The Experiences of Living with a Stuttering Disorder

Across the Lifespan:
Psychosocial Impact and Acceptance and Commitment Therapy

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This thesis is presented for the degree of
Doctor of Philosophy
of
Curtin University

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university. The published papers have co-authors whose contributions are identified, authorised and included in Appendix A.

Signed:  

Date: 3/3/2013
Acknowledgements

These acknowledgements might just end up as long as the thesis. After all, I have over 30 years of professional associations with valued and supportive colleagues, friends and family behind this submission. The joy is finally seeing over three decades of hard, frustrating, poignant, always challenging and uplifting clinical research culminate in this document.

I have had the joy of working with some inspiring academics in my professional career and I want to thank John Fisher, Nola Nicholson, Daniel Boone, Dick Curlee, Tom Hixon, Jenny Baker, Kathryn Hird, Kate Taylor, Neville Hennessey, Jan Piek, Jade Cartwright, Brooke Sanderson and Josephine Hudson for their incredible commitment and for sharing enduring laughter with me over such an amazing time together. You have inspired me in ways you will never fully appreciate and I want to thank you all most sincerely for such wonderful good times.

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Dedication

This thesis is dedicated to my father, Lawrence Arthur Coolahan for his eternal love and support. He always believed so much in our education because his was so limited.

I hope your nose is twitching now Loh.
Abstract

In recent stuttering disorders research, increasing importance has been placed on viewing the disorder from a multidimensional perspective. Researchers have shown how the impact of the disorder reaches far beyond the surface speech components. There have been demonstrated psychosocial and anxiety effects for the person living with a stutter which underpins the value of taking a more comprehensive view of this complex problem. Concurrently, there has been research in allied speech and language areas addressing the impact of communication difficulties not only on the person themselves but on family members with whom they share daily life.

The primary aim of this thesis was to explore the experiences of living with a stuttering disorder across the lifespan. The aim was to do this by investigating the impact of the disorder on the individual (child, adolescent and adult), and on their family members (siblings, parents and partners). The context of the thesis presents this impact on a number of different planes including behavioural and social difficulties, self-awareness of stuttering, reactions to stuttering, communication difficulties in daily situations, and overall quality of life. The impact on the relationships the person who stutters shares with intimate others is also disclosed.

An overview of stuttering across the lifespan in the first two papers is discussed in terms of the impact of a stuttering disorder on children and adolescents living in Western Australia. A comparison is drawn between the reactions and experiences of individuals who stutter to those of people who do not stutter. Significant levels of adverse impact as a result of living with a stutter are described.

The next two papers in the thesis present the impact of the stuttering disorder on the parents and siblings of children who stutter. These papers describe the
relationship between siblings, the impact on the fluent sibling and the impact on the parent-child relationship. Significant findings pertaining to lack of attachment and trust between the young people and their parents emerged. The responsibilities and demands on parents and siblings in the family context are highlighted.

The focus of the fifth paper is the experience of living with a person who stutters from the perspective of their life partner. This paper explores perceived quality of life with unexpected differences unfolding between the quality of life experienced by the adult who stutters and their partner’s perceptions of this experience. Apprehensions and demands around emotional support, social interactions, communication dependencies and therapy support are described.

In the context of the overall findings from the preceding five lifespan impact papers, the sixth paper proposes an overview of a holistic Acceptance and Commitment Therapy (ACT) for the treatment of stuttering disorders in adults. The positioning of ACT as a novel and valid treatment for stuttering disorders is discussed and the unique platform from which the potential for this treatment to produce fluency gains and psychosocial outcome improvements is described. Finally, the seventh paper investigates the effectiveness of an ACT group intervention program for adults who stutter. Significant results and clinical research support are presented in terms of improvements in psychosocial functioning, readiness for therapy and change, utilisation of mindfulness skills and psychological flexibility, and improved frequency of stuttering as a result of this preliminary ACT treatment programme.

This thesis documents the impact of stuttering and proposes an
original approach to the resolution of impact through intervention for the
demonstrated psychosocial concerns of the individual and their immediate family
members.
List of Publications Included in Thesis


Statement of Author Contribution

The nature and extent of the intellectual input by the candidate and co-authors has been validated by all authors, and can be found in Appendix A.

Janet Beilby (Candidate)

Neville Hennessey (Supervisor)
List of Additional Publications Since 2008


Patient focused goal planning process and outcome after spinal cord injury rehabilitation: Quantitative and qualitative audit. *Clinical Rehabilitation, 26*, 1141-1149. [Impact Factor 2.123]

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<td>ICF</td>
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Introduction
Introduction

Stuttering as a Multidimensional Disorder.

Stuttering is an intriguing multidimensional disorder that causes involuntary disruption to a person’s natural spontaneous and fluent speech. It has been described as a speech motor disorder that interrupts the timing and/or coordination between the respiratory, laryngeal, and vocal tract subsystems of speech (Caruso, Max, & McClowry, 1999; Kent, 2000; Nudelman, Herbrich, Hess, Hoyt, & Rosenfield, 1992; Peters, Hulstijn, & van Leishout, 2000; Peters & Starkweather, 1990; van Lieshout, Hulstijn, & Peters, 2004). In addition, other authors have described the cognitive, linguistic and psycholinguistic components of the disorder that influence a person’s overall competence in communication (Healey, Trautman, & Susca, 2004; Wall & Myers, 1984). The pervasive nature of stuttering defies a uniform definition, however, because stuttering includes core surface speech elements, such as repetitions, prolongations and cessations of sounds interwoven with elements that exist below the surface. Such covert or affective components include stress, anxiety, and negative reactions to speaking in general. These layers of difficulty often manifest in significantly reduced quality of life for the individual living with a stutter (Blomgren, 2010; Manning, 2010).

Many clinical researchers have noted that there is more to the stuttering disorder than just the surface features (Cooper, 1993; Manning, 1999, 2010; Murphy, 1999; Shapiro, 1999; Sheehan, 1970; Starkweather & Givens-Ackerman, 1997; Van Riper, 1982; Yaruss, 1998; Yaruss & Quesal, 2004). Historically, Sheehan (1970) described stuttering using an “iceberg” analogy in which the speaker’s experience of the stuttering disorder is represented as the region “under the surface”. The nature of stuttering has the potential to elicit ridicule, embarrassment, frustration and/or pity
from the listener; therefore, it is inevitable that it is associated with some degree of
fear, anxiety and/or frustration in the person who stutters (Bloodstein and Bernstein
Ratner, 2008; Lincoln et al., 1996; Menzies et al., 1999; Reitzes, 2006).

Traditionally, there has been no operational definition that captures the
essence of stuttering behaviours in a speaker in an all-encompassing or truly
adequate way (Bloodstein & Bernstein Ratner, 2008). There have been attempts to
consistently identify features of stuttered speech, as sound or syllable repetitions,
prolonged sounds, broken words, with indications of effort expended during normal
conversational speech (Blomgren, 2010; Bloodstein & Bernstein Ratner, 2008).
However, the boundaries distinguishing stuttered speech from normal disruptions in
fluency remain imprecise. The semantics of what to call fluency breaks have created
much debate throughout history. A comprehensive account summarised by
Bloodstein (1995) included a famous description by Aristotle, who believed that
stuttering was due to an “abnormality of the tongue”. The emergence of
psychoanalysis in the 19th century profoundly changed the attitude towards health
and behaviour when Freud interpreted stuttering as resulting from an “oral-anal
fixation” on the part of the patient (Manning, 2010). Such historical theories have
been surpassed today.

In recent times, researchers and clinicians have argued for a more expansive
conceptualisation of stuttering, which aims not only to demarcate the surface
behaviours present in an individual’s speech, but also the psychosocial impact or
consequences stuttering has on their life (Cooper & Cooper, 1996; Gabel, 2006;
Quesal, 1989; Rustin, Cook, & Spence, 1995; Yaruss & Quesal, 2004, 2006). In
order to effectively treat the stuttering disorder, it is important to examine not only
the overt symptoms of the disorder, but also to holistically evaluate other
components such as the speaker’s affective, behavioural and cognitive reactions; the self-awareness of stuttering indicated by the difficulty of different speaking situations and the reactions of others; and the overall impact of stuttering on the speaker’s life indicated by the limitations in communication activities and restrictions in participation in daily life. In 2004, Yaruss and Quesal adapted the multidimensional nature of the International Classification of Functioning, Disability, and Health (ICF) presented by the World Health Organization (WHO) as it related to a model of stuttering. The authors identified that the ICF, when adapted, is an effective tool in looking at the stuttering disorder because it considers factors that are beyond the observable characteristics of the impairment. Aside from the physiological features of stuttering, personal factors, environmental factors, and the individual’s performance in life activities constitute components in this holistic model of stuttering. The authors devised a measurement instrument which assesses this holistic impact of the stutter (Yaruss & Quesal, 2006, 2010) namely the Overall Assessment of the Speaker’s Experience of Stuttering (OASES; Yaruss & Quesal, 2006, 2010). Recent research has employed this measurement instrument to assess the adverse impact or negative consequences associated with stuttering.

The psychosocial impact and consequences that stuttering has across the life-span needs to be assessed and addressed in order to integrate holistic models of therapeutic support for individuals who stutter (Andrews & Craig, 1988; Andrews, Craig & Feyer, 1985; Blood, 1995; Blood, Blood, Tellis, & Gabel, 2001; Boyle, 2011; Craig & Andrews, 1985; Craig, Feyer, & Andrews, 1987; Howie, Tanner, & Andrews, 1981; Menzies et al., 2008; Menzies, Onslow, Packman, & O’Brian, 2009; Neilson; 1999; Stein, Baird, & Walker, 1996). In addition, such models need to address the influence stuttering has not only on the individual, but on their marital
and family life as well. The people with whom the person lives most often constitute the primary base for their core psychosocial support and quality of life. There has been a recent shift in Quality of Life (QoL) research literature to examine the person’s subjective opinions about and perceptions of their own satisfaction with all aspects of their life beyond simply their surface stuttered speech performance (Craig, 2010). The most important emotional unit to which most individuals belong, and one that may affect the course and outcome of our lives the most, is the family. No single component of the family can be understood in isolation from the others, and recent clinical research has shown that it is imperative to understand how the impact of a disorder, and responsibility for its treatment, is distributed among the entire family unit and all the members therein. Ultimately, the whole family, not just the isolated individual with the disorder, is described as the most accurate and correct definition of “client” (Botterill, 2011).

