuttering, the costs and benefits for PWS to reveal or conceal their identity as a person who stutters are not well documented in the literature. This may be due to the variable characteristics of stuttering which cover a wide spectrum of symptomatology (core and secondary characteristics) and severity (mild to severe) that may or may not be concealable to others. In addition, as discussed earlier, disclosure could mean different things as it relates to stuttering. It could mean simply stuttering while speaking as opposed to remaining silent, stuttering openly and then discussing it, or talking about the fact that one stutters even during periods of fluent speech. Concealment of stuttering can be accomplished in a variety of ways including avoidance of words or sounds anticipated to cause stuttering through pretending to be lost in thought or searching for a word, using diversion tactics, knowingly providing false information, using nonverbal communication, circumlocution, or staying silent ([Boyle & Blood, 2015](#); [Sheehan, 1970](#)).

There has been some survey research conducted that aimed to document disclosure practices among individuals who stutter. [Blood, Blood, Tellis, & Gabel \(2003\)](#) surveyed 48 adolescents who stutter and found 60% of the sample never or rarely discussed stuttering, and 40% reported that they sometimes or often kept their stuttering a secret from others. When asked how they thought others found out about their stuttering, the largest percentage (48%) reported that others saw them stutter. Fewer participants reported telling others directly that they stutter (15%), experiencing a stuttering moment and then explaining it to the listener (15%), or someone else mentioning that they stutter (22%). [Erickson and Block \(2013\)](#) surveyed 38 adolescents who stutter using the same questions as [Blood et al. \(2003\)](#) and found that 62% sometimes or often kept their stuttering a secret from others, and 73% rarely or never talked about their stuttering to other people. [Erickson and Block \(2013\)](#) found that 47% of the sample reported that people discovered that they stutter by seeing/hearing the stuttering, 33% reported stuttering and providing an explanation for it, and 19% reported telling other people that they stutter. A recent study by [McGil, Siegel, Nguyen, and Rodriguez \(2018\)](#) found that disclosure statements of adults who stutter could most easily be categorized as either educational, apologetic, or direct, illustrating the variety of approaches that PWS may take in verbally disclosing to communication partners.

[Boyle \(2016\)](#) surveyed 245 adults who stutter about their disclosure practices and found that disclosure is not an all-or-none phenomenon (please note that the 2016 study utilized a completely different sample than the current study). Rather, there was a continuum of disclosure ranging from avoidance to deliberate or voluntary stuttering. When asked to select the option that best described their level of disclosure, 11% of the participants reported avoiding social situations to hide stuttering, 30% reported hiding stuttering by avoiding certain words or sounds, 7% reported only disclosing stuttering to trusted and understanding people, 48% reported not actively hiding stuttering, but not going out of their way to tell people about it, and 4% reported stuttering voluntarily and actively seeking out situations to disclose stuttering to others. The findings of that study also showed that PWS who avoided situations in order to hide their stuttering demonstrated significantly reduced levels of self-esteem than participants who selected all other responses. In addition, participants who disclosed stuttering indiscriminately, and those who 'broadcasted' their stuttering to others voluntarily, had significantly higher levels of self-efficacy compared to participants who hid their stuttering by avoiding social situations.

Qualitative research has also documented that PWS may attempt to avoid stuttering altogether through word, sound, or situation avoidance in order to come across as fluent speakers or minimize overt stuttering ([Butler, 2013](#); [Constantino et al., 2017](#); [Plexico et al., 2009a](#)), and that stuttering is rarely talked about among family or friends ([Hearne, Packman, Onslow, & Quine, 2008](#)). Individuals who conceal their stuttering to the extent that they do not come across as PWS to listeners are known as "covert" or "passing as fluent" ([Constantino et al., 2017](#); [Murphy, Quesal, & Gulker, 2007](#)). It should be noted that concealment of stigmatized identities does not always need to be seen as a negative avoidance technique that is only used among people who are ashamed. On the contrary, many people conceal stigmatized identities to maintain privacy and protect a sense of well-being from what they view as a hostile and unfair social response. Therefore, rather than being viewed as a passive act, for some PWS, the act of concealment may be perceived as empowering ([Constantino et al., 2017](#)). A desire to evade the possible social, emotional, and psychological

disadvantages of openly stuttering can make avoidant coping strategies a logical response (Plexico et al., 2009a, 2009b).

