Self-stigma associated with stuttering: Implications for well-being and strategies for change

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Abstract. This paper describes the concept of self-stigma and how it is relevant for individuals who stutter. Self-stigma can have a profound impact on psychological well-being and societal participation of people who stutter. Assessment of self-stigma specifically related to stuttering can be accomplished by several methods, including the Self-Stigma of Stuttering Scale (4S), which is a psychometrically sound scale currently being used by clinicians and researchers internationally. The scale taps into domains of awareness, agreement, and application of stigma. Research studies have demonstrated that self-stigma can be reduced through a variety of mechanisms including disclosure, cognitive restructuring, and peer support. It is recommended that future research continues to explore best practices for diminishing self-stigma in people who stutter.

1. Background
As will be demonstrated in this paper, the construct of stigma is an important factor to consider in the disorder of stuttering. As a field, speech-language pathology is concerned with affective, cognitive, social, and behavioral aspects of communication disorders. This paper reviews the evidence suggesting that internalized stigma is a relevant component of the disorder that should be taken into account in order to increase well-being and communicative participation of individuals who stutter. The disorder of stuttering will not be fully understood unless knowledge of these more hidden aspects of the disorder is gained by professionals, family members, and members of the public. This paper intends to describe (1) the concept of self-stigma and its definition, (2) evidence suggesting that self-stigma is relevant for PWS, (3) assessment of self-stigma in PWS, (4) strategies for reducing self-stigma in PWS, and (5) ideas for future research in the area of self-stigma related to stuttering.

2. Self-stigma and its relevance for individuals who stutter
Stigma has been described as both an attribute and a process (Jones et al., 1984). As an attribute, a stigma is some signal (trait, appearance, label, skill deficit) that is linked to negative social perceptions. As a process, these negative social meanings are attached to the individual displaying that signal, resulting in stereotypes (knowledge structures learned by society), prejudice (negative emotional reactions and agreement with stereotypes), and discrimination (the behavioral outcome) (Link & Phelan, 2006). Importantly, stigma is a process involving cognitive (stereotypes), affective (prejudiced reactions), and behavioral (segregation, discrimination, avoidance) components. Current conceptualizations of stigma discuss the notion that stigma is not an intrinsic trait of an individual, rather it only exists in certain social contexts in which the signal is devalued and perceived negatively (Crocker, Major, & Steele, 1988).

Another aspect of stigma is that the cognitive, affective, and behavioral components can be public or private. This distinction has been referred to as public stigma vs. self-stigma (Corrigan, Larson, & Kuwabara, 2010). Public stigma is what the public does to individuals with stigmatized conditions, including stereotyping, demonstrating prejudice, and discrimination. Self-stigma involves the same components; however, they are directed inward. A person becomes aware of negative public perceptions and reactions, and agrees with them. Then, the individual applies those negative perceptions to him or herself personally. This internalization of stigma results in experiencing negative emotions about the self, and limiting oneself behaviorally (e.g., not applying for a job). Eventually, the person may begin to think “why should I even try?” and experience diminished psychological well-being and societal participation (Corrigan, Larson, & Rüsch, 2009). The individual who self-stigmatizes may also undergo identity transformation (e.g., “a person like me couldn’t do something like that.”). Although self-stigma is often described as being distinct from public stigma, the two are closely related. The person self-stigmatizes as a result of previous experiences, perceptions, or the anticipation of negative social reactions (e.g., interpersonal rejection) on the basis of stuttering (Livingston & Boyd, 2010).

It is not difficult to see how the concept of stigma can be applied to PWS (Boyle & Blood, 2015; St. Louis, 2015). Regarding public stigma, there has been extensive literature documenting how PWS are perceived as having negative or devalued personality traits (Craig, Tran, & Craig, 2003), and reduced competence (Silverman & Bongey, 1997). There is also evidence that people who do not stutter become physiologically and emotionally tense when...
hearing stuttering (Guntupalli, Kalinowski, Nanjuedeswaran, Saltuklaroglu, & Everhart, 2006). These types of reactions on the part of the public can result in consequences such as not putting PWS in leadership roles or roles that require lots of speaking (Davis, Howell, & Cook, 2002). Regarding self-stigma, there has been previous evidence that PWS are aware of negative public perceptions toward them due to their stuttering (Bricker-Katz, Lincoln, & McCabe, 2010), agreement with those negative perceptions for other PWS (Kalinowski, Lerman, & Watt, 1987), and application of those beliefs to themselves personally which impact well-being and participation (Plexico, Manning, & Levitt, 2009). According to the World Health Organization (WHO, 2002), conceptualizations of disability and functioning must take into account not only the body functions and structures of a health condition, but also contextual factors (environmental and personal) that interfere with the participation and activity of the individual with the condition. Personal factors include perceptions of oneself, and therefore self-stigma is relevant as a contextual factor that should be addressed by professionals who help PWS.