The Impact of Stuttering on Children and Adolescents.

Stuttering is a disorder that affects individuals of all ages. There is confirmation that a child as young as 3 years of age can recognise stuttering in their peers and they may appraise stuttering negatively as early as 4 years of age (Ezrati-Vinacour & Levin, 2004). Children who stutter as young as 3 and 4 years of age, have been found to experience more negative attitudes towards speech than those who are normally fluent, and these negative attitudes appear to exacerbate with age and stuttering severity (De Nil & Bruten, 1990, 1991; Vanryckeghem, 1995; Vanryckeghem & Bruten, 1997; Vanryckeghem, Bruten, & Hernandez, 2005; Vanryckeghem, Hylebos, Bruten, & Peleman, 2001). Parental reports have indicated that children who stutter are aware of their stuttering shortly after its onset,
and thus the potential for social interaction to be impaired can occur from an early age (Ambrose & Yairi, 1994; Packman, Onslow, & Attanasio, 2003).

Research into anxiety in individuals who stutter has focused primarily on adults, with limited investigation in children and even less in adolescents. Previous research has suggested that anxiety may contribute to the cause of stuttering, but may also be a symptom of the impact of living with the condition as well (Craig & Hancock, 1996; Hancock et al., 1998; Miller & Watson, 1992). The general findings suggest that increased levels of trait anxiety are symptomatic of the ongoing experience of stuttering (Blood et al., 2001; Craig & Hancock, 1996; Craig & Tran, 2005; Davis, Shisca & Howell, 2007). That is, trait anxiety is not a native characteristic of people who stutter, but rather, is secondary to the persisting negative communicative experiences, negative perceptions of those experiences, and/or negative anticipation of imminent communicative interactions and situations. It is accepted clinically that individuals who stutter do indeed experience increased levels of state anxiety, termed “communication apprehension”, compared to normally fluent speakers, particularly in social situations (Lincoln et al., 1996; Messenger, Onslow, Packman, & Menzies, 2004; McCroskey, 1978). The nature of the relationship between anxiety and stuttering particularly in terms of the timing and assessment of increased levels of anxiety may elucidate information regarding the developmental impact in young people.

Given the myriad of ways in which stuttering may affect children and adolescents, there is a need for better information regarding the adverse influence the disorder has on the lives of young people. This is particularly true considering the fact that even children and adolescents who do not stutter are likely to experience personal and environmental reactions to their developing speaking abilities. These
ages represent times of transformation in young people's lives, and it is not necessarily clear which aspects of the experience of stuttering are unique to stuttering and which are perhaps just part of growing up and learning to communicate with others (Manning, 2010). Accordingly, comparison of the experiences of children and adolescents who stutter with the experiences of their fluent peers may highlight specific social, emotional and mental health concerns for this population of young people coping with communication difficulties. In the lifespan perspective, research addressing such important disquiets in school aged children and adolescents who stutter is lacking.

The Impact of Stuttering on Parents and Siblings.

It is without doubt that parents play a vital role in their child's development. Through nurturing and education, parents provide their child with an important foundation on which values, beliefs and ideas are built, exchanged and transferred. In addition, parents provide their child with working models of relationships and interactions with people around them (Engels, Pfnkenauer, Deković & Meeus, 2001). It has been reported previously that parental responsibilities in the successful management of stuttering are fundamental. Since stuttering is typically a developmental disorder beginning in early childhood, and the parents are the most influential factors in the child's learning, successful intervention necessitates involvement by parents and caregivers (Bottrill, Kelman, & Rustin, 1991; Conture, 1990, 2001; Conture & Schwartz, 1984; Ham, 1986; Johnson, Brown, Curtis, Edney & Keaster, 1967; Peters & Guitar, 1991; Riley & Riley, 1983; Rustin, 1987; Starkweather, Gottwald, & Halfond, 1990).

Evidence from psychology and psychiatry has suggested that optimal parenting furnishes children with effective social adjustment and coping resilience
(Engels et al., 2001; Hoeskma, Oosterlaan & Schipper, 2004; McGillicuddy-De Lisi & De Lisi, 2007; Padilla-Walker, 2007). A hallmark longitudinal study found that securely attached children emerged as more enthusiastic and with better problem-solving skills than other children without the same degree of attachment. Dismissively attached children were found to be more easily frustrated and less persistent in problem-solving skills in general (Ainsworth, 1979).

The nature of the attachment between children who stutter and their parents has yet to be determined. The growing demands placed on the school-aged child who stutters, with expectations for increasingly adult-like social, communicative and academic competence, may intensify communication anxiety for some young people. Therefore, the quality of parent-child relationships might play an important role in providing the child with models of social competence, coping strategies and motivational orientation (Bukatko & Daehler, 2004). The exact nature and degree of influence of parent-child relations in terms of attachment and perceived trust in school aged children who stutter remains undetermined.

As has been outlined, stuttering influences the child in a variety of ways, notably in terms of communicative impairment and psychosocial impact. In addition, the stuttering disorder has a holistic impact, affecting those with whom the child who stutters lives. Treatment approaches for young children who stutter usually necessitate a significant amount of family involvement. Therapy strategies are provided by the clinician in the clinical setting, however the suggested therapy techniques are implemented at home in the context of the family environment (Millard, Nicholas & Cook, 2008; Yaruss, Coleman, & Hammer, 2006). Within the family constellation, the closest person to the individual who stutters is often their sibling. It has been suggested that the emotional ties between siblings are second
only to those between children and their parents (Furman & Buhrmester, 1985), and that these sibling relationships are unique in terms of their power and vitality (Young, 2007). Despite these findings, the impact of stuttering and stuttering therapy on the siblings of a child who stutters and the subsequent quality of the sibling relationship has previously not been thoroughly explored.

The two major relationships in the family constellation between the parents and the siblings of the child who stutters are narratives in the experience of living with a stutter across the lifespan. The exploration of the impact of stuttering on these relationships remains incomplete.

**The Impact of Stuttering on Partners of Adults who Stutter.**

The social need for intimacy and companionship is a driving force that sustains human beings in day-to-day living. Accordingly, the impact of disability on the formation and maintenance of intimate relationships is an important though previously limited topic in stuttering disorder literature. Given that people who stutter have reported concerns about their ability to form intimate relationships (Hayhow, Cray & Enderby, 2002; Van Borsel, Brepoels, & Do Coeng, 2011), it is particularly important to explore how the experience of stuttering may affect partners of people who stutter. If individuals who stutter are limited in their ability to communicate with their partners, this may lead to problems in the formation of long-term relationships or difficulties with problem-solving within the family unit. In addition, if a person who stutters is dependent upon their partner for communication, this may have an adverse bearing on the speaker's ability to participate fully in life experiences outside of the home.

Klompas and Ross (2004) investigated the impact of stuttering on key psychosocial aspects of the life of the adult who stutters. Measures included
employment, self-esteem, marital and family status as well as overall emotional functioning. The study found that participants identified stuttering to have a negative influence on their marital and family life; however, the research did not explore how the quality of life of the partner of the person who stuttered was also affected. Specific issues relating to how a stuttering disorder might affect the quality of life of fluent partners, or how the presence of a fluent partner might affect an individual who stutters, have not previously been examined.

**Acceptance and Commitment Therapy for People who Stutter.**

As delineated in preceding sections, stuttering has been shown to result in adverse emotional and cognitive reactions to communicating in daily living situations (Craig, Blumgart, & Tran, 2009). However, the ability of an individual who stutters to communicate effectively in a variety of every day speaking situations is not necessarily determined by the amount of stuttering they experience (Blumgart, Tran, Yaruss & Craig, 2012; Koedoot, Versteegh & Yaruss 2011). Rather, it can be determined by how completely the person is able to convey their spoken message in each situation.

It is well documented that individuals who stutter experience a variety of emotional reactions to their stuttering (Cooper, 1993; DeNil & Brutten, 1991; Guitar, 2006; Logan & Yaruss, 1999; Manning, 2010; Shapiro, 1999; Sheehan, 1970; Vanryckeghem & Brutten, 1996; 1997; Watson, 1988; Yaruss, 1998; Yaruss & Quesal, 2004, 2006). These emotional reactions include feelings of embarrassment, anxiety and fear, shame and guilt, anger, isolation and loneliness, inadequacy, and apprehension regarding speaking in general (Cooper, 1993; Watson, 1988; Yaruss & Quesal, 2006). Yaruss (2010) has consistently described that the crux of the speech-
language pathologist's profession is to address the clients' quality of life and explore fully their life experiences.

Former clinical initiatives have incorporated treatment for the psychosocial impact and consequences that stuttering has on the person's life (Cooper & Cooper, 1996; Gabel, 2006; Quesal, 1989; Rustin et al., 1995; Yaruss & Quesal, 2004, 2006). Such programmes addressed behaviour and attitude change and involved both speech retraining and social and assertiveness skills training. In addition to speech management, a direct attempt was made to change maladaptive attitudes towards communication and social anxieties with the implementation of cognitive therapy in conjunction with behavioural therapy. This integrated cognitive therapeutic program involved the use of thought stopping and cognitive relaxation to reduce fears, speech and social anxieties and enhance feelings of responsibility towards maintaining therapy skills (Andrews et al., 1983; Craig et al., 1987). Such attempts to control undesirable private events may be effective in the short term, and rationalizing thoughts and distraction may prove helpful at times, however, the literature indicates that such efforts may be impractical and even counter-productive at other times (Wegner, 1994; Wenzlaff, Wegner & Roper, 1988). The struggle to remove unwanted thoughts appears to highlight and reinforce them further which can result in intensification of such thoughts especially in times of stress (Wegner, 1994; Wenzlaff et al., 1988; Wenzlaff & Wegner, 2000). Considering the chronic environmental stressors in the lives of people who stutter, it is appropriate to submit that efforts directed at cognitive avoidance may actually amplify negative thoughts for such individuals.

