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The impact of stuttering on the quality of life in adults who stutter

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Abstract

Stuttering is an involuntary fluency disorder that is not uncommon in society. However, the impact of stuttering on a composite measure such as quality of life has rarely been estimated. Quality of life (QOL) assesses the well-being of a person from a multidimensional perspective, and valid and reliable general QOL measures are available that can be used to estimate the impact of stuttering on QOL. This study involved the use of a general measure of QOL called the Medical Outcomes Study Short Form-36 (SF-36) in order to assess the impact of stuttering in 200 adults who stutter (AWS). Comparisons to 200 adults of similar age and sex ratio who do not stutter were made so that the unique contribution of stuttering on QOL could be estimated. Findings indicated that stuttering does negatively impact QOL in the vitality, social functioning, emotional functioning and mental health status domains. Results also tentatively suggest that people who stutter with increased levels of severity may have a higher risk of poor emotional functioning. These findings have implications for treatment such as the necessity to address the emotional and psychological aspects of QOL in AWS and the need for additional clinical resources to be invested in stuttering treatment.

Educational objectives: The reader will be able to: (a) summarize the method used in quality of life assessment using the SF-36; (b) describe the impact of stuttering on the quality of life of adults who stutter; (c) compare the impact of stuttering to the quality of life of adults who do not stutter; (d) describe the relationship between frequency of stuttering and quality of life.

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1. Introduction

Stuttering is a fluency disorder that mostly begins in childhood, and with an estimated overall prevalence of 0.72% of the population, it affects a large number of people in our societies (Craig, Hancock, Tran, Craig, & Peters, 2002). It is a disorder with a number of possible subtypes (Yairi, 2007) in which the adult who stutters (AWS) will have involuntary disruptions to the fluency of their speech, consisting largely of syllable repetitions, prolongations, blocking of sounds, substitutions and avoidance of words (Bloodstein & Bernstein Ratner, 2008; Craig, Hancock, Chang, et al., 1996). It more than likely has neurological deficit origins (Namasivayam & van Lieshout, 2008; Smits-Bandstra & De Nil, 2007). Due to its involuntary and potentially socially problematic nature, stuttering has been found to have a potentially negative influence on emotional and mental health and this influence has been systematically reviewed elsewhere (Bloodstein & Bernstein Ratner, 2008; Craig & Tran, 2006; Menzies, Onslow, & Packman, 1999). The

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majority of the latest research suggests that stuttering is associated with significantly elevated levels of trait and social anxiety (Alm, 2004; Craig, 1990; Craig, Hancock, Tran, Craig, & Peters, 2003; DiLollo, Manning, & Neimeyer, 2003; Ezrati-Vinacour & Levin, 2004; Kraaimaat, Vanryckeghem, & Van Dam-Baggen, 2002; Mahr & Torosian, 1999; Messenger, Onslow, Packman, & Menzies, 2004).

Most studies that have investigated anxiety levels in AWS have studied people who were seeking or had sought out treatment for their stuttering (Craig & Tran, 2006). It has been suggested that AWS who seek treatment would stutter more severely than AWS who do not seek treatment, and that perhaps, as a consequence, those who seek treatment will have elevated anxiety levels (Craig, Hancock, et al., 2003; Craig, Tran, & Craig, 2003). However, Craig, Hancock, et al. (2003) utilized a randomized population design in which they studied AWS who had sought out treatment as well as those AWS who had not ever sought out treatment. They found that a minority (about 30%) of AWS living in the community had never received treatment for their stuttering. Interestingly, though, this minority were still found to have significantly elevated anxiety levels compared to non-stuttering controls (Craig, Hancock, et al., 2003). Despite the design limitations in most studies that have investigated the relationship between levels of anxiety in AWS (Craig, 1994; Craig & Tran, 2006), the accumulated evidence from these studies suggests that AWS, regardless of whether they have sought treatment for their stuttering or not, are likely to be more highly anxious than adults who do not stutter (AWDNS). Furthermore, there are other outcome measures that suggest AWS are at higher risk of experiencing negative mental and social health. For instance, the ability to obtain and maintain employment is known to have a beneficial psychosocial influence, and is often used as an outcome measure in QOL research (Garcia, Laroche, & Barette, 2002). Importantly, research has shown that AWS can experience difficulties with employment due to their stuttering (Bloodstein & Bernstein Ratner, 2008; Craig & Calver, 1991; Klein & Hood, 2004). Relapse following treatment for stuttering has also been a source of difficulty and anxiety for AWS and a large proportion of treated AWS do experience relapse (Craig, 1998; Craig & Hancock, 1998), and AWS have been found to have negative stereotypes of themselves (Craig, Tran, et al., 2003; MacKinnon, Hall, & MacIntyre, 2007).

The above research suggests many AWS may be at risk of having reduced QOL. What is needed is a broad QOL measure of the extent of the impact of stuttering, as individual outcome measures like anxiety, relapse, vocation, social activity and so on are too specific individually (Francic & Bothe, 2008). QOL is a construct that ideally assesses the well-being of a person from a multidimensional perspective including physical, psychological, social, and vocational aspects. Approaches include obtaining subjective measures of a person's perceptions of their life and health, life preferences, and measures of the impact of a disease such as the socioeconomic costs of a disorder (Bramlett, Bothe, & Francic, 2006; Cummins, 2005; Francic & Bothe, 2008; Ware & Gandek, 1998). QOL research has been extensively conducted in order to assess the life impact of many diseases including diabetes (Gonder-Frederick, Cox, & Ritterband, 2002), spinal cord injury (Middleton, Tran, & Craig, 2007), cancers (Ballatori, 2001), and some communication disorders such as aphasia (Cruice, 2008). While it has been noted that QOL is a potentially important measure when estimating the impact of communication disorders and the efficacy of treatment (American Speech-Language and Hearing Association, 2001; Klompas & Ross, 2004; Yaruss & Quesal, 2006), unfortunately, QOL research in the area of stuttering has only recently been conducted (Francic & Bothe, 2008; Klompas & Ross, 2004; Yaruss & Quesal, 2006). In contrast, QOL research has been conducted in other communication disorders for some years, for instance, an entire issue of the journal *Aphasiology* was dedicated to the study of QOL in people with aphasia (Worrall & Holland, 2003).

Klompas and Ross (2004) investigated QOL in a small group of AWS using multiple measures including employment, self-esteem, marital and family status, and emotional and social function. They found a variable impact of stuttering in that stuttering did not seem to impact negatively the quality of marital or family dynamics. Rather, it was thought to influence negatively emotional stability and self-esteem. Bramlett et al. (2006) used a preference and standard gamble based approach to assess perceived QOL in 75 non-stuttering adults. Findings suggest this technique could be a valid outcome strategy for assessing reduced QOL in AWS (Bramlett et al., 2006). Yaruss and Quesal (2006) reported on the development of the Overall Assessment of the Speaker's Experience of Stuttering (OASES), which is a self-report instrument. The instrument was designed to estimate the impact of stuttering on QOL (Yaruss, 2001). The OASES contains dimensions such as the affective, behavioral, and cognitive reactions to stuttering, functional communication difficulties, and the impact of stuttering on the speaker's quality of life (Yaruss & Quesal, 2006).

It is clear from the above research that the impact of stuttering on QOL needs urgent clarification. Additionally, there is a need for stuttering specific QOL measures (Francic & Bothe, 2008; Yaruss & Quesal, 2006). Nevertheless, non-disease specific measures of QOL have been widely used to determine the impact of various diseases, with QOL researchers agreed that the assessment of QOL should include multiple dimensions, such as mental and emotional

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