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## Quality of life in adults who stutter

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## ABSTRACT

Although persistent developmental stuttering is known to affect daily living, just how great the impact is remains unclear. Furthermore, little is known about the underlying mechanisms which lead to a diminished quality of life (QoL). The primary objective of this study is to explore to what extent QoL is impaired in adults who stutter (AWS). In addition, this study aims to identify determinants of QoL in AWS by testing relationships between stuttering severity, coping, functioning and QoL and by testing for differences in variable scores between two AWS subgroups: receiving therapy versus not receiving therapy. A total of 91 AWS filled in several questionnaires to assess their stuttering severity, daily functioning, coping style and QoL. The QoL instruments used were the Health Utility Index 3 (HUI3) and the EuroQoL EQ-5D and EQ-VAS. The results indicated that moderate to severe stuttering has a negative impact on overall quality of life; HUI3 derived QoL values varied from .91 (for mild stuttering) to .73 (for severe stuttering). The domains of functioning that were predominantly affected were the individual's *speech*, *emotion*, *cognition* and *pain* as measured by the HUI3 and *daily activities* and *anxiety/depression* as measured by the EQ-5D. AWS in the therapy group rated their stuttering as more severe and recorded more problems on the HUI3 speech domain than AWS in the non-therapy group. The EQ-VAS was the only instrument that showed a significant difference in overall QoL between groups. Finally, it was found that the relationship between stuttering severity and QoL was influenced by the individual's coping style (emotion-oriented and task-oriented). These findings highlight the need for further research into stuttering in relation to QoL, and for a broader perspective on the diagnosis and treatment of stuttering, which would take into consideration quality of life and its determinants.

**Learning outcomes:** Readers will be able to: (1) Understand how the Wilson and Cleary (1995) model of quality of life could be applied to comprehensively assess the quality of life in adults who stutter, (2) describe how health related quality of life is impaired in adults who stutter, (3) mention affected domains of functioning that are related to health related quality of life impairment in adults who stutter, (4) describe the relationship between stuttering severity, functioning, coping and health related quality of life in adults who stutter, (5) describe differences in stuttering severity, coping style, functioning and health related quality of life between adults who stutter who have registered for therapy and adults who stutter who have not.

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## 1. Introduction

How stuttering affects the overall quality of life (QoL) of adults who stutter (AWS) has not yet been extensively researched. This is surprising since about 1% of the adult population stutters (Bloodstein & Bernstein-Ratner, 2008) and because it is known that AWS often experience negative affective, behavioral, and cognitive reactions. Moreover, stuttering significantly limits the speaker's ability to participate in daily activities (Yaruss & Quesal, 2006). AWS frequently experience disabling levels of social anxiety (Kraaimaat, Vanryckeghem, & Van Dam-Baggen, 2002; Messenger, Onslow, Packman, & Menzies, 2004; Schneier, Wexler, & Liebowitz 1997). Whether this occurs, depends on their fear of a negative evaluation in social relations because of their stuttering, and whether or not they act upon that fear by adoption of a strategy of avoidance (Menzies, Onslow, Packman, & O'Brian, 2009). Recognizing the complexity of the stuttering disorder in adults, researchers have established the need to document not only speech symptoms, but also broad-based outcome parameters such as QoL (e.g. Craig, Blumgart, & Tran, 2009; Franic & Bothe, 2008; Ingham, 2003; Yaruss & Quesal, 2006). Recently, a special edition of the Journal of Fluency Disorders dedicated to the QoL of people who stutter also raised awareness for the topic (e.g. Craig, 2010; Cruice, Worrall, & Hickson, 2010; Yaruss, 2010). Until now, the magnitude of and mechanisms underlying the QoL effects of stuttering in adults have not been fully explored. The purpose of this study is to evaluate QoL in AWS by means of a comprehensive assessment.