There is empirical evidence for acceptance-based interventions such as dialectical behaviour therapy (Linehan, 1993), mindfulness-based cognitive therapy
(Segal, Williams, & Teasdale, 2002), and Acceptance and Commitment Therapy (ACT) (Hayes, Strosahl, & Wilson, 1999) in the allied health domains. Of these, ACT is unique in that it focuses directly on values identification, values clarification, and behavioural decisions linked to personal values. It is particularly suitable for individuals who stutter given that their daily struggle is often defined by the value placed on communicating fluently.

It is a common feature of adult stuttering programs for participants following treatment to experience significant rates of relapse back to pre-treatment stuttered speech levels (Bloodstein & Bernstein Ratner, 2008; Craig, 1998; Kuhr & Rustin, 1985; Martin, 1981). Considering this finding, an acceptance based approach to clinical management that does not emphasise a cure for chronic stuttering is defensible. Rather than offering a remedy for the symptoms of stuttering, the predominant goal of ACT is to encourage psychological flexibility through honing the ability to connect with the present moment more fully. ACT trains increased consciousness which in turn changes persistent behaviour to more valued based outcomes (Hayes, Luoma, Bond, Masuda & Lillis, 2006). The focus of the therapy is not on attempting to eradicate negative thoughts and feelings; rather, frustration is reduced through acceptance and an emphasis on valued living. More specifically, treatment involves approaches that focus on awareness, acceptance and understanding of the context of thoughts rather than on direct challenges or changes to the content of thoughts (Hayes, 2004; Hayes et al., 2006). Emphasis on communicative effectiveness rather than fluency per se, is a fundamental principle in ACT therapeutic programs. The six core processes that contribute to psychological flexibility in the ACT model are self-concept, defusion, acceptance, mindfulness, values and committed action. Such a holistic therapeutic model may be beneficial to
enhance quality of life for individuals living with a stutter. To date, however, a theoretical model incorporating ACT therapy with fluency enhancing or stuttering modification treatment programmes has not been developed.

Aims and Objectives of the Series of 7 Published Works

The primary aim of this thesis was to address the experiences of living with a stuttering disorder across the lifespan. The impact of the disorder on the individual (child, adolescent and adult), and their family members (siblings, parents and partners) is described. From such outcomes, a holistic ACT therapeutic model is proposed which integrates psychosocial and fluency goals in a treatment program for the disorder of stuttering. Finally, an intervention and maintenance evaluation is presented of the integrated ACT intervention program which provides clinical research support for this novel intervention for individuals who stutter.

Paper 1:


Objectives:

To identify the reactions of children and adolescents who stutter compared to their fluent peers and to identify the relationship between the adverse impact they experience and their stuttered speech frequency.

Paper 2:

Objectives:

To examine the relationship between anxiety and attitude toward daily communication in adolescents who stutter compared to their fluent peers. In addition, for these adolescents who stutter, to investigate the relationship between their stuttering symptomatology and the levels of trait, state and social anxiety that they experience.

Paper 3:


Objectives:

To investigate whether parenting styles, parent and peer attachment patterns and behavior management are different for parents of children who stutter compared to parents of children who are normally fluent. In addition, to determine what important themes exist regarding school, peers and parents for school aged children who have a stuttering disorder.

Paper 4:


Objectives:

To examine whether a significant difference exists in the quality of the sibling relationship between families in which there is a child who stutters compared to those families whose children are normally fluent. In addition, to determine the
themes which exist regarding the impact of living with a sibling who has a clinically
diagnosed stuttering disorder.

Paper 5:

of stuttering on adults who stutter and their partners. *Journal of Fluency
Disorders.*

Objectives:

To determine what personal experiences and themes exist for both members
of a couple dyad regarding forming and maintaining personal relationships when one
member of the couple stutters. In addition, to evaluate whether the individual who
stutters and the fluent partner have significantly different experiences with respect to
the impact of stuttering on their lives?

Paper 6:

people who stutter. *Perspectives in Fluency Disorders, American Speech
Language Hearing Association Special Interest Group – Fluency and
Fluency Disorders, 22*(1), 34-46.

Objectives:

To appraise the literature regarding combined speech pathology and
psychology therapeutic programs for people who stutter. In addition, to provide an
overview of Acceptance and Commitment Therapy in the context of stuttering and
the relevant psychosocial outcome measures which constitute therapeutic change.

Paper 7:

Therapy for adults who stutter: Psychosocial adjustment and speech fluency.

*Journal of Fluency Disorders, 37, 289-299.*

**Objectives:**

To examine the effectiveness of an ACT group program for adults who stutter in terms of whether participants experience improvements in overall fluency, psychosocial functioning, readiness for therapy and change, utilisation of mindfulness skills and psychological flexibility. In addition, to determine if these improvements are maintained over 3 month follow-up period of time?

**Methods**

A mixed methods research design incorporating qualitative semi-structured interviews and quantitative questionnaires was implemented in papers 3, 4, and 5 of this thesis. Such a mixed methods research design has been demonstrated to be meaningful and important in the field of health disorders research (Hughes, Gabel, Irani & Schlagheck, 2010). This design was deemed appropriate for these papers because of the greater insight to be gained in combining the results of quantitative and qualitative work than by using either form in isolation (Creswell, 2009). The goal of the mixed methods design was to gain an in-depth understanding through qualitative interviews and subsequent analyses, of the experiences of 1) the children, and their parents and siblings, and 2) the adults who stuttered and their life partners. Simultaneously, the perspectives of these children and adults were also assessed using quantitative assessments.

In the quantitative research papers in this thesis (papers 1, 2, 5 and 7) the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES; Yaruss & Quesal, 2006, 2010) measurement instrument was the primary tool used to assess the adverse impact or negative consequences associated with stuttering. These
consequences were described in terms of 1) the speaker’s general perceptions of the stuttering *impairment*, 2) the speaker’s affective, behavioural and cognitive *reactions* to stuttering, 3) the impact of stuttering on a speaker’s *functional* communication in daily situations, and 4) the impact of stuttering on the speaker’s overall *quality of life*.

In the qualitative research component of this thesis, phenomenological enquiry research methods were employed to study the life experiences of the family members. The qualitative methodology used was derived from theory which provides a flexible set of inductive strategies for collecting and analysing qualitative data (Creswell, 2009; Glaser & Strauss, 1967; Plexico, Manning & Levitt, 2009). This approach builds inductive theories through data analyses which allow for theoretical categories that are directly ‘grounded’ within the data (Charmaz, 2008). The data provided personal examples of the experiences of living and coping with stuttering and explored the interconnections between the participants’ experiences which might otherwise have been underestimated or lost (Plexico et al., 2009).
Paper 1

The Impact of a Stuttering Disorder on
Western Australian Children and Adolescents.

disorder on Western Australian children and adolescents. Perspectives in
Fluency Disorders, American Speech Language Hearing Association Special
Interest Group – Fluency and Fluency Disorders, 22, 51-62.
The Impact of a Stuttering Disorder on Western Australian Children and Adolescents

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Disclosure: J Scott Yaruss is the co-author of the OASES and receives royalties from its sale.

Abstract

In this study, we examined the impact of a stuttering disorder on children (n=50) and adolescents (n=45) living in Western Australia. We compared the reactions and experiences of children and adolescents who stutter to children and adolescents who do not stutter. We compared the participants who stuttered and the fluent participants using adapted versions of the Overall Assessment of the Speaker’s Experience of Stuttering (OASES). We also examined the relationship between biopsychosocial impact and stuttered speech frequency. We saw higher levels of adverse impact in young people who stuttered compared to their fluent peers. In addition, we found moderate correlations between OASES scores and stuttered speech frequency in children. These findings provided a baseline for establishing the degree of negative impact that a stuttering disorder may bring about in children and adolescents. The experiences of young people who stuttered were significantly different from the experiences of young people who were typically fluent. These findings reinforce the notion that stuttering is a disorder that can lead to negative impact for young people.

Biopsychosocial Model of Stuttering

Researchers and clinicians working in the field of stuttering disorders have argued for a conceptualization of stuttering that delineates both the surface behaviors present in an individual’s speech and the biopsychosocial impact or consequences that stuttering has on his or her life (Cooper & Cooper, 1996; Gabel, 2006; Quesal, 1989; Rustin, Cook, & Spence, 1995; Yaruss & Quesal, 2004, 2006). For instance, Yaruss and Quesal (2004) adapted the
International Classification of Functioning, Disability and Health (ICF), presented by the World Health Organization (WHO, 2001) to describe the multidimensional nature of stuttering. They stated that they selected that framework because it considers factors beyond the observable characteristics of the stuttering impairment. Specifically, these added factors can be viewed in terms of an integrated holistic biopsychosocial model that contains several interacting components: biological factors, which consist of the presumed aetiology or underlying causes of the disorder, as well as the impairment in body function evident in the observable characteristics of stuttering; psychological factors, which include the speaker's affective, behavioral, and cognitive reactions to stuttering; social factors, which include the effects of the environment on stuttering, such as the reactions of others, and which may be indicated by the difficulty the speaker may have in different speaking situations; and the overall impact of stuttering on the speaker's life, as indicated by the limitations in communication activities and restrictions in participation in daily life.

The study of the biopsychosocial effects of the stuttering disorder on children and adolescents who stutter is particularly important, because research to date has not fully delineated the nature or extent of the negative impact that stuttered speech may have for these age groups. Many adults who stutter experience a variety of affective or emotional reactions to their stuttering. Examples include feelings of embarrassment, anxiety, fear, shame, guilt, anger, isolation, loneliness, inadequacy, and other negative emotions accompanying stuttered speech (e.g., Cooper, 1993; DeNil & Brutten, 1991; Guitar, 2006; Logan & Yaruss, 1999; Manning, 2010; Shapiro, 2011; Sheehan, 1970; Vanryckeghem & Brutten, 1996, 1997; Watson, 1988; Yaruss, 1998; Yaruss & Quesal, 2004, 2006). In addition, cognitive reactions such as low self-esteem, diminished self-confidence, and reduced feelings of self-efficacy also are common (Blood & Blood, 2004; Healey & Scott, 1995; Manning, 2010; Ornstein & Manning, 2002; Ramig & Bennett, 1995; 1997; Ramig & Dodge, 2005; Reeves & Yaruss, 2012; Starkweather & Givens-Ackerman, 1997; Vanryckeghem, Brutten, & Hernandez, 2005; Yaruss, 1998; Yaruss & Quesal, 2004, 2006).

