Journal of Fluency Disorders 38 (2013) 368–381

Contents lists available at ScienceDirect

Journal of Fluency Disorders

Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience

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ARTICLE INFO

Article history:
Received 24 August 2013
Received in revised form
14 September 2013
Accepted 16 September 2013
Available online 1 October 2013

Keywords:
Stuttering
Support groups
Self-esteem
Life satisfaction
Stigma

ABSTRACT

Purpose: To compare adults who stutter with and without support group experience on measures of self-esteem, self-efficacy, life satisfaction, self-stigma, perceived stuttering severity, perceived origin and future course of stuttering, and importance of fluency.
Method: Participants were 279 adults who stutter recruited from the National Stuttering Association and Board Recognized Specialists in Fluency Disorders. Participants completed a Web-based survey comprised of various measures of well-being including the Rosenberg Self-Esteem Scale, Generalized Self-Efficacy Scale, Satisfaction with Life Scale, a measure of perceived stuttering severity, the Self-Stigma of Stuttering Scale, and other stuttering-related questions.
Results: Participants with support group experience as a whole demonstrated lower internalized stigma, were more likely to believe that they would stutter for the rest of their lives, and less likely to perceive production of fluent speech as being highly or moderately important when talking to other people, compared to participants with no support group experience. Individuals who joined support groups to help others feel better about themselves reported higher self-esteem, self-efficacy, and life satisfaction, and lower internalized stigma and perceived stuttering severity, compared to participants with no support group experience. Participants who stutter as an overall group demonstrated similar levels of self-esteem, higher self-efficacy, and lower life satisfaction compared to averages from normative data for adults who do not stutter.
Conclusions: Findings support the notion that self-help support groups limit internalization of negative attitudes about the self, and that focusing on helping others feel better in a support group context is linked to higher levels of psychological well-being.

Educational objectives: At the end of this activity the reader will be able to: (a) describe the potential psychological benefits of stuttering self-help support groups for people who stutter, (b) contrast between important aspects of well-being including self-esteem self-efficacy, and life satisfaction, (c) summarize differences in self-esteem, self-efficacy, life satisfaction, self-stigma, perceived stuttering severity, and perceptions of stuttering between adults who stutter with and without support group experience, (d) summarize differences in self-esteem, self-efficacy, and life satisfaction between adults who stutter and normative data for adults who do not stutter.

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http://dx.doi.org/10.1016/j.jfludis.2013.09.001

1. Introduction

Recent studies have reported troubling findings regarding the cognitive, affective, and social well-being of people who stutter (PWS). Studies have reported lower levels of quality of life in domains of vitality, social, and mental health functioning (Craig, Blumgart, & Tran, 2009). There is evidence of an elevated risk of trait and social anxiety, social phobia (Blumgart, Tran, & Craig, 2010; Craig, Hancock, Tran, & Craig, 2003; Iverach, Jones, O'Brian, et al., 2009; Iverach, O'Brian, Jones, et al., 2009), and negative affect (Tran, Blumgart, & Craig, 2011) among people who stutter compared to those who do not. However, recently other researchers have collected data disputing the extent to which PWS experience certain psychological problems, especially personality disorders (Manning & Beck, 2013).

It is also commonly reported that PWS may experience shame and guilt and attempt to hide their stuttering through avoidance of specific sounds, words, and speaking situations (Ginsberg, 2000; Murphy, Yaruss, & Quesal, 2007). This avoidance may become so extreme that certain individuals may not even identify themselves as PWS to unfamiliar or familiar others (Murphy, Quesal, & Gulker, 2007). This concealment and avoidance can lead to severe restrictions on societal participation and overall well-being (Bricker-Katz, Lincoln, & McCabe, 2010; Klompass & Ross, 2004; Plexico, Manning, & Levitt, 2009a). In addition, empirical evidence has recently been obtained that demonstrates that romantic partners (Beilby, Byrnes, Meagher, & Yaruss, 2013), siblings (Beilby, Byrnes, & Young, 2012), and parents (Lau, Beilby, Byrnes, & Hennessey, 2012) of PWS can detect the challenges experienced by these individuals and experience negative emotional reactions to stuttering as well.