Most previous research in the area of disclosure and stuttering has analyzed public perceptions of stuttering and PWS, and mixed findings have been reported. Some studies have reported noticeable benefits of PWS disclosing their stuttering on variables such as perceived personality traits of PWS, emotional reactions, discriminatory intentions, and affirming attitudes toward PWS (Boyle, Dioguardi, & Pate, 2017; Boyle, Dioguardi, & Pate, 2016; Byrd, McGill, Gkalitsiou, & Cappellini, 2017; Byrd, Croft, Gkalitsiou, & Hampton, 2017; Collins & Blood, 1990). However, other studies have reported little positive impact in these areas (Healey, Gabel, Daniels, & Kawai, 2007; Lee & Manning, 2010). There are many potential variables that could explain the inconsistency of past findings. For example, disclosure appears to be more effective in improving attitudes of listeners when PWS reveal their stuttering at the beginning rather than the end of their message (Healey et al., 2007), when the speaker disclosing comes across as confident and positive (Boyle et al., 2017), when the wording of the disclosure is non-apologetic (Byrd, Croft et al., 2017; Collins & Blood, 1990), and when the person who discloses is a male (Byrd, McGill et al., 2017).

Although the effects of disclosure on self-attitudes of PWS have not been examined directly, research has been conducted on self-acceptance of stuttering by PWS, which involves being more open about stuttering. The coping style adopted by PWS (using avoidant/escape strategies or approach strategies) and its influence on achieving acceptance of stuttering has been explored. Replacing avoidant strategies (word replacement, refusing to speak in social contexts) with approach strategies (being proactive about changing the desired behavior) appears to be important in the process of self-acceptance (Plexico et al., 2009b). Plexico et al. (2009b) posited that acceptance “involves acknowledging to the self and others that a problem exists, that the problem does not define the speaker’s identity, and that the individual is capable of being an active agent in the change process” (p. 121). In addition, PWS have reported several benefits to being open about stuttering and acknowledging to others that they stutter including reducing time-pressure expectations to produce a message quickly and generating support from the listener (Plexico et al., 2009b). De Nardo, Gabel, Tetnowski, and Swartz (2016) also found that self-acceptance of stuttering was positively correlated with self-esteem and negatively correlated with perceived discrimination and hostility.

There is not much research to date that can explain why certain PWS are more open about stuttering than others, however, it is widely believed that self-help/support groups for PWS can facilitate this process. Previous research has suggested that participation in support groups for stuttering can increase opportunities for social interaction and affiliation with other PWS, and increase self-disclosure of stuttering (Ramig, 1993; Trichon & Tetnowski, 2011; Yaruss et al., 2002). Furthermore, involvement in support groups for stuttering has been linked to reduced levels of self-stigma among PWS and increased levels of acceptance of stuttering as a chronic condition (Boyle, 2013b), as well as increased social support, self-esteem, group identification, and community activism (Boyle, 2015b). This is important because self-acceptance of stuttering and the use of approach oriented coping strategies have been reported by PWS to increase QOL (Plexico et al., 2009b), an important outcome measure for speech-language pathologists. QOL refers to an individual’s reported satisfaction and/or fulfillment in activities and experiences in important life domains, and in life in general (Endicott, Nee, Harrison, & Blumenthal, 1993). As per ASHA’s scope of practice, “the overall objective of speech-language pathology services is to optimize individuals’ ability to communicate and to swallow, thereby improving quality of life” (American Speech-Language-Hearing Association, 2016, p. 5). Increasing QOL is therefore indicated as a core objective in the provision of therapy by SLPs and as a measurement of achieving successful treatment outcomes.