3. Assessment of self-stigma related to stuttering

Boyle (2013a) developed a scale called the Self-Stigma of Stuttering Scale (4S) to measure components of a multi-level model of self-stigma including awareness, agreement, and application of stigma (Corrigan, Rafacz, & Rüsch, 2011). Awareness measures how much the PWS perceives that others have negative perceptions of PWS (e.g., “I think that the public believes that PWS are nervous.”). Agreement measures how much PWS agree with negative public perceptions of PWS (e.g., “I agree, PWS are nervous.”). Application measures how much the person internalizes the stigma and applies it to him or herself personally (e.g., “Because I stutter, I feel less confident than people who do not stutter.”). The scale was developed after an in-depth literature review, interviews with 18 individuals who stutter, expert review, and a pilot project with participant feedback. Psychometric analysis was then conducted with a sample of 291 adults who stutter. The factor structure of the scale included components of awareness, agreement, and application as a parsimonious model. The scale demonstrated adequate to excellent reliability in areas of internal consistency and temporal stability across different scale components. Preliminary evidence of construct validity was demonstrated by self-stigma being negatively correlated with self-esteem, self-efficacy, and life satisfaction. In particular, these correlations were strongest when looking at stigma application. The implications of these findings are that assessing awareness of stigma is not sufficient to document its full effect. Rather, internalization in the form of stigma application demonstrated the most negative implications. Eighty-six percent of the sample demonstrated high levels of stigma awareness, but only 18% demonstrated high stereotype agreement. Thirty-eight percent of the sample however demonstrated high levels of stigma application. These results could be interpreted to mean that PWS are harder on themselves than other PWS (i.e., they apply more negative stereotypes to themselves personally than they do to other PWS).

A follow up study was conducted on the construct validity of the 4S with a sample of 354 PWS (Boyle, 2015a). The factor structure and reliability estimates were replicated, and it was found that self-stigma, especially stigma application, was negatively correlated with quality of life, hope, social support, and empowerment. Self-stigma was positively correlated with anxiety, depression, and perceived severity of speech disruption. Another finding of interest was that mere awareness of negative public perceptions of PWS was associated moderately with increased anxiety and depression. The implication of this finding is that continued efforts for public stigma reduction will be important for researchers to address. The percentages of the PWS in the sample demonstrating high levels of stigma were similar to the findings of the previous study (Boyle, 2013a). Eighty-four percent of the sample demonstrated high levels of stigma awareness, 27% demonstrated high levels of agreement, and 32% demonstrated high stigma application. The author concluded as a result of these studies that the 4S demonstrated sufficient psychometric properties to be used for clinical and research purposes. The scale is currently being used internationally by clinicians and researchers, and is being translated to several different languages.

4. Diminishing self-stigma related to stuttering

Identifying self-stigma in PWS should lead to measures taken during intervention to reduce this stigma. In the psychology literature, there are many evidence based strategies for self-stigma reduction including disclosure of the disability, cognitive restructuring, and peer support (see Corrigan & Rao, 2012, for further discussion). Disclosure can bring feelings of relief to the individual with a stigmatized condition through reducing the need to hide aspects of him- or herself from the public. This can increase feelings of openness and control over one’s life. In addition, if one is open about a disability, it creates the opportunity to connect with similar others and work together for positive change. Disclosure is also the mechanism through which a very effective public stigma reduction strategy, contact, can operate in real world settings. Contact between PWS and those who do not stutter can only be made if PWS are willing to disclose stuttering, or at least demonstrate it in public. Cognitive restructuring involves identification of
self-stigmatizing thoughts (e.g., “I stutter, so I must be a bad person”) and reframes them as irrational statements. Then, the individual can challenge the irrational beliefs and change them into something more empowering and positive (“Stuttering doesn’t make me a bad person.”). Evidence is collected that disputes the previous negative beliefs and positive self-talk is established. Peer support, through self-help support groups, family and friends, serves an important role in self-stigma reduction as well. Sharing experiences can help create a sense of community, and an opportunity for people to support others who may be struggling coping with the disorder. Another vital function of self-help support groups is to reduce public stigma as a group and even enhance group pride.