From a developmental perspective, researchers have not yet clarified when these reactions emerge in young people. It has long been known that negative attitudes can develop when children are relatively young (Bloodstein, 1960), and more recent research has highlighted the importance of considering negative reactions even in very young children who stutter (Ezrail-Vinacour, Platzky, & Yairi, 2001; Vanryckeghem et al., 2005). Nevertheless, researchers have not yet fully explored the way in which these negative reactions and experiences affect school-age children and teenagers.

Researchers have found that stuttering has a significant impact on a speaker's overall quality of life (Craig Blumgart, & Tran, 2009; Prattali, 1998; Klompas & Ross, 2004; Yaruss & Quesal, 2006). Specifically, previous researchers suggest that adults with an increased severity of stuttering may have a higher risk of poor emotional functioning (Craig et al., 2009). Children and adolescents have reported instances of school yard bullying and teasing; such experiences may negatively affect the person's full participation in future vocation and recreational opportunities (Blood & Blood, 2004; Davis, Howell, & Cook, 2002; Langvin, 1997, 2000; Langvin, Bortnick, Hammer, & Wiebe, 1998; Murphy & Quesal, 2002; Murphy, Yaruss, & Quesal, 2007a, 2007b; Yaruss, Murphy, Quesal, & Reardon, 2004). Therefore, tools to assess the experiences facing young people living with a stutter warrant increased prominence and exploration.

Given the myriad ways in which stuttering may affect children and adolescents, there is a need for better information regarding the adverse impact of the disorder for young people. This is particularly true given the fact that even children and adolescents who do not stutter are likely to experience personal and environmental reactions to their developing speaking abilities. These ages represent times of change in young people's lives, and it is not necessarily clear which aspects of the experience of stuttering are unique to stuttering and which are part of growing up and learning to communicate with others. Accordingly, comparison of the
experiences of children and adolescents who stutter with the experiences of their fluent peers may highlight specific social, emotional, and mental health concerns for this population of young people coping with communication difficulties.

Aims of Study

The aims of this study were to identify: (a) the reactions of children who stutter (CWS) and adolescents who stutter (AWS) compared to their fluent peers as measured by scores on the OASES questionnaire (Yaruss & Quesal, 2006, 2010) and (b) the relationship between adverse impact and stuttered speech frequency as measured by percent syllables stuttered (%SS).

Methods

Participants

The group of children and adolescents who stuttered consisted of 95 young people, 50 children ($M=9.64$ years; $SD=1.03$ years; range=8–11 years) and 45 adolescents ($M=13.59$ years; $SD=1.55$ years; range=12–17 years). They consisted of 75 males and 20 females. All participants were on the waiting list for treatment at a metropolitan university stuttering clinic. The clinic provides specialized stuttering treatment expertise and is respected as a second opinion clinic for previously unsuccessful treatments. All the participants attended primary or secondary suburban or rural schools. Eighty-five participants resided in the metropolitan area and the remaining 10 lived in rural areas ranging from 200 kilometers southwest to 1,600 kilometers northeast of the clinic. Clinicians in the specialist university stuttering treatment clinic assessed all of the participants. Parents and caregivers of the participants who stuttered reported that their children started stuttering during early childhood between the ages of 2.5 and 4 years. Onset of stuttering by parental and caregiver report was described in a manner consistent with developmental stuttering. All participants had previously attended other speech-language pathology clinics for treatment of their stuttering difficulties. None of the participants had received any stuttering treatment in the 3 months prior to the start of this study.

The group of children and adolescents who do not stutter consisted of 95 young people, 50 children ($M=9.66$ years; $SD=1$ year; range=8–11 years) and 45 adolescents ($M=13.71$ years; $SD=1.55$ years; range=12–17 years). They were recruited and age- and sex-matched as a cohort to the individuals in the stuttering subject group. Researchers obtained parental and caregiver reports for each control participant with no difficulties identified with reading, fluency, or other aspects of speech, language, or communication in the participant's developmental history. In addition, there were no reports of any familial history of stuttering.

Measures

Researchers determined stuttered speech frequency by rating a representative natural conversational speech sample for each of the 95 participants who stuttered. They obtained a sample of a minimum of 2,000 syllables of conversational speech for each person and elicited when the young person engaged in a conversation with the first author regarding school, family, recreational activities, hobbies, and weekend activities. In the elicitation approach, the author used open-ended prompts that yielded short narratives. The speech samples then were rated by two speech-language pathologists with at least 10 years of experience in the assessment and management of childhood stuttering. Researchers used the Stuttering Measurement System computer program (Ingham, Bakker, Ingham, Moglia, & Kilgo, 2005) to obtain the percentage of syllables stuttered (%SS). Interrater reliability was calculated with a correlation coefficient of .91 obtained using a one-way independent group random effect model of analyses (Howell, 2007). This indicates that judgments were both satisfactorily correlated and in agreement. Researchers calculated intrarater reliability using the same method and obtained an intraclass correlation coefficient of .89, demonstrating satisfactory correlation and agreement.
Researchers used the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES; Yaruss & Quesal, 2006, 2010) measurement instrument to assess the adverse impact or negative consequences associated with stuttering. These consequences were described in terms of the speaker's general perceptions of the stuttering *impairment*; the speaker's affective, behavioral, and cognitive *reactions* to stuttering; the impact of stuttering on a speaker's *functional* communication in daily situations; and the impact of stuttering on the speaker's overall quality of life. The adult version of the OASES has demonstrated strong reliability and validity, with Pearson product moment correlation coefficients for impact scores reported to range from .90 to .97 and concurrent validity correlation coefficients ranging from .68 to .83 (Yaruss & Quesal, 2006).

Researchers administered a modified version of the original OASES that has been adapted for use with children and adolescents who stutter. The child and adolescent questionnaires used in this study (OASES-C) differed from the published adult version (Yaruss & Quesal, 2010) in that more simple wording was used on certain items. (Note: This study was conducted before the published version of the OASES-S for school-age children and OASES-T for teenagers was available. The adaptations were very similar to the published OASES –S and –T versions and were developed with input and consent from the original authors of the OASES). The OASES-C instruments consisted of 100 items, each scored on a Likert scale ranging from 1 to 5, with higher scores indicating greater negative impact of stuttering.

As in the original published OASES instruments, the adapted questionnaires were divided into 4 sections. Section I (General Information) contained 20 items pertaining to the speakers’ perceived fluency and speech naturalness, knowledge about stuttering and stuttering treatment, and overall perceptions about stuttering. Section II (Reactions) contained 30 items examining the speakers’ affective, behavioral, and cognitive reactions to stuttering. Section III (Communication in Daily Situations) contained 25 items assessing the degree of difficulty speakers have when communicating in general situations, at school, in social situations, and at home. Section IV (Quality of Life) contained 25 items assessing how much stuttering interferes with the speakers’ satisfaction with their ability to communicate, their interpersonal relationships, their ability to participate actively in life, and their overall sense of well-being. These modified OASES tools took each participant 20 minutes on average to complete.

For participants who did not stutter, researchers administered an adapted version of the OASES-C questionnaire scale (OASES-NC) that has previously been used to successfully compare results with fluent speakers (Mulcahy, Hennessy, Bellby, & Byrnes, 2008). In this adaptation, the word *stuttering* is replaced with the phrase *speaking ability* to assess the general impact of speaking on the person’s life (Tellis et al., 2000). Researchers converted raw scores for all participants to impact scores using the procedure outlined by Yaruss and Quesal (2010).

**Procedures**

Researchers obtained ethical approval for this study through the requisite Human Research Ethics Committee. They obtained informed consent from all participants and their parents or caregivers. Initially, researchers contacted the parents or caregivers of the children and adolescents and provided them with information sheets and informed consent ethics forms. Parents discussed participation with their son or daughter, who confirmed their willingness to participate further in the research. Researchers assessed participants individually in a quiet room within the university clinic. They used an initial 10-minute screening conversation to assess the absence of stuttering in the fluent control participants. They obtained a 30-minute recorded conversation sample based on a series of open-ended questions designed to elicit dialogue and establish rapport for all participants who stuttered. All participants completed the appropriate version of the OASES-C or OASES-NC questionnaire.
Results

Between-Group Comparisons

Descriptive statistics, computed for the %SS, OASES, and Age, are shown in Tables 1 and 2. Researchers scanned the data for any univariate outliers, calculating mahalanobis distances to identify multivariate outliers. There were no significant outliers. Researchers calculated effect size using Cohen’s d (Cohen, 1988). Researchers used an alpha level of .01 (two-tailed) for all statistical tests based on a Bonferroni alpha correction, which was implemented to control for the increased risk of Type I errors when conducting multiple comparisons.

