



Health-related quality of life of preschool children who stutter



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ABSTRACT

Purpose: The purpose of this study is to compare the health-related quality of life (HrQoL) of preschool children who stutter (CWS) and a reference population of children who do not stutter, and to evaluate the association between stuttering severity and HrQoL.

Methods: Baseline data were used from 197 children participating in a multicenter Randomized Clinical Trial in the Netherlands. Information on stuttering severity and time since onset (TSO) of stuttering was obtained from the baseline evaluation by speech- and language therapists. Stuttering severity was measured using the SSI-3. HrQoL was assessed using proxy versions of two Child Health Questionnaires (ITQOL-97 and CHQ-PF28), the Health Utility Index 3 (HUI3) and the EuroQoL EQ-VAS (EQ-VAS).

Results: While the outcomes on the EQ-VAS and the HUI3 showed that the HrQoL of CWS is slightly poorer than that of the Dutch reference population, results on the different dimensions of the CHQ-instruments did not reveal any difference in scores between stuttering children and reference groups. Within the group of CWS, two ITQOL-97 and four CHQ-PF28 scales showed statistically different scores for children in different SSI stuttering severity or TSO categories. However, the effect sizes showed that these differences were so small that they could be considered negligible.

Conclusion: The results of this study do not reveal a diminished HrQoL for preschool CWS. Future research should include a larger cohort of children with severe stuttering, study the longitudinal course of HrQoL and incorporate additional parameters such as the characteristics of the child and his environment.

Educational objectives: The reader will be able to: (a) summarize the current evidence base on HrQoL in people who stutter; (b) describe the HrQoL of preschool CWS on different HrQoL measures; (c) describe the relationship between stuttering severity and HrQoL in preschool CWS.

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1. Introduction

Stuttering frequency and stuttering severity have traditionally been the primary outcome measures for childhood stuttering. However, these measures provide little information about the potentially broader impact of this disorder on daily life. Although health-related quality of life (HrQoL) measures have become an essential outcome in pediatric disorders (Raaijmakers, Mohangoo, & Grootenhuis, 2006; Solans et al., 2008), limited research has been conducted into the impact of speech and language disorders in general and stuttering in particular (Feeney, Desha, Ziviani, & Nicholson, 2011).

So far, research on the burden of stuttering has mainly focused on the impact of persistent stuttering. Several studies report a diminished functioning and/or (health related) quality of life for stuttering adolescents and adults (e.g. Craig, Blumgart, & Tran, 2009; Hayhow, Cray, & Enderby, 2002; Klein & Hood, 2004; Klompas & Ross, 2004; Koedoot, Bouwmans, Franken, & Stolk, 2011). For school aged children who stutter (CWS), the impact of stuttering on HrQoL has been less frequently studied. In fact, we are only aware of the study by Gooding and Davis (2004), in which the generic HrQoL of 33 stuttering children and matched controls aged 8–16 years was assessed by the Child Health Questionnaire (CHQ-PF50). Their results did not reveal any significant group differences on general health, but significantly more behavioral problems were reported in stuttering children compared to matched controls.

Other studies applied disease (or disorder-) specific instruments to investigate the impact of stuttering on the daily life of school aged children. Chun, Mendes, Yaruss, and Quesal (2010) showed a moderate negative impact of stuttering as measured by a draft version of the Overall Assessment of the Speaker's Experience of Stuttering for school aged children (OASES-S) in seven children aged 7–12 years, with a tendency toward a positive correlation between stuttering severity and the impact of stuttering on quality of life. Cook, Donlan, and Howell (2013) also used a disorder-specific instrument (Fragebogen Zum Sprechen; FZS speech questionnaire) to assess the psychosocial impact of stuttering in 54 children aged 9–20 years, and found that higher stuttering severity was correlated with a greater psychosocial impact. Furthermore, Kawai, Healey, Nagasawa, and Vanryckeghem (2012) and Vanryckeghem, Brutten, and Hernandez (2005) showed a negative speech-associated attitude for school aged CWS compared to non-stuttering peers, and Blood and Blood (2007) reported increased vulnerability to bullying for school aged CWS. A negative speech-related attitude and negative social reactions increase the child's risk for developing social anxiety (Smith, Iverach, O'Brian, Kefalianos, & Reilly, 2014). Indeed, increased levels of social anxiety have been reported in older CWS, albeit not consistently (Smith et al., 2014). A social anxiety disorder is known to hamper normal social development and functioning and is likely to result in a diminished quality of life (Iverach & Rapee, 2014).

In the age group where stuttering starts to develop, i.e. the preschool years, Reilly et al. (2013) was the first to apply a validated descriptive HrQoL instrument (PedsQL). The results of their population-based study indicated that stuttering in young children was not associated with a diminished quality of life. Surprisingly, for CWS aged 4 years, a better social and preschool functioning was reported compared with non-stuttering children. In addition, a study into social anxiety in preschool CWS by van der Merwe, Robb, Lewis, and Ormond (2011) reported no significant differences between stuttering preschoolers and matched controls. However, other studies suggest that stuttering in children under the age of six may be related to psychosocial impairment. CWS as young as 3 or 4 years of age seem to be aware of their speech problems and, on average, evaluate their speech more negatively than their non-stuttering peers (Vanryckeghem et al., 2005). Awareness of stuttering in young children increases with time since onset and age, and stuttering could provoke frustration and facilitate emotional and behavioral reactions even in early childhood (e.g. Boey et al., 2009). Furthermore, differences in temperament characteristics and emotional behavior between preschool stuttering and non-stuttering children were found by various researchers (for an overview, see: Conture, Kelly, & Walden, 2013; Kefalianos, Onslow, Block, Menzies, & Reilly, 2012). These characteristics (such as exhibiting poorer adaptability skills and more negative emotions) might amplify the psychosocial effects of stuttering, although speculations as to this connection are highly premature. Recently, a study by Kefalianos, Onslow, Ukoumunne, Block, and Reilly (2014) suggested that preschool CWS do not have innately different temperaments from control children.

Negative reactions by listeners may also give rise to psychosocial consequences of stuttering. Negative evaluation of perceptually salient stuttering by preschool peers has been reported by Ambrose and Yairi (1994) and Ezrati-Vinacour, Platzky, and Yairi (2001). While these studies were based on research using puppet-play, one study based on real-life interactions with peers also reported that preschool classmates reacted negatively to moments of severe stuttering (Langevin, Packman, & Onslow, 2009). Besides, the authors of the latter study observed that the stuttering preschool children had some difficulties in expressing themselves in social interactions, for instance in trying to take the lead in play or contributing to problem-solving activities. In a further study by Langevin, Packman, and Onslow (2010), which focused on the parental evaluation of the impact of stuttering on the lives of their preschool stuttering children ($N=77$), the majority of parents reported that stuttering had a negative impact on their child's life. Both in children and parents, emotional consequences were reported. For example, children became frustrated because of their stuttering or had a low self-esteem, and stuttering affected the children's general mood. However, only 8% of the parents perceived that stuttering affected their child's quality of life (Langevin et al., 2010).

From this overview it can be concluded that, although several studies suggest impairment in the psychosocial domains of HrQoL in preschool CWS, so far few attempts have been made to perform a comprehensive study to measure this impact with validated generic HrQoL instruments. These instruments allow comparison of the HrQoL between preschool children with and without stuttering and thereby provide a basis to evaluate possible consequences of stuttering across multiple

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