In a sample of 354 adults who stutter, Boyle (2015b) documented that stigma application is negatively related to openness about stuttering (large effect size), feelings of personal empowerment (large effect size), social support from friends (medium effect size), self-help support group participation in the last three years (small effect size), and group identification (i.e., identifying with other PWS) (small effect size). Taken together, these variables accounted for 48% of the variance in stigma application scores of the participants. In another study, Boyle (2013b) found that individuals who stutter who were self-help support group members demonstrated significantly lower stigma application than PWS with no self-help support group experience. Therefore, there is correlational evidence of the relevance of disclosure, cognitive restructuring, and peer support for stigma application in PWS. Regarding evidence from treatment studies, researchers have utilized cognitive-behavioral approaches for reduction of cognitive and affective challenges associated with stuttering. Even though most of these treatment studies do not necessarily mention the term “stigma” they do address cognitive and affective aspects of the disorder that are very relevant to this construct. Menzies et al. (2008) tested the effects of a cognitive-behavioral therapy (CBT) approach on a variety of psychological and speech outcomes of 30 PWS. Compared to a control group that received only speech modification treatment, the group that received CBT demonstrated significantly higher levels of psychological functioning, reduced anxiety and avoidance, and more willingness to enter feared speaking situations. Helgadóttir, Menzies, Onslow, Packman, and O’Brien (2014) recently followed up on this study using a web based treatment approach called CBTPsysch with 13 adults who stutter. They found that following the treatment the participants demonstrated significantly reduced fear of negative evaluation, social phobia, and unhelpful thoughts and beliefs about stuttering, as well as improved overall scores on the Overall Assessment of the Speaker’s Experience of Stuttering (OASES) (Yaruss & Quesal, 2006). In addition, Beilby, Byrnes, and Yaruss (2012) found that PWS demonstrated significantly improved OASES scores, indicating reduced negative thoughts and emotions about stuttering, fewer avoidance tactics used, and less difficulty communicating, following a two month program on Acceptance and Commitment Therapy (ACT).

Psychological research, particularly in the area of mental illness, has created specific programs dedicated to stigma reduction, and the results are promising. Lucksted et al. (2011) developed a manualized program (Ending Self-Stigma) in a group of 50 individuals with schizophrenia and mood disorder. After nine sessions targeting various aspects of self-stigma, significant reductions in internalized stigma, and significant increases in perceived social support and recovery orientation were demonstrated. Rüsch et al. (2014) examined the effects of the “Coming Out Proud” program for stigma reduction in individuals with mental illness. This program taught effective ways of disclosing mental illness and encouraged participants to craft their own personal stories to share with others. Results indicated that the group receiving the Coming Out Proud treatment exhibited reduced stigma related stress and disclosure stress, as well as reduced secrecy. Participants in the program also reported increased disclosure related self-efficacy. These examples of research studies in the field of psychology have lots to offer the field of speech language pathology as professionals work toward reducing self-stigma in PWS.

5. Conclusions and future research directions related to self-stigma in individuals who stutter
Future research on the topic of stigma in individuals who stutter should be multifaceted. Although the focus of this paper has been self-stigma, it is important to not lose sight of the importance of public stigma. Stigma is a societal problem, and it would be unfortunate if PWS perceived that self-stigma is their fault, or just another one of their problems. Societal change is needed if stigma is to be mitigated, and so emphasis on public stigma reduction toward stuttering will be important for researchers moving forward. In particular, specific strategies that are carefully crafted to include evidence based components from the psychology literature will be useful to test for stigma reduction related to stuttering. Despite the importance of public stigma reduction, it would be naïve to suggest that complete eradication of negative attitudes towards stuttering will be possible in the short term. Therefore, individuals who stutter may need to develop strategies for coping with public stigma and limiting self-stigma. Treatment programs specifically targeting self-stigma should continue to be developed and tested.

It should be remembered that noticeable physical speech disruption associated with stuttering is not synonymous with life impact. In fact, there is some evidence that frequency of stuttering measured by percentage of syllables stuttered is not significantly related to psychological well-being (Manning & Beck, 2013). Therefore, if
stuttering is more than just speech disruptions, assessment and intervention with PWS should focus on more than speech disruptions as well. If self-stigma is to be managed and treated, it also needs to be measured with a valid tool. The 4S described in this paper is a psychometrically sound scale for achieving that aim. The field of speech-language pathology has made considerable progress in realizing that stuttering as a disorder is more than the surface features or behaviors of stuttering. However, we have a great deal more to learn regarding the impact of stigma on well-being and the best ways to address it in order to improve participation and quality of life. In summary, self-stigma certainly exists in many PWS. However, it is not inevitable that PWS will internalize that stigma. Self-stigma can be documented with reliable tools. Self-stigma can also be treated so that PWS who are struggling to cope with the disorder can increase their participation in society, well-being, and overall quality of life. Research documenting the most effective ways to accomplish these aims should continue to be conducted.

References


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