1.3. Purpose of the current study

Taken altogether, the literature reviewed above highlights the importance of better understanding the disclosure practices of PWS and how they might relate to important aspects of personal well-being. Although prior published research has found positive effects of disclosure on public opinion about stuttering and PWS, very little research has been conducted that looks at how the level of disclosure, or amount of openness, demonstrated by PWS is associated with their own sense of well-being. Therefore, the purpose of this preliminary study is to explore whether higher self-reported QOL is associated with increased levels of disclosure of stuttering. If improvement in QOL is one of the core objectives of the profession of speech-language pathology, it seems relevant to examine if it is linked to increased disclosure of stuttering in PWS. As described in previous sections, disclosure of a stigmatized condition is not without its risks and concealment may yield advantages in certain situations. However, based on research reviewed above that describes several potentially important benefits of disclosure, it was hypothesized that overall the advantages of disclosure would outweigh disadvantages and that increased disclosure of stuttering would be linked to higher self-rated QOL. A secondary purpose of this study was to explore the disclosure habits of a large sample of adults who stutter with a more detailed and lengthier set of items than what has been used in prior research on disclosure of stuttering (Boyle, 2016). Because this was a purely exploratory question, no a priori hypothesis was made. Finally, based on previous findings suggesting that participation in self-help support groups for stuttering is linked to increased disclosure, it was hypothesized that participants who self-reported such involvement would score higher on disclosure than those reporting no involvement in support groups.

2. Methods

2.1. Participants

Participants were 322 adults who stutter. They were recruited from Board Certified Specialists in Fluency Disorders, speech-language pathologists on therapy referrals lists for stuttering, and chapter leaders of self-help support groups for adults who stutter in the United States. There were 218 males (67.7%) and 102 females (31.7%) (1 participant preferred not to report sex, and another

reported being non-binary/third gender) ranging in age from 18 to 87 years ($M = 37.95$, $SD = 15.56$). Three hundred and seven of the participants (95.3%) had reported previously receiving treatment for their stuttering. Two hundred and fifty-eight (80.1%) participants reported having previously been involved in self-help support groups for stuttering, and 64 (19.9%) did not. It should be noted that data from participants in the current study came from a larger research project seeking to further understand the experiences of stigma and communicative participation in adults who stutter (other results reported in Boyle, 2018; Boyle, Beita-Ell, Milewski, & Fearon, 2018; Boyle & Fearon, 2018). The results reported in the current paper present only part of the results from the larger research project. Those participants who completed questions about disclosure and QOL were included in this study. Demographic information of the participants is similar, however, the current study has different aims, hypotheses, and results, and reports on a different set of primary variables than the previous reports. Data for the current project were collected from January through April of 2017. The sample for the current study was different from any sample reported on by the first author in any publication prior to 2018.

2.2. Procedure

Professionals and self-help support group leaders were e-mailed a web link for the study which was developed using Qualtrics survey software. They were contacted with three separate requests to forward the survey to clients, chapter members, or other acquaintances who stutter who were age 18 or older. One week separated each contact. Individuals who were interested in completing the survey read a brief summary of the purpose of the study and an informed consent form. This study was approved by the authors' institutional review board and the National Stuttering Association Research Committee. In the survey, participants completed demographic information including age, sex, treatment history, and self-help support group for stuttering history, as well as items that assessed self-perceived QOL and level of disclosure of stuttering.

2.3. Measurement

2.3.1. Disclosure of stuttering

Items used to evaluate disclosure of stuttering were developed by the first author after a thorough literature review of various scales that have been created to measure disclosure of stigmatized conditions including mental illness (King et al., 2007; Link, 1987; Ritsher, Otilingam, & Grajales, 2003), HIV/AIDS (Berger, Ferrans, & Lashley, 2001; Sayles et al., 2008), and stuttering (Blood et al., 2003). These previously established scales all included subscales that measure individuals' level of disclosure or concealment of the condition. Relevant questions from these scales were examined and wording was modified to be applicable to PWS. Response options ranged from 1 (strongly disagree) to 5 (strongly agree) and responses for each of the 10 items were summed to calculate an overall score of disclosure. Possible scores ranged from 10 to 50. Negatively worded items were reverse scored so that higher scores represented more openness and disclosure regarding stuttering. All items can be seen in Table 1.

2.3.2. Quality of life

QOL was evaluated with a single measure from the Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF; Endicott et al., 1993) that evaluated participants' overall ratings of their self-perceived life satisfaction and contentment during the past week. The authors of the scale developed this one item to be used as a stand-alone measure that could allow participants to summarize their overall experience in one global rating. This item was used to capture QOL because it assesses the global QOL perception that was of interest in this study, rather than the specific domains measured on the scale that were not deemed relevant for

