

Assessing quality of life in stuttering treatment outcomes research

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Abstract

Stuttering can affect many aspects of a person's life. People who stutter report that they experience negative reactions to stuttering, difficulty communicating in key situations, diminished satisfaction with life, and a reduced ability to achieve their goals in life. Unfortunately, most treatment outcomes studies have focused on changes in the observable characteristics of stuttering, with significantly fewer studies examining the broader consequences of stuttering. This paper proposes that evaluation of stuttering treatment outcomes can be enhanced through assessment of impact of stuttering on a speaker's quality of life. A means of assessing quality of life is described, based on the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES; Yaruss & Quesal, 2006, 2008). The OASES is a multi-dimensional assessment instrument built upon the World Health Organization's *International Classification of Functioning, Disability, and Health* (ICF; WHO, 2001; see also Yaruss & Quesal, 2004). One section of the OASES is designed to assess specific aspects of quality of life in individuals who stutter. Preliminary data from two ongoing studies involving the OASES are briefly summarized in order to demonstrate: (a) that individuals who stutter do report an adverse impact on their quality of life as a result of stuttering and (b) that quality of life can improve following treatment for stuttering. It is recommended that future stuttering treatment outcomes studies directly examine the broader consequence of stuttering by focusing, in part, on quality of life.

Educational objectives: After reading this article, the participant will be able to: (1) describe some of the adverse consequences of stuttering reported by individuals who stutter; (2) define quality of life as it relates to the study of the stuttering disorder; (3) explain the value of assessing quality of life in stuttering treatment outcomes research.

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1. The broad-based nature of stuttering

Stuttering is a communication disorder that can affect many aspects of a person's life. To an observer, the most obvious aspect of the disorder is the production of certain types of disruptions in the forward flow of speech, such as repetitions of parts of words, prolongations, and blocks (see Bloodstein & Bernstein Ratner, 2008). To the speaker, however, stuttering can involve far more than just observable speech disfluencies (Cooper, 1993; Manning, 1999, 2010; Mulcahy, Hennessey, Beilby, & Byrnes, 2008; Murphy, 1999; Shapiro, 1999; Sheehan, 1970; Starkweather & Givens-Ackerman, 1997; Van Riper, 1982). Personal reports, biographical accounts, and empirical research all confirm

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that people who stutter may experience feelings of shame, embarrassment, and anxiety; difficulty communicating; and a sense of dissatisfaction with life due to stuttering (e.g., Ahlbach & Benson, 1994; Bobrick, 1995; Carlisle, 1985; Corcoran & Stewart, 1998; Craig, Blumgart, & Tran, 2009; Hood, 1998; Jezer, 2003; Johnson, 1930; Klompas & Ross, 2004; Manning, 1999; Manning, 2010; Shapiro, 1999; St.Louis, 2001; Yaruss & Quesal, 2006; Yaruss et al., 2002).

This distinction between surface behaviors seen by an observer and life experiences of those who live with the disorder is reflected, in part, in the many definitions and theories about stuttering that have been offered over the years (e.g., Bloodstein, 1993). Some definitions and theories have focused on trying to explain the surface speech disruptions, while others have also addressed the consequences of stuttering and the speakers' experiences (Bloodstein & Bernstein Ratner, 2008). The nature of the definitions offered by different authorities are no doubt linked to the theoretical orientations to the disorder. Still, the sheer number of definitions highlights the various and varied experiences that are associated with the difficulty in producing fluent speech.

The varied nature of stuttering is also reflected in the wide range of available treatment approaches. Many treatments focus primarily on reducing or eliminating stuttering behaviors (e.g., Ingham, 1984; Neilson & Andrews, 1993; Onslow, Costa, Andrews, & Harrison, 1996; Ryan, 1979; Webster, 1980). Other approaches seek to reduce the negative consequences of the disorder *in addition to* reducing observable speech disruptions (e.g., Breitenfeldt & Lorenz, 2000; Manning, 2010; Shapiro, 1999; Van Riper, 1973). The wide range of options, and the varied success of these approaches with different individuals (Bloodstein & Bernstein Ratner, 2008), speaks to the complexity of the disorder—and to the importance of considering each speaker's unique experiences with stuttering and with life in general.

1.1. *The evaluation of stuttering in treatment outcomes research*

Examination of the stuttering treatment outcomes literature reveals that most studies to date have focused primarily or exclusively on changes in the observable characteristics of stuttering, with relatively little consideration given to the broader consequences of the disorder experienced by the speaker (see Andrews, Guitar, & Howie, 1980; Bothe, Davidow, Bramlett, & Ingham, 2006; Cordes, 1998; Prins & Ingham, 2009; Thomas & Howell, 2001). This emphasis on reduced disfluency is understandable, for the observable speech disruption is a central feature of the disorder, and people who seek therapy certainly want to reduce the amount of stuttering they exhibit. Surface stuttering behavior is also the most salient aspect of the disorder for listeners, and, as such, it is the easiest aspect to measure (though the reliability of stuttering frequency counts has long been questioned; Cordes, 1994; Cordes & Ingham, 1994). Still, when people who stutter are asked about the nature of their "complaint" (Baer, 1988, 1990), the negative consequences of stuttering are also cited as key features of their daily experience (Yaruss et al., 2002). Thus, treatment research should *also* examine these aspects of the disorder.

The lack of focus on the consequences of stuttering in treatment outcomes research is not due to a lack of measurement tools, for there are many instruments that evaluate the broader experience of stuttering (e.g., Ammons & Johnson, 1944; Andrews & Cutler, 1974; Brutton & Shoemaker, 1974; Crowe, Di Lollo, & Crowe, 2000; Erickson, 1969; Lanyon, 1967; Ornstein & Manning, 1985; Riley, Riley, & Maguire, 2004; Watson, 1988; Woolf, 1967; Wright & Ayre, 2000; Yaruss & Quesal, 2006). For example, the original "S-Scale" (Erickson, 1969) and the S-24 adaptation (Andrews & Cutler, 1974), as well as Watson's (1988) Inventory of Communication Attitudes (ICA), measure a speaker's reactions to stuttering in different situations. Instruments have also examined other aspects of the speaker's experience of stuttering, confirming the broad variety of experiences and challenges reported by people who stutter.

In spite of the long-standing availability of such tools, however, these types of instruments have not been widely used in treatment research. Certainly, there are exceptions, as some studies have included measures of how affective and cognitive reactions to stuttering may change during the course of treatment (e.g., Blomgren, Roy, Callister, & Merrill, 2005; Boberg & Kully, 1994; Montgomery, 2006). Even so, the primary focus of those studies was still an examination of the measurable changes in observable speech fluency. Even those studies that *did* consider the speakers' reactions to stuttering did not directly examine the functional difficulties the speakers may have had when communicating in daily situations or the overall consequences of stuttering for their lives as a whole. Furthermore, as Ulliana and Ingham (1984) pointed out, results from some scales that examine a speaker's attitudes toward stuttering in different situations may simply reflect the speaker's degree of fluency in those situations. Thus, even taking these exceptions in account, it seems clear that the study of stuttering treatment outcomes has focused primarily on measuring changes in the observable characteristics of stuttering.

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