Table 1: Means and Standard Deviations for Children Who Stutter (CWS) and Children Who Do Not Stutter (CWNS)

<table>
<thead>
<tr>
<th>Measures</th>
<th>CWS (N=50)</th>
<th>CWNS (N=50)</th>
<th>t</th>
<th>P</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>% SS</td>
<td>5.71</td>
<td>4.03</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>OASES - SI</td>
<td>2.92</td>
<td>0.40</td>
<td>2.29</td>
<td>0.42</td>
<td>7.68</td>
</tr>
<tr>
<td>OASES - SII</td>
<td>3.04</td>
<td>0.47</td>
<td>1.72</td>
<td>0.27</td>
<td>17.29</td>
</tr>
<tr>
<td>OASES - SIII</td>
<td>3.25</td>
<td>0.53</td>
<td>1.44</td>
<td>0.32</td>
<td>20.58</td>
</tr>
<tr>
<td>OASES - SIV</td>
<td>2.88</td>
<td>0.53</td>
<td>1.10</td>
<td>0.23</td>
<td>21.93</td>
</tr>
<tr>
<td>Age</td>
<td>9.64</td>
<td>1.03</td>
<td>9.67</td>
<td>1.00</td>
<td>-0.10</td>
</tr>
</tbody>
</table>

Table 2: Means and Standard Deviations for Adolescents Who Stutter (AWS) and Adolescents Who Do Not Stutter (AWNS)

<table>
<thead>
<tr>
<th>Measures</th>
<th>AWS (N=45)</th>
<th>AWNS (N=45)</th>
<th>t</th>
<th>P</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>% SS</td>
<td>5.41</td>
<td>3.90</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>OASES - SI</td>
<td>3.08</td>
<td>0.44</td>
<td>2.10</td>
<td>0.41</td>
<td>10.98</td>
</tr>
<tr>
<td>OASES - SII</td>
<td>3.24</td>
<td>0.36</td>
<td>1.64</td>
<td>0.22</td>
<td>25.47</td>
</tr>
<tr>
<td>OASES - SIII</td>
<td>3.30</td>
<td>0.43</td>
<td>1.50</td>
<td>0.29</td>
<td>23.20</td>
</tr>
<tr>
<td>OASES - SIV</td>
<td>2.97</td>
<td>0.48</td>
<td>1.08</td>
<td>0.22</td>
<td>24.02</td>
</tr>
<tr>
<td>Age</td>
<td>13.69</td>
<td>1.55</td>
<td>13.71</td>
<td>1.55</td>
<td>-0.07</td>
</tr>
</tbody>
</table>

An independent samples t-test showed no significant difference between the ages of CWS and CWNS (Table 1).

The majority (62%) of CWS demonstrated stuttered speech frequency levels between 2 and 5 %SS, with the remaining (38%) demonstrating greater than 5 %SS (Figure 1).
Researchers computed independent samples t-tests to test for significant differences between the CWS and the CWNS on the OASES subsection scores. Results (Table 1) demonstrated significant differences between the groups on all measures with large effect sizes (Howell, 2007). All four comparisons of the OASES subscales revealed significant differences between children who stuttered and children who did not stutter (Figure 2).

An independent samples t-test showed no significant difference between the ages of AWS and AWNS (Table 2).

A majority of AWS (53%) demonstrated stuttered speech frequency levels between 2 and 5 %SS with the remainder (47%) demonstrating in excess of 5 %SS (Figure 1).

Researchers computed independent samples t-tests to test for significant differences between the group of AWS and the fluent AWNS group on the OASES subsection scores.
Results (Table 2) demonstrated significant differences between the groups on all measures with large effect sizes (Howell, 2007). All four comparisons of the OASES subscales revealed significant differences between adolescents who stuttered and adolescents who did not stutter (Figure 3).

Figure 3: Group Mean ± SD of OASES Subsection Items Completed by Adolescents Who Stutter (AWS) and Adolescents Who Do Not Stutter (AWNS)

Correlations Between Variables
Researchers computed Pearson product-moment correlations to determine the interrelationship between each measure within each group.

For the group of CWS, stuttered speech frequency (%SS) was significantly associated with each of the OASES subscales (Table 3). In addition, children who stuttered demonstrated significant associations between each of the subsections of the OASES questionnaire.

Table 3. Intercorrelations for CWS (N=50)

<table>
<thead>
<tr>
<th>Measures</th>
<th>%SS</th>
<th>OASES - SI</th>
<th>OASES - SII</th>
<th>OASES - SIII</th>
<th>OASES - SIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>%SS</td>
<td>-</td>
<td>.53*</td>
<td>.48*</td>
<td>.50*</td>
<td>.42*</td>
</tr>
<tr>
<td>OASES-SI</td>
<td>-</td>
<td>-</td>
<td>.68*</td>
<td>.70*</td>
<td>.48*</td>
</tr>
<tr>
<td>OASES - SII</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.76*</td>
<td>.82*</td>
</tr>
<tr>
<td>OASES - SIII</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.82*</td>
</tr>
<tr>
<td>OASES - SIV</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. *p<.01

For the group of AWS, stuttered speech frequency (%SS) was significantly associated with the OASES-I subscale (Table 4). Moderate correlations between %SS and other sections of the OASES did not reach significance following the application of the Bonferroni correction.
In addition, AWS demonstrated statistically significantly associations between each of the subscales of the OASES questionnaire.

<table>
<thead>
<tr>
<th>Measures</th>
<th>%SS</th>
<th>OASES - SI</th>
<th>OASES - SII</th>
<th>OASES - SIII</th>
<th>OASES - SIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>%SS</td>
<td>-</td>
<td>.43*</td>
<td>.32</td>
<td>.34</td>
<td>.32</td>
</tr>
<tr>
<td>OASES-SI</td>
<td>-</td>
<td>-</td>
<td>.51*</td>
<td>.76*</td>
<td>.47*</td>
</tr>
<tr>
<td>OASES - SII</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.76*</td>
<td>.87*</td>
</tr>
<tr>
<td>OASES - SIII</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.76*</td>
</tr>
<tr>
<td>OASES - SIV</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. *p<.01

**Discussion**

A principal outcome of this study is the finding that children and adolescents who stuttered experienced greater adverse impact on their lives as a result of stuttering than children who stuttered less. The young people who stuttered showed greater overall concern about their speaking, magnified affective, behavioral, and cognitive reactions to their speaking ability and significantly compromised communication in daily situations. Further, findings were underpinned by the fact that these young people experienced a reduced quality of life compared to their fluent peers in society.

The young people who stuttered reported significantly reduced self-awareness and knowledge of their speaking ability; greater affective, behavioral, and cognitive reactions to their speaking ability; greater impact of the environment on their speaking ability; and poorer quality of life compared to children and adolescents who did not stutter. The pattern of results observed in the present study for participants who stutter supports the utility of using a biopsychosocial model when studying quality of life issues with this population.

Previous research has highlighted the prominence of negative reactions to stuttering in very young children (Eerati-Vinacour et al., 2001; Vanryckeghem et al., 2005). In addition, parental reports have indicated that children who stutter are aware of their stuttering shortly after its onset (Ambrose & Yairi, 1994; Packman, Onslow, & Attanasio, 2003). Such findings underpin the potential that stuttering has to affect social interaction from an early age. Analysis of interactive components of the assessment in this study indicate that children and adolescents who stuttered displayed a significant association between stuttered speech frequency (%SS) and self-awareness and knowledge of their stuttering experience (OASES-SI). A possible interpretation is that young people who continue to stutter, over time, experience an escalation in negativity regarding their communications skills. Interestingly, however, researchers did not find significant correlations between %SS and other sections of the OASES among adolescents, thereby highlighting the fact that adverse impact can exist independent from the degree of stuttering that a listener may observe (e.g., Blumgart, Tran, Yaruss, & Craig, 2012; Koedoot, Versteegh, & Yaruss, 2011; Mulcahy et al., 2008).

In this study, researchers directly compared reactions of children and adolescents who stutter to children and adolescents who do not stutter, the first time researchers have done so.
The young people in the study who stuttered displayed significantly higher affective, behavioral, and cognitive reactions to their stuttering/speaking ability (OASES-SII) than their fluent counterparts. A small but expected finding was that fluent participants did not show a complete absence of response in terms of their speaking abilities. By comparison, however, the experimental groups of children and adolescents showed significantly much higher affective, behavioral, and cognitive reactions. This has important clinical implications for realistic goal-setting that does not strive for an absence of negative reactions overall.

In this study, children who stuttered demonstrated a significant, positive correlation between %SS and reactions to stuttering, self-awareness of stuttering, difficulties in daily communication, and quality of life. The children appeared to have developed negative affective, behavioral, and cognitive reactions to their stuttering in comparison to their fluent peers. Such a relationship between stuttered speech and negative reactions supports previous literature (Cooper, 1993; DeNil & Bruten, 1990; Gutar, 2006; Logan & Yaruss, 1999; Manning, 2010; Shapiro, 1999; Sheehan, 1970; Vanzuyckeghem & Bruten, 1996, 1997; Watson, 1988; Yaruss, 1998; Yaruss & Quesal, 2004, 2006).

Researchers have determined that quality of life is a potentially important measure when assessing the impact of stuttering (Craig et al., 2009; Klompas & Ross, 2004; Yaruss & Quesal, 2006). To date, there is limited literature assessing the impact of stuttering on quality of life in children and adolescents (Mulcahy et al., 2008). A noteworthy finding from this study is the fact that children and adolescents who stuttered displayed significantly lower quality of life responses than did their fluent peers.

In addition, previous researchers investigating quality of life impact suggest that adults with an increased severity of stuttering may have a higher risk of poor emotional functioning (Craig et al., 2009). Such findings have important therapeutic implications for the treatment of children who stutter. The assumption is that the negative impact of stuttering on quality of life is a consequence of chronic stuttering over time (Bloodstein & Bernstein Ratner, 2008). It is therefore imperative that treatments for children and adolescents improve so that fewer children and adolescents grow into adults who remain stuttering at elevated or severe levels (Craig et al., 2009).

Researchers discovered an important clinical implication from the research, that young people who were fluent also had some degree of negative reaction to their speaking ability. Thus, the goals of treatment addressing negative reactions to stuttering do not necessarily need to seek an outcome of "zero negative reactions" in order to be successful. Helping a child achieve "normal" reactions (which may include some low level of concern about speaking) may be a reasonable outcome, provided those reactions do not interfere with communication.

It also possible for some people who stutter, as a result of treatment, to have scores on measures of communication and psychosocial functioning that are better or more desirable than typically fluent speakers (Manning, 2010).