Table 1
Percentages of participants agreeing or disagreeing with disclosure statements.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1. I rarely feel the need to hide the fact that I stutter.	19.3	28.9	10.9	21.1	19.9
2. In many areas of my life, no one knows that I stutter.	32.2	18.9	11.8	25.8	11.2
3. I am comfortable talking to everyone I know about my stuttering.	13.7	17.4	10.0	29.8	29.2
4. Telling someone about stuttering is risky.	36.7	23.3	13.4	19.9	6.8
5. It is important to keep my stuttering a secret from co-workers.	55.0	21.7	12.1	7.8	3.4
6. When I meet people for the first time, I make a special effort to keep the fact that I stutter to myself.	19.9	18.9	16.8	26.7	17.17
7. I am comfortable talking about my stuttering with my family.	4.7	14.6	6.8	31.4	42.6
8. I am comfortable talking about my stuttering with my friends.	5.9	14.3	7.1	32.0	42.6
9. It is important for a person to keep stuttering a secret from others.	69.3	15.2	9.9	4.0	1.6
10. If I had a friend who stuttered, I would advise him or her not to tell anyone about it.	85.1	9.3	4.4	0.3	1.0

this study (e.g., satisfaction with medication, physical health, economic status, etc.). In previous research, the one global rating correlated highly and significantly with the summary scores for the Q-LES-Q-SF (correlation coefficients of 0.84 were observed between this one item and the overall summary score in a dataset described by Boyle, 2015b). Therefore, the ratings from this one question can be viewed as being largely redundant with summary scores for the scale. Response options range from 1 (very poor) to 5 (very good), with higher scores representing increased ratings of QOL.

For statistical purposes, three QOL subgroups were created. QOL scores were divided into low, average, and high subgroups based on the sample data. This was done because, as can be seen in the results section, a small number of participants selected the “poor” and “very poor” response options, and a relatively large number of participants selected the “good” option. Therefore, because the “good” response option was by far the most commonly selected, we labeled this “average QOL.” The participants who chose response options of “very low,” “low,” and “fair” were therefore categorized as “low QOL” because they reported lower ratings than the most common response. Participants in the “high QOL” subgroup were those that chose the “very high” QOL response. These labels should be interpreted as relative to the current sample, rather than being absolute. Creating the subgroups in this way created more even distribution in number of participants across different groups, and therefore enhanced the statistical power of the analysis.

2.4. Data analysis

Because the disclosure scale was developed by the first author of this study, reliability analysis using Cronbach’s coefficient alpha was calculated to determine the internal consistency, or degree of interrelatedness of the items that comprised the scale. Percentages of participants who chose particular response options for each of the 10 items in the disclosure scale were also obtained in order to determine disclosure practices for the overall sample. An independent samples *t*-test was conducted to determine if there were differences in level of disclosure of stuttering between individuals reporting a previous history of support group participation for stuttering and those who did not. Analysis of variance was utilized for the primary analysis that compared QOL subgroups on disclosure scores. Tukey’s honestly significant difference post hoc multiple comparison test was utilized to detect which QOL subgroup pairs differed significantly on disclosure scores. If pairwise comparisons of post hoc tests were statistically significant, Cohen’s *d* was calculated for a measure of effect size of the difference (small = 0.20–0.49; medium = 0.50–0.79; and large = > 0.80) (Cohen, 1992).

3. Results

Cronbach’s α for the items in the disclosure of stuttering scale was 0.85, which is considered good for basic research purposes (George & Mallery, 2003). Because it was of interest to explore the disclosure habits of adults who stutter, percentages of participants selecting particular response options (extent of agreement or disagreement) for each of the 10 items are shown in Table 1. Some findings from Table 1 regarding disclosure practices are worth highlighting. Although almost everyone (94.4%) in the sample would advise a friend against concealing stuttering from other people, many participants agreed that they personally make an effort to not disclose their stuttering when they meet someone new (43.9%). The discrepancy in these findings appears to represent a gap between what PWS would suggest for a friend and what they would do personally. A minority (41%) agreed that they rarely feel the need to hide the fact that they stutter. In addition, over one-third (37%) of participants agreed that in many areas of life, no one knows they stutter. This might indicate that these individuals try to conceal their stuttering, or perhaps they exhibit milder types of disfluencies that aren’t easily detectable. In any case, these data suggest that concealment (or attempting to conceal) stuttering is not an uncommon phenomenon for PWS, at least in certain life situations. Notwithstanding, positive findings included participants’ reported comfort talking about their stuttering with family and friends. The scores on the disclosure scale ranged from 12 to 50 ($M = 37.53$, $SD = 8.04$).