There has been much debate about the importance of dealing with social, emotional, and cognitive aspects of stuttering directly in treatment and the value of these approaches for improving outcomes for PWS (Bothe, Davidow, Bramlett, & Ingham, 2006; Ingham, 2012; O'Brain, Packman, Onslow, & Menzies, 2012). However, many authors believe that it is beneficial to take a multidimensional approach when working clinically with PWS (Guitar, 2013; Healey, Scott Trautman, & Susca, 2004; Manning, 2004; Yaruss, 2010). This notion is supported by The American Speech-Language-Hearing Association (ASHA, 2007), stating that treating communication disorders involves not only addressing the structural impairment, but also quality of life through reducing participation restrictions, activity limitations, and barriers created by contextual factors. The implications of this are that professionals could benefit from being equipped with a wide range of tools in behavioral, cognitive, and affective domains to address quality of life and well-being in clients who stutter (Craig et al., 2009; Plexico et al., 2009a; Tran et al., 2011; Yaruss, Coleman, & Quesal, 2012).

There is evidence of the potential importance of treating stuttering in a multidimensional framework. Many PWS believe that therapy should address feelings and attitudes about stuttering (Yaruss, Quesal, & Murphy, 2002) and that treatment focused only on speech change does not adequately address speech related fears during and following therapy (Yaruss, Quesal, Reeves, et al., 2002). Indeed for many PWS, fears and concerns about stuttering often persist after fluency treatment (Cream, Onslow, Packman, & Llewellyn, 2003; Plexico et al., 2009a). It has also been demonstrated that the presence of mental health problems such as anxiety are predictors of avoidance of speaking situations following treatment as well as failure to maintain benefits of speech restructuring after therapy (Iverach, Jones, O'Brian, et al., 2009), and that treatment including cognitive components improves global life functioning and entry into feared situations to a greater extent than treatments focusing purely on speech change (Menzies et al., 2008). There is increasing evidence that treatments with cognitive components can decrease negative attitudes about the self and improve psychosocial adjustment (Beilby, Byrnes, & Yaruss, 2012; de Veer, Brouwers, Evers, & Tomic, 2009).

Recent research suggests that PWS with higher introversion may be particularly at risk for lower quality of life (Bleek et al., 2012). Some professionals recommend enhancing social support, activity, and engagement among PWS (Craig, Blumgart, & Tran, 2011). One potential means of achieving this is through involvement in support groups (Reeves, 2006; Yaruss, Quesal, & Reeves, 2007).

1.1. *Support groups for stuttering*

A brief note on terminology is warranted before proceeding. Reeves (2006, 2007) stated that the term "self-help/mutual aid group" is preferable to "support group" when describing organizations like the National Stuttering Association (NSA) because of the former's emphasis on autonomy and experiential knowledge whereas the latter refers to groups established and maintained by professionals with clinical knowledge. However, it is also true that many professionals in the field of speech-language pathology are involved in these groups without any aim of incorporating clinical aspects or speech modification. There is a trend of professional involvement in self-help groups across many fields including mental health, which has made the "purist" model of self-help groups (i.e., only lay members without professionals) no longer valid (Barlow, Burlingame, Nebeker, & Anderson, 1999, p. 54). In addition, previous research involving members of the NSA included the term "support group" rather than "self-help/mutual aid group" (Yaruss, Quesal, Reeves, et al., 2002), and the NSA often describes its function as a "support group" or "self-help support group" on its website (NSA, 2013). As a result of this lack of consensus on a meaningful distinction between self-help/mutual aid groups and support groups, the terms "self-help support group" and "support group" will be used interchangeably in this paper. A distinction must also be made between support groups and group therapy for stuttering. The latter focuses on speech change as a primary focus using clinical expertise of a professional, whereas the former focuses on sharing of experiences in a nonjudgmental environment, without the necessity of speech change (Reeves, 2006, 2007). It is the support, not therapy group, that is of interest in this paper.