**Limitations and Future Research**

This research used self-report measures to assess the adverse impact of stuttered speech in young people. This form of quantitative measurement presents a number of issues, including the operation of response bias and shared variance between the measures. However, self-report methods are currently one of few available methodologies for the collection of the speaker's attitudes and emotions about their communication. Further, the use of questionnaire methodology is widely accepted as valid and reliable methodology (Turk & Melzack, 1992). Subsequent research might consider qualitative research methods to verify and cross-validate the self-report responses of such children and adolescents who stutter.

This study constitutes a cross-sectional analysis and the findings have elucidated the adverse impact and negative consequences associated with living with a stutter from a young person's perspective. A recommended longitudinal study evaluating the impact of stuttering in children and adolescents could highlight factors that evolve as prognostic indicators in the
long-term adjustment to and acceptance of stuttering. In addition, it would be worthwhile to pursue any potential differences between male and female participants in future studies.

We hope that future studies will investigate further empirical support for a biopsychosocial model for stuttering in children and adolescents. It follows that such studies may well elucidate strategies for managing the psychosocial impact of stuttering in a holistic approach to the assessment and treatment of young people who stutter.

Acknowledgements

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Paper 2

Social Anxiety and the Severity and Typography of Stuttering in Adolescents.

Social anxiety and the severity and typography of stuttering in adolescents

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Abstract

The present study examined the relationship between anxiety, attitude toward daily communication, and stuttering symptomatology in adolescent stuttering. Adolescents who stuttered (n=19) showed significantly higher levels of trait, state and social anxiety than fluent speaking controls (n=18). Trait and state anxiety was significantly associated with difficulty with communication in daily situations for adolescents who stutter, but not for controls. No statistically significant associations were found between anxiety and measures of communication difficulty, and the severity or typography of stuttering surface behaviours. These results highlight some of the psychosocial concomitants of chronic stuttering in adolescence, but challenge the notion that anxiety plays a direct mediating role in stuttering surface behaviours. Rather, the results suggest stuttering is a disorder that features psychosocial conflict regardless of its surface features.

Educational objectives: The reader will be able to: (1) summarise findings from previous studies with regards to stuttering and anxiety; (2) identify the sub-types of anxiety that may impact on the individual who stutters; and (3) discuss the clinical implications of the results with regards to working with adolescents who stutter.

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Keywords: Stuttering; Adolescence; Anxiety; Severity; Typography

1. Introduction

Researchers and clinicians have argued for the adoption of a broader conceptualisation of stuttering, which aims not only to delineate the surface behaviours present in an individual’s speech, but also the psychosocial impact stuttering may have on their life (Cooper & Cooper, 1996; Rustin, Cook, & Spence, 1995; Yaruss & Quesal, 2004, 2006). Negative emotions (such as anxiety, fear and guilt) have been attributed to the disorder for over 2000 years (Fitzgerald, Djurjic, & Maguin, 1992). The role of psychosocial factors in the aetiology of stuttering has also long been proposed. Early writings have linked stuttering to a range of phenomena including suppressed anger, sexual fixations and approach–avoidance conflicts (Bobrock, 1995; Sheehan, 1975). Some theorists maintained that individuals who stutter are psychologically different to those who do not stutter (Adams, 1969), and some of the major research conducted during the 1970s and
1980s has attempted to disprove the psychogenic notions of the diagnosogenic era, whereby stuttering was thought to be caused by parents drawing negative attention toward a child's normal dysfluencies (Johnson, 1942; Quesal, 1989). The link between emotions, negative evaluation and stuttering has therefore been a focus in research for many years.

In contemporary research, stuttering is viewed primarily as a disorder of speech motor control with psychosocial etiological theories essentially neglected (Bloodstein, 1995). It has been suggested, however, that many variables may affect speech motor processes through effects on synaptic inputs to motor neuron pools (Zimmerman, Smith, & Hanley, 1981). The particular role of one such variable, anxiety, and its determinants, is a matter of contemporary debate and is the focus of this study (Alm & Risberg, 2007; Craig, Hancock, Tran, & Craig, 2003; Menzies, Onslow, & Packman, 1999). Research into anxiety in individuals who stutter has focussed primarily on adults, with limited investigation in children and even less in adolescents. The current literature examining the relationship between anxiety and stuttering, however, remains inconclusive.

1.1. Anxiety in children, adolescents and adults who stutter

Anxiety is described as an aversive emotional and motivational state occurring in perceived threatening circumstances (Eysenck, Derekhshan, Santos, & Celso, 2007). In its molar sense, anxiety is often dichotomised into trait and state anxiety. State anxiety reflects a temporary emotional state characterised by subjective, consciously perceived feelings of tension and apprehension, and enhanced autonomic nervous system activity (Spielberger, 1983). It may fluctuate over time and can vary in intensity. In contrast, trait anxiety denotes relatively stable individual differences in anxiety proneness and refers to a general tendency to respond with anxiety toward perceived threats in the environment (Spielberger, 1983).

Results from studies that have examined trait and state anxiety in those with chronic stuttering and also in children who stutter have produced conflicting findings. In the case of those with chronic stuttering, Craig (1990) and Ezraty-Vinacour and Levin (2004) found higher trait anxiety scores for adults who stuttered than control participants. Craig et al. (2003) replicated this finding with a population study of anxiety levels in people who stutter in the community using random selection procedures. Davis, Shisca, and Howell (2007) examined state and trait anxiety in adolescents who stuttered, with results suggesting that adolescents who stutter have higher state anxiety than controls, but not higher trait anxiety. Miller and Watson (1992), however, found no difference between adults who stuttered and a control group in relation to either state or trait anxiety levels. Hancock et al. (1998) examined state and trait anxiety in children and adolescents who stutter from treatment to two and 6 years post-treatment, with no significant differences across time or groups for children or adolescents with regards to state or trait anxiety at any stage. Craig and Hancock (1996) found that children who stutter were no more anxious (trait anxiety) than children of a similar age who did not stutter. State anxiety, however, was found to be associated with greater risks of stuttering in children (Weiss & Zebrowski, 1992).

These findings (with the exception of Craig & Hancock, 1996; Hancock et al., 1998; Miller & Watson, 1992), may be taken to suggest that anxiety has an aetiologcal contribution in stuttering, however, they are also consistent with the possibility that anxiety may be a direct consequence of chronic stuttering with the cause of stuttering (e.g., deficient speech motor control) being extraneous to these psychosocial issues. In short, there are reasons to believe that there is a relationship between stuttering, and trait and state anxiety, with its theoretical and clinical importance to date remaining equivocal (Messenger, Onslow, Packman, & Menzies, 2004).

1.2. Anxiety and a fear of negative social evaluation

Contrary to the traditional trait–state anxiety dichotomy, a contemporary model of anxiety holds that both trait and state anxiety are multidimensional and interactive, consisting of various components including social evaluation (Endler, Edwards, & Vitelli, 1991). It is suggested that global measures may not adequately capture the particular aspects of anxiety that are directly related toward stuttering (Menzies et al., 1999). In the ongoing development of measurement procedures for anxiety in individuals who stutter, attention needs to delineate exactly what components of anxiety and its determinants should be measured.

Modern clinical psychology includes the expectancy of harm as a key construct in anxiety measurement, suggesting that anxiety is not present without a perceived danger (Beck & Emery, 1985; Endler et al., 1991; Eysenck et al., 2007; Messenger et al., 2004). This fear of being negatively evaluated by others, particularly in social situations, is described as social anxiety (Messenger et al., 2004). Social anxiety disorder is described in DSM-IV-TR as, “clinically
significant anxiety provoked by exposure to certain types of social or performance situations, often leading to avoidance behavio" (Firth, 2004, p. 429).

In individuals who stutter, social anxiety is not surprising given the likely negative evaluation of speech that has been experienced for some time (Messenger et al., 2004). There is evidence that fluent children as young as 3 years of age recognize stuttering in their peers and that they may evaluate stuttering negatively as early as 4 years of age (Ezrati-Vinacour & Levin, 2004). Conflicting and variable responses from fluent communication partners and negative communication experiences have also been reported in adults who stutter (Blood, Blood, Maloney, Meyer, & Qualls, 2007; Cooper & Cooper, 1996; Kraaimaat, Vanyucckeghem, & Van Dam-Baggen, 2002; Miller & Watson, 1992). Adults who stutter have demonstrated significantly greater expectancies of social harm than those who do not stutter (Davis et al., 2007; Kraaimaat et al., 2002; Messenger et al., 2004) and concerns about publicly acknowledging and discussing stuttering have been reported in adolescents who stutter (Blood, Blood, Tellis, & Gabel, 2003; Hearne, Packman, Onslow, & Quine, 2008). Results from such studies suggest that anxiety levels in stuttering may be more directly manifested in a fear of being negatively evaluated (social anxiety). No studies to date have attempted to measure both traditional trait and state anxiety and a fear of negative evaluation in adolescents who stutter.

1.3. The mediating role of anxiety on stuttering events

Results from recent studies suggest that anxiety may play a mediating role in the disorder, being determined by interplay between variables such as communication attitude and apprehension (Davis et al., 2007; Messenger et al., 2004). The communication-emotional model of stuttering developed by Conture et al. (2006) suggests that stuttering events, resulting from inefficiencies in speech planning and/or production, are influenced by emotional regulation (including anxiety). Anxiety and its determinants may therefore mediate and exacerbate instances of stuttering including its surface features, severity (frequency of stuttering) and typography (type of stuttering), due to the effect of this arousal on speech motor control (Conture et al., 2006). Considering the association between communication and anxiety, it appears that social anxiety potentially mediates the surface features of stuttered events in daily communication (Messenger et al., 2004). Limited evidence exists for such a relationship although it has been suggested in a range of literature (Alm & Risberg, 2007; Blood et al., 2007; Conture et al., 2006; Davis et al., 2007; Messenger et al., 2004). A study by Davis et al. (2007), for example, found that adults with persistent stuttering had higher state anxiety than a control and a recovered group, which provides experimental evidence for the suggested mediating role of anxiety in stuttering.