Regarding participants’ ratings of their overall contentment and life satisfaction over the past week, 72 (21.9%) participants reported “very good,” 149 (45.3%) reported “good,” 78 (23.7%) reported “fair,” 26 (7.9%) reported “poor,” and 4 (1.2%) reported “very poor.” As reported in Section 2.3.2, “low,” “average,” and “high” QOL subgroups were created based on these results. Table 2 shows descriptive statistics of level of disclosure across the different QOL subgroups. Fig. 1 shows a bar graph comparing average disclosure scores across QOL subgroups. As can be seen, level of disclosure increases consistently as QOL becomes higher across groups.

The primary analysis of this study compared disclosure across subgroups of QOL. Levene’s test for equality of variances indicated that the variances could be considered equal across QOL subgroups, $p > .05$. There was a significant overall effect for level of disclosure, $F(2, 321) = 10.62$, $p < .001$, $\eta^2 = .062$ (medium effect size). Pairwise comparisons revealed that the “low QOL”

Table 2
Summary data for disclosure for overall sample and all QOL subgroups.

Group	<i>N</i> or <i>n</i>	<i>M</i>	<i>SD</i>	Range possible	Range observed
Overall sample	322	37.53	8.04	10–50	12–50
Low QOL subgroup	103	34.99	7.49	10–50	18–50
Average QOL subgroup	147	37.88	8.13	10–50	12–50
High QOL subgroup	72	40.44	7.58	10–50	22–50

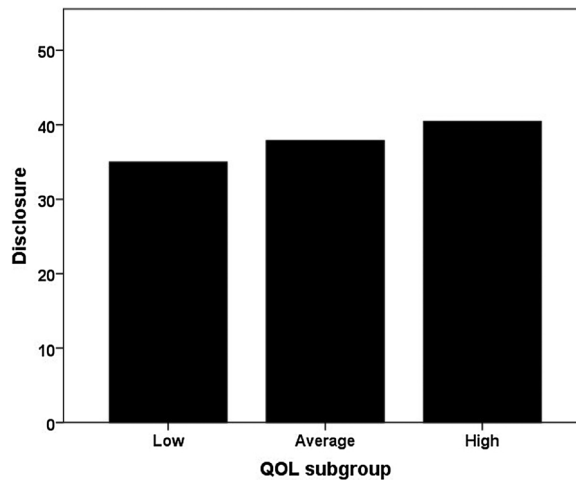


Fig. 1. Bar graph comparing average disclosure scores across QOL subgroups.

subgroup reported significantly lower disclosure than the “average QOL” subgroup, $p = .012$, $d = 0.37$ (small effect size), and significantly lower disclosure than the “high QOL” subgroup, $p < .001$, $d = 0.72$ (medium effect size). The “high QOL” subgroup did report a higher level of disclosure than the “average QOL” subgroup, however, this difference did not reach statistical significance, $p = .059$.

An independent samples t -test was conducted to determine if there were differences in disclosure between individuals who reported support group experience for stuttering and those who did not. Because group sizes were unequal, Levene’s test for equality of variances was conducted to determine whether equal variances could be assumed between the groups. Results of that test indicated that the variances could be considered equal, $p > .05$, between participants with and without support group experience. It was found that the group of PWS with previous self-help/support group history reported significantly higher levels of disclosure ($M = 38.26$, $SD = 7.72$) of stuttering than those without such experience ($M = 34.56$, $SD = 8.64$), $t(320) = 3.35$, $p < .001$. Cohen’s d was calculated to determine the magnitude of the difference between groups and the effect size was small, $d = 0.45$. Therefore, the group with support group experience scored close to one-half of a standard deviation higher on the disclosure scale than the group without such experience. Level of disclosure was not significantly correlated with age and there was no significant difference in disclosure between males and females. There was also no significant difference in disclosure between participants who had received prior stuttering treatment and those who had not.