A review of existing literature with respect to the QoL in AWS revealed that the majority of studies use a narrow conceptualization of QoL. That is, most studies investigated the QoL of AWS by focusing on the influence that stuttering has on the specific life domains which are believed to be most affected by stuttering (e.g. Andrade, Sassi, Juste, & Ercolin, 2008; Crichton-Smith, 2002; Hayhow, Cray, & Enderby, 2002; Klein & Hood, 2004; Klompas & Ross, 2004). For example, Hayhow et al. (2002) showed the major adverse effects of stuttering on school life and occupational choice. The negative impact of stuttering on school performance, relationships with teachers and classmates, and performance at work was confirmed by Klompas and Ross (2004), who interviewed 16 AWS. Klein and Hood (2004) found that the majority of the AWS perceived their stuttering to be a handicap in relation to employment opportunities and job performance. By exploring specific life domains potentially affected by the condition stuttering, these studies provide significant, but only limited, information on QoL. A disadvantage of such *condition-specific* QoL studies is that little insight is gained into the *overall* QoL (e.g. Brazier, Ratcliffe, Tsuchiya, & Salomon, 2007; Craig et al., 2009; Franic & Bothe, 2008). In other words, although these studies provide insight into problems associated with stuttering, not all aspects of QoL relevant to a person are taken into account. In addition, due to the incorporation of dissimilar domains, condition-specific QoL instruments cannot be used to compare different health conditions.

In contrast to condition-specific QoL instruments, generic QoL instruments embrace a broad conceptualization of QoL by measuring a comprehensive set of domains. A common element in these generic QoL instruments is the incorporation of physical, emotional and social domains of health. These domains are relevant for anyone, irrespective of the specific health problem. As a result, generic QoL instruments are suitable for comparison of stuttering to other health states. Well-known examples are the Medical Outcomes Study Short Form 36-Item Health Survey (SF-36) and the Nottingham Health Profile (NHP). A limitation of these descriptive generic QoL instruments is that they do not quantify how each dimension contributes to overall well-being. That is, if some domains are significantly affected but others are not, the effect on overall QoL cannot be established. To overcome this problem, QoL researchers frequently move beyond a multidimensional generic description of health by attaching a single value to the overall health status (Brazier et al., 2007). This value or 'utility' summarizes all the positive and negative aspects of health into one single QoL index, which is usually set between 0, which corresponds to a health state valued as equivalent to death, and 1, which corresponds to perfect health. Such QoL values can be established in two ways. Firstly, health states can be estimated by using validated 'preference based' techniques (Torrance, Furlong, & Feeny, 2002): Visual Analogue Scale (VAS), Time Trade-Off (TTO) or Standard Gamble (SG). Alternatively, a special class of generic QoL instruments can be used, for which QoL values are available for all health states described by the instrument (Coons, Rao, Keininger, & Hays, 2000). Well known examples are the EQ-5D, Health Utilities Index (HUI) and the SF-6D (derived from the SF-36 by Brazier, Roberts, & Deverill, 2002).

So far, only two studies have attempted to gain insight into overall QoL of AWS by using generic QoL instruments or by preference based techniques. Craig et al. (2009) used the SF-36 to explore the negative impact caused by stuttering in a population of AWS and adults who do not stutter (AWNS). The authors showed that, compared to a non-stuttering control group, stuttering affects social and emotional functioning, as well as vitality and mental health status. The effect sizes (standardised mean difference between the groups) on these domains varied between .28 and .59, indicating small to moderate QoL impairments in AWS. Because the associated SF-6D utilities were not reported by Craig et al. (2009), the effect on overall QoL remains unclear. The study by Bramlett, Bothe, and Franic (2006) is the only study that we are aware of that adopted a preference based approach to estimate utilities. Bramlett et al. (2006) obtained overall QoL values for mild, moderate and severe stuttering from 75 AWNS using the three validated preference based techniques mentioned before: VAS, TTO and SG. The results suggested that QoL is negatively affected by stuttering. Using the TTO method, non-stuttering adults valued their own health at .98 (SD .07), while they rated mild, moderate and severe stuttering at respectively .93 (SD .14), .85 (SD .18) and .63 (SD .24) (Bramlett et al., 2006, Table 2). Considering that a QoL weight of .63 has been found for living with home dialysis (Sackett and Torrance, 1978 in Bramlett et al., 2006), the results suggest that severe stuttering has a substantial impact on a person's overall QoL. However, the differences in QoL values between methods were substantial: VAS and SG resulted in QoL values of .44 (SD .20) and .81 (SD .19) respectively for severe

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