1.4. Severity, typography and anxiety

The direct influence of anxiety on the surface symptomatology of stuttering has not been clearly evaluated. Two aspects of stuttering behaviour that may demonstrate such a link are stuttering severity (or frequency), commonly measured as the percentage of syllables stuttered, and stuttering typography, such as the percentage of repetition type stutters out of the total number of stutters (Ambrose & Yairi, 1999; Franklin, Taylor, Hennessey, & Beilby, 2008; Ingham & Andrews, 1971).

It is suggested that, within the variable range of stuttering behaviours, two levels of speech disability exist. Repetition type stutters, referred to as primary stuttering by Ingham and Andrews (1971), are similar to normal dysfluencies and tend not to disturb the overall rate of communication exchange with a conversational partner. Sound prolongations and blocks, however, referred to as secondary stuttering by Ingham and Andrews (1971) are reported to be more disruptive to a communicative interaction because they interrupt the normal flow of speech to a greater extent than do repetition type stutters. A similar distinction between repetition and prolongation/block typographies has been made in the developmental literature, with the latter being more associated with chronic stuttering (Ambrose & Yairi, 1999; Guitar, 2005). Typography analysis has been shown to be useful in experimental studies of stuttering behaviour. For example, a study by Franklin et al. (2008) found that time-out procedures not only reduced stuttering severity but also resulted in a statistically significant increase in the percentage of repetition type stutters. Ingham and Andrews (1971) also provide evidence that the measurement of individual dysfluency types may lead to "knowledge that could not have been gained any other way" (p. 268) in their study of rhythmic speech intervention. Whilst typography has been used successfully in some studies to profile stuttering behaviour, it has also been criticised as having limited heuristic value because of its poor reliability (Einarsdóttir & Ingham, 2005). If social anxiety is a consequence of chronic stuttering,
the impact on communicative evaluation may be increased for those with more severe stuttering and potentially more secondary stuttering behaviours. Increased social anxiety on the speech motor control system may also impact directly upon stuttering events, particularly for those participants with more severe and/or secondary stuttering behaviours.

Limited studies have examined this link between anxiety, severity and typography in stuttering. Craig et al. (2003) reported that adults with more severe stuttering (measured by the percentage of syllables stuttered) were not significantly more anxious than those who had less severe stuttering. Their data, however, were limited to trait anxiety and the role of social anxiety and attitude toward communication in daily situations was not investigated. Results from a study by Blood et al. (2007) demonstrated no significant correlations between a standard anxiety measure and the severity of stuttering in adolescents who stuttered. Results from Blood, Blood, Tellis, and Gabel (2001), however, showed the severity of stuttering as measured by the Stuttering Severity Instrument (Riley, 1994) to be significantly, positively correlated with communication apprehension in adolescent participants as measured by the Personal Report of Communication Apprehension (McCroskey, 1984) and the Self-Perceived Communication Competence scales (McCroskey & McCroskey, 1988). Existing studies may have failed to find a consistent relationship between anxiety measures and stuttering symptomatology because they have not differentiated typography in addition to severity.

1.5. Anxiety in adolescents who stutter

Adolescence is an important developmental period in which to examine the role of social anxiety and communication attitude in individuals who stutter. The adolescent years are typically characterised by emotional conflicts that potentially interact with the anxieties and negative feelings associated with stuttering (Manning, 2001). It can be assumed that adolescents who stutter have been doing so for some time and the likelihood of spontaneous recovery decreases as age progresses (Schwartz, 1993). This fact has implications for potential psychosocial manifestations because stuttering in this population is a chronic disorder. Anxiety disorders are amongst the most prevalent forms of psychopathology during adolescence, with rates of 3–20% being reported (Langsford, Houghton, Douglas, & Whiting, 2001; Preboth, 2000). Lower levels of peer acceptance and support have been reported in socially anxious adolescents (La Greca & Lopez, 1998; Voci, Beitchman, Brownie, & Wilson, 2006).

In summary, few studies have examined the role of trait and state anxiety, a fear of being negatively evaluated (social anxiety) and attitude toward communication in adolescents who stutter. It was proposed that adolescents who stutter will have higher levels of anxiety than control participants and also that this will be associated with reported difficulty communicating in daily situations as a result of speech being chronically negatively evaluated by others. High levels of anxiety and communication difficulty may also be associated with increased stuttering severity and/or differing typography (e.g., a lower percentage of repetition type stutters and more prolongations and blocks). Consequently, the present study aimed to determine if:

(a) adolescents who stutter demonstrate significantly higher levels of trait, state and social anxiety, and a poorer attitude toward daily communication than adolescents who do not stutter;
(b) anxiety levels are positively correlated with difficulty in daily communication amongst adolescents who stutter but not for adolescents who do not stutter; and
(c) anxiety (whether trait, state or social) or difficulty with communication in daily situations are positively associated with stuttering severity and negatively associated with typography to suggest a potentially mediating role of social anxiety on stuttering outcomes.

2. Method

2.1. Participants

Participants were 37 adolescents between the ages of 11 and 18 who attended suburban and rural schools in Western Australia. An independent samples t-test showed no significant difference between the ages of adolescents who stuttered and the adolescents who did not stutter [t(36) = .32, p = .75]. Four of the 19 participants who stuttered lived in a rural area (ranging from 200 km south-west of Perth to 1600 km north-east of Perth). All other participants resided in the Perth metropolitan region. Participants who stuttered were recruited through the Curtin University of Technology Stuttering
Treatment Clinic’s wait list (Perth, Western Australia) and also via clinicians throughout Western Australia. Control participants were recruited through staff and students of Curtin University’s School of Psychology.

The participants who stuttered were age matched as a cohort to a control group, with 18 participants in the fluent control group ($M = 14.5$ years, $SD = 1.6$) and 19 participants who stuttered ($M = 14.3$ years, $SD = 2.3$). The group of participants who stuttered consisted of 18 males and 1 female and the control group consisted of 16 males and 2 females. None of the participants in the control group reported any history of stuttering or stuttering-like behaviour. Caregivers of participants who stuttered reported onset in early childhood in a manner consistent with developmental stuttering and all participants who stuttered had at some stage attended speech pathology treatment for their stuttering difficulties. Thirteen (68%) of the adolescents who stuttered were currently enrolled in treatment. None of the participants reported a history of pharmacological intervention for anxiety-related disorders.

2.2. Measures

2.2.1. State and trait anxiety

Each participant completed the State and Trait Anxiety Inventory (STAI; Spielberger, 1983). This questionnaire measures state and trait anxiety in a self-report format and comprises 20 statements for each state and trait section. Participants were instructed to read each statement and indicate their response on a scale of 1–4. The state measure was completed before the trait, with participants being instructed to “think about how you feel, right now, in this room with a stranger” in addition to the standard instructions provided by Spielberger (1983). The STAI took approximately 10 min to complete.

The reliability and validity of the STAI is well supported in the literature, with alpha reliability coefficients for high school aged respondents reported as .86 (for the state scale) and .90 (for the trait scale) (Spielberger, 1983). The correlations reported for high school aged students between the trait anxiety scale and other similar measures range from .52 to .85 and the correlations between state and trait anxiety scores range from .64 to .72, demonstrating satisfactory validity (Spielberger, 1983).

2.2.2. Fear of negative evaluation

Each participant completed the Fear of Negative Evaluation scale (FNE; Watson & Friend, 1969). This comprises 30 statements that address the apprehension about evaluation of oneself by others, the expectations that such evaluations would be negative and the distress incurred by this (Watson & Friend, 1969). Participants were instructed to read each statement and indicate whether or not it applied to them by circling either true or false. The FNE took approximately 15 min to complete. It is reported that the scale correlates significantly with other tests of anxiety (with Pearson correlations ranging from .18 to .60) and has strong reliability (the KR-20 reliability statistic was reported as .94; Durm & Glaze, 2001). The reliability and validity of this scale has been replicated by other researchers (Durm & Glaze, 2001).

2.2.3. Attitude toward communication

The Overall Assessment of the Speaker's Experience of Stuttering Teen Version (OASES-T; Yaruss & Quesal, 2006) was used to obtain information from participants regarding their attitude toward communication in daily situations. The OASES-T contains four sections, which include the respondent's general knowledge of, their reactions to, and quality of life as a result of their speaking ability. Section three of the OASES-T (OASES-T:S3) was used for group comparison because this section is identical for both groups and measures the communication difficulty experienced by speakers, not their fluency, in daily situations (Yaruss & Quesal, 2006). Items on the OASES-T are self-scored on a Likert scale ranging from 1 to 5. The teen version differs from the adult version in terms of alternative wording on certain items with simpler vocabulary being used. The adult version has demonstrated strong reliability, with coefficients for impact scores reported to range from .90 to .97 (Yaruss & Quesal, 2006). Concurrent validity is also strong, with coefficients reported to range from .68 to .83 (Yaruss & Quesal, 2006). No reliability or validity data are currently available for the teen version. This needs to be considered when interpreting results from the study.

An adapted scale was created for the fluent speakers, with the word stuttering being replaced with speaking ability. This version was presented to the fluent control group whilst the original OASES-T was presented to stuttering participants. Administration of the OASES-T took approximately 20 min. Raw scores were converted to impact scores using the procedure outlined by Yaruss and Quesal (2006) and these impact scores were used in data analyses to account
for participants who may not have responded to all questions. A higher impact score on the OASES-T:S3 indicates greater self-perceived difficulty with functional communication.

2.2.4. Severity of stuttering

Stuttering severity in the group of adolescents who stuttered was determined by rating a conversational speech sample obtained in a clinic setting for 17 out of the 19 participants. Samples were not available for two participants due to time constraints. A minimum of 1000 syllables of speech were obtained and rated by two final year speech pathology students from Curtin University of Technology (Perth, Western Australia) who each analysed eight samples. The remaining randomly selected sample was analysed by both raters for the purpose of assessing inter- and intra-rater reliability. The computer program Stuttering Measurement System (Ingham, Bakker, Ingham, Moglia, & Kilgo, 2005) was used to obtain the percentage of syllables stuttered (%SS). This program uses mouse-clicks to count syllables and stuttering events whilst the audio recording is played. A higher %SS indicates more severe stuttering behaviour. Stutters were identified as word or part-word repetitions, prolongations or blocks as per Guitar (2005).