4. Discussion

This study aimed to better understand disclosure practices among PWS and examine the associations between disclosure of stuttering and QOL. It was hypothesized that increased disclosure would be associated with higher self-reported QOL, and this hypothesis was supported by the results of the study. The secondary hypothesis, that support group attendance would be positively related to disclosure of stuttering, was also supported. These findings appear to support previous research on other stigmatized conditions that suggest a positive association between disclosure of the condition and well-being (Corrigan et al., 2011; Zea et al., 2005). The findings also support prior qualitative research describing benefits of disclosure and openness of stuttering (Plexico et al., 2009b). Previous studies have demonstrated several benefits of disclosure related to improved public perceptions of stuttering (Boyle et al., 2016; Byrd, McGill et al., 2017, 2017b, Collins & Blood, 1990). However, Lee and Manning (2010) suggested that “...self-acknowledgment of stuttering is likely to be more beneficial for the speaker than for the listener” (p. 119). Despite that prediction, there has been a lack of empirical evidence regarding disclosure among PWS themselves. The current findings provide empirical support for the association between level of disclosure and self-rated QOL. Effect sizes for pairwise comparisons ranged from small to medium. In addition, the current results are similar to previous studies demonstrating that involvement in self-help/support groups for stuttering is associated with increased social support (Boyle, 2015b) and opportunities for disclosure of stuttering (Trichon & Tetnowski, 2011). It is likely the case that being involved in these groups gives PWS an opportunity to learn from other PWS about methods of successful disclosure, which may result in increased willingness to disclose. The group difference yielded a small effect size, bordering on a medium effect size, which is also similar to previous quantitative studies focusing on the differences in well-being between PWS with and without support group experience (Boyle, 2013b, 2015b).

This study also contributed information about disclosure and concealment practices among a large group of PWS. The findings seem to support earlier quantitative (Blood et al., 2003; Erickson & Block, 2013) and qualitative investigations (Butler, 2013; Constantino et al., 2017; Hearne et al., 2008; Plexico et al., 2009b) in their conclusions that concealment of stuttering is not uncommon. The results could be interpreted to suggest that the phenomenon of covert stuttering, or ‘passing as fluent’ (see Constantino et al. (2017) for a detailed investigation of this phenomenon) could be more prevalent than previously thought, at least in certain life situations. The fact that over 44% of participants in this large sample reported making a special effort to not share the fact that they

stutter when meeting someone new highlights the idea that it is not an uncommon phenomenon for PWS to withhold this information when making a first impression. It is not clear from the data however, if participants conceal by attempting to minimize stuttering during speech, or by avoiding speaking altogether. In addition, nearly half of the sample reported that they more than sometimes feel the need to hide the fact that they stutter (48.2%), and 37% agreed that in many areas of life, no one knows that they stutter. Participants' motives for concealment of stuttering are not clear from the current study. It cannot be determined whether this concealment occurs due to a personal sense of shame, a desire to avoid social penalty, or for other reasons. Qualitative studies should be conducted to investigate the motives or goals behind disclosure and concealment of stuttering among PWS.

Results of the study are limited in a few regards. First, as this is a correlational study it is not possible to make claims about causal determination between the variables of interest that were measured. In addition, due to the exploratory nature of this study, there are other variables that were not measured that need to be taken into account in order to explain QOL among adults who stutter. Also, the construct of QOL was measured by one item. Although this one item was intended to be used as a stand-alone global rating of self-rated QOL, the use of a longer and more detailed scale of QOL that is broken down into several relevant domain specific components (e.g., education, work, social settings, etc.) would be helpful for obtaining more detailed information. Due to the cross-sectional nature of the study and the survey methodology utilized, it was not possible to obtain rich descriptions of how disclosure and concealment practices among PWS develop and change over time, and how responsive they are to intervention. Qualitative studies analyzing PWS' perceptions of disclosure and concealment over time across different situations would be a valuable addition to the literature. In addition, quantitative studies that include frequency of different types of disclosure as response options, rather than degree of agreement or disagreement, could provide important additional details about disclosure practices. It will also be important to implement treatment studies that focus on helping PWS disclose in an effective manner and measuring the impact that this has on QOL and communicative participation.

Regarding the external validity of the study, there may be some limits to generalizability based on how the sample was obtained. Participants were recruited through professionals or self-help support group chapters, and therefore it is highly probable that as a whole, they were more likely to have sought help for their stuttering in some way. It could be possible that individuals who have not sought help for their stuttering are different in their levels of disclosure and QOL compared to people who have sought such help. People who have not sought help might disclose less (after all, disclosure is necessary to obtain services for stuttering). If more individuals who disclosed less often were included in the study, the increased variability in responses may have led to larger effect sizes between subgroups of QOL than was observed in the current study. However, it should not always be assumed that concealment of stuttering is necessarily indicative of lower QOL. It is possible that for some PWS, concealing stuttering is an act of empowerment that gives a sense of pride in being able to access opportunities that could possibly be blocked due to stuttering (Constantino et al., 2017). This variability in how disclosure and concealment is perceived by PWS is likely a reason why effect sizes for the primary analyses were not stronger in magnitude. Therefore, although it is a difficult task, future research should strive to obtain participants outside the framework of therapy or support groups to maximize generalizability of findings.

Although there are limitations, the current study contributes knowledge of how QOL is linked to disclosure of stuttering among PWS. Previous research has focused primarily on the benefits of disclosure on public perceptions of PWS, however there has been a lack of empirical studies that document the implications of disclosure among PWS themselves. This study was a preliminary attempt to address the shortage of research in this area. The findings suggest that speech-language pathologists and other professionals should take into account a client's level of disclosure or openness about stuttering during assessment and when determining treatment goals. As it is the primary goal of speech-language pathologists to enhance clients' QOL, clients who are at a higher risk for reduced QOL should be identified and given appropriate treatment. Because PWS who are less open about their stuttering and disclose less often are more at risk for reduced QOL, appropriate treatment for these individuals may include discussing options for disclosure (e.g., weighing advantages and disadvantages of disclosure in certain situations, considering different ways of disclosing, creating disclosure messages for certain situations, etc.). Recent research has begun to identify important elements of disclosure of stuttering as perceived by the general public that lead to enhanced attitudes about PWS (see Boyle et al., 2017). These evidence-based strategies can be used in therapy by clinicians and advocates to create disclosure messages that people who stutter feel comfortable making in specific situations, thus optimizing the effectiveness of their disclosure.

Despite the primary finding of this study showing that disclosure and QOL are positively associated, it is still a well-known phenomenon that many PWS are devalued or responded to negatively when stuttering is made public (Boyle, 2018). It will therefore be important moving forward to further uncover what combination of personal and environmental factors predicts more successful disclosures. For example, in a qualitative study, Boyle and colleagues (2017) found that a speaker who comes across as having a positive attitude and who appears comfortable and confident when disclosing is helpful in improving public attitudes about stuttering. That study also showed that disclosure can improve public attitudes about PWS when the person who discloses includes specific content in the disclosure message (e.g., description of daily struggles and challenges with stuttering, accomplishments achieved despite stuttering, affirming goal statements for how the public should interact with PWS). McGill and colleagues (2018) recommended that PWS consider using straightforward or educational, non-apologetic disclosure statements that occur in the beginning of an interaction. Despite these recommendations, there is a lack of evidence regarding personal factors within PWS themselves that predict why certain people choose to disclose or conceal in certain situations, or the success of their disclosure. It could be important to measure factors such as extraversion and self-esteem to better understand how disclosure is related to psychological well-being. Future studies should attempt to measure several variables that could help deepen our understanding of the process of disclosure in PWS. A better understanding of disclosure could help professionals and advocates to better support PWS in making optimal decisions about disclosure. Ultimately, these disclosure decisions could improve QOL among PWS through increased social support and reduced feelings of internalized stigma.

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Conflicts of interest

The authors have no conflicts of interest to disclose.

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Michael P. Boyle, Ph.D., CCC-SLP, is an Associate Professor in the Department of Communication Sciences and Disorders at Montclair State University. He is an active researcher who studies psychosocial aspects of stuttering including stigma and empowerment. Dr. Boyle received his Ph.D. and M.S. degrees from the Pennsylvania State University in communication sciences and disorders. He received his B.A. in psychology from the University of Delaware.

Kathryn Milewski, B.A., is currently working on her master's degree in communication sciences and disorders, with a focus in speech-language pathology, at Montclair State University. She received her B.A. in psychology from the College of New Jersey, and has worked as a mental health case manager.

Carolina Beita-Ell, M.S., CCC-SLP, is pursuing a doctoral degree in communication sciences and disorders at Montclair State University with a focus in psychosocial aspects of stuttering. She received her M.S. degree in speech-language pathology from William Patterson University and has worked as a speech-language pathologist in public schools in Jersey City, New Jersey.