Inter-rater reliability was examined by dividing each sample into 30 s time frames and then comparing the number of stutters identified across the time frames for two independent raters. An intra-class correlation coefficient of .84 was obtained using a one-way independent group random effect model of analyses (as described by Howell, 2007) which shows judgements were both satisfactorily correlated and in agreement. Intra-rater reliability was calculated using the same method and an intra-class correlation coefficient of .77 was obtained, demonstrating satisfactory correlation and agreement within each rater’s judgements.

2.2.5. Typography

Each stuttering event from each sample was subsequently coded as one of two stutter types, a repetition (collapsing across word and part-word repetitions), or a prolongation/block, with the support of a visual display of the acoustic speech signal using the program Prat (Boersma & Weenink, 2007). The visual representation of the acoustic signal, both the speech waveform and a wide-band spectrogram, was used to assist perceptual judgements following guidelines described by Czyzewski, Kaczmarek, and Kostek (2003). The percentage of word and part-word repetitions (%WPWR) out of the total number of stuttering events was then calculated. Inter-rater reliability was evaluated by calculating the percent agreement of typography category (repetitions vs. prolongations/blacks) for one randomly selected sample for two independent raters. This sample contained a range of fluency types. Raters agreed on typography category for 88% of stutters. Intra-rater reliability was obtained using the same method and calculated to be 86% in agreement for each rater. While some stuttering events are ambiguous in terms of typography, the reliability analysis suggests there is general agreement for the majority of stutters.

2.3. Procedure

Ethics approval was obtained for this study through Curtin University’s Human Research Ethics Committee. All adolescents and their parents provided informed consent prior to participating in the study. Participants were tested individually in a quiet room at the Curtin University Stuttering Treatment Clinic. An initial 10 min screening conversation was used to assess the presence of stuttering behaviours in the fluent control participants. A 10 min conversation sample (based on a series of open-ended questions designed to elicit language and establish rapport) was obtained for participants who stuttered and digitally recorded using a Creative MuVo digital media player. All participants were asked to complete the FNE, STAI and OASES-T questionnaires and an information sheet (which outlined any history of previous stuttering treatment and pharmacological intervention for anxiety disorders). The order of presentation of questionnaires was counterbalanced to control for order effects. Participation was voluntary and participants were neither paid nor compensated for their time.

3. Results

An alpha level of .05 was used for all statistical tests as per Rom's sequentially rejective method (Wilcox, 1996). Univariate and multivariate outliers were identified and removed following recommendations of Tabachnick and Fidell (2007) to prevent extreme cases having an undue influence on the means and correlations. One adolescent from the group who stuttered was removed from all further analyses because the participant demonstrated non-compliance and
Table 1
Means (M), standard deviations (SD), ranges, p values and effect size (as indexed by Cohen’s d) for Stuttering and Control Participant Groups for FNE, STAI (state and trait), OASES-T section three (excluding outliers) and age in years.

<table>
<thead>
<tr>
<th></th>
<th>Stuttering (n = 19)</th>
<th>Control (n = 18)</th>
<th>p value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>Range</td>
<td>M</td>
</tr>
<tr>
<td>FNE</td>
<td>12.4</td>
<td>5.9</td>
<td>3-23</td>
<td>7.8</td>
</tr>
<tr>
<td>STAI Trait</td>
<td>43.4</td>
<td>6.3</td>
<td>24-59</td>
<td>30.6</td>
</tr>
<tr>
<td>STAI State</td>
<td>34.2</td>
<td>7.1</td>
<td>21-49</td>
<td>26.4</td>
</tr>
<tr>
<td>OASES-T:S3</td>
<td>56.0</td>
<td>9.3</td>
<td>40-73</td>
<td>29.7</td>
</tr>
<tr>
<td>%SS</td>
<td>6.2</td>
<td>5.2</td>
<td>11-18</td>
<td>–</td>
</tr>
<tr>
<td>%WPWR</td>
<td>26.0</td>
<td>25.8</td>
<td>1-100</td>
<td>–</td>
</tr>
<tr>
<td>Age</td>
<td>14.3</td>
<td>2.3</td>
<td>11-18</td>
<td>14.5</td>
</tr>
</tbody>
</table>

Note. FNE = Fear of Negative Evaluation; STAI = State and Trait Anxiety Inventory; OASES-T:S3 refers to section three of the overall assessment of speaker’s experience of stuttering; %WPWR = percentage of word and part word repetitions.

a non-willingness to complete the questionnaires appropriately. In addition, the participant’s results were 2.80 standard deviations below the group mean on the OASES-T and trait anxiety measures. One adolescent from the control group was also removed as a univariate outlier with a z-score of 2.30 on the trait anxiety measure. No multivariate outliers were found based on Mahalanobis distances. Descriptive statistics were computed for the FNE, OASES-T:S3, STAI, %SS, %WPWR and age, and are shown in Table 1.

Mean scores for both groups on the FNE were below the mean scores of 14.0 (for males) and 16.1 (for females) reported in normative data for university students (Watson & Friend, 1969). For the adolescents who stuttered, their trait anxiety mean was above the mean in the normative data sample.

Twelve percent of participants who stuttered demonstrated mild (0–2%SS) stuttering behaviour, 47% demonstrated moderate (2–5%SS) and 41% demonstrated severe (>5%SS), as classified by Guitar (2005). On average the adolescents who stuttered showed more prolongations and blocks than repetitions.

Independent samples t-tests showed that adolescents who stuttered demonstrated a greater fear of being negatively evaluated, t(33) = 2.53, p = .02, significantly higher mean state anxiety score, t(33) = 3.58, p < .01, and a significantly higher mean trait anxiety score, t(33) = 6.05, p < .01 than their fluent peers. Significant differences were also found between the two group means on the OASES-T:S3, t(33) = 8.98, p < .01.

3.1. Correlations between variables

Pearson correlations were computed to examine the relationship between measures within each group (see Table 2). Within the group of adolescents who stuttered, statistically significant correlations were obtained between the FNE and trait anxiety scores, r(18) = .54, p = .02; OASES-T:S3 and trait anxiety scores, r(18) = .60, p = .01; and OASES-T:S3 and state anxiety scores, r(18) = .47, p < .05. The correlation between trait and state anxiety scores was significant, r(18) = .66, p < .01. Within the cohort of control participants, significant correlations were obtained between the FNE and trait anxiety scores, r(17) = .64, p < .01, and also between state and trait anxiety scores, r(17) = .71, p < .01. No other correlations were significant.

As also shown in Table 2, none of the psychosocial variables correlated significantly with %SS or %WPWR. A partial correlation with %SS as a control variable also showed no significant association between %WPWR and the FNE, state, trait and OASES-T:S3 scores.

Standard multiple regression analyses were used to further evaluate whether combinations of the psychosocial variables were related toward stuttering severity and typography. As a group, the measures were not significantly associated with severity (multiple R = .46) or typography (multiple R = .31). They explained 21% of the variance in severity, F(4,11) = .75, p = .58, and 10% of the variance in typography, F(4,11) = .30, p = .87. Standardised beta slope coefficients, t values and corresponding significance levels are shown in Table 3 for both severity and typography regression analyses. These results confirm that individual predictors do not contribute significant unique variance to either severity or typography of stuttering in adolescents and that in combination the psychosocial measures remain independent of stuttering severity and typography.
Table 2
Results from the correlations between variables in stuttering and control participant groups.

<table>
<thead>
<tr>
<th>Variable</th>
<th>FNE</th>
<th>STAI Trait</th>
<th>STAI State</th>
<th>OASES-T:S3</th>
</tr>
</thead>
<tbody>
<tr>
<td>%SS</td>
<td>Adolescents who stutter (n = 18)</td>
<td>-.21</td>
<td>.09</td>
<td>.04</td>
</tr>
<tr>
<td>%WPWR</td>
<td>.13</td>
<td>-.10</td>
<td>-.09</td>
<td>-.16</td>
</tr>
<tr>
<td>FNE</td>
<td>.54*</td>
<td>.34</td>
<td>.66**</td>
<td>.60**</td>
</tr>
<tr>
<td>STAI Trait</td>
<td>-</td>
<td>-</td>
<td>.71**</td>
<td>.08</td>
</tr>
<tr>
<td>STAI State</td>
<td>-</td>
<td>-</td>
<td>.47*</td>
<td></td>
</tr>
<tr>
<td>OASES-T:S3</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Adolescents who did not stutter (n = 17)</th>
<th>FNE</th>
<th>STAI Trait</th>
<th>STAI State</th>
<th>OASES-T:S3</th>
</tr>
</thead>
<tbody>
<tr>
<td>%SS</td>
<td>-</td>
<td>.64**</td>
<td>.07</td>
<td>-.05</td>
<td></td>
</tr>
<tr>
<td>%WPWR</td>
<td>STAI Trait</td>
<td>-</td>
<td>.71**</td>
<td>.08</td>
<td></td>
</tr>
<tr>
<td>FNE</td>
<td>-</td>
<td>-</td>
<td>.24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>STAI State</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OASES-T:S3</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .05
** p < .01

Table 3
Standardised beta coefficients, t-values and significance for predictors used in multiple regression analyses for severity and typography.

<table>
<thead>
<tr>
<th>Variable (%SS)</th>
<th>Predictor</th>
<th>Standardised beta coefficient</th>
<th>t value</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>FNE</td>
<td>-.49</td>
<td>1.42</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td>STAI Trait</td>
<td>.26</td>
<td>0.38</td>
<td>.57</td>
</tr>
<tr>
<td></td>
<td>STAI State</td>
<td>-.15</td>
<td>0.42</td>
<td>.68</td>
</tr>
<tr>
<td></td>
<td>OASES-T:S3</td>
<td>.38</td>
<td>1.12</td>
<td>.28</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable (%WPWR)</th>
<th>Predictor</th>
<th>Standardised beta coefficient</th>
<th>t value</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typography</td>
<td>FNE</td>
<td>.34</td>
<td>0.93</td>
<td>.37</td>
</tr>
<tr>
<td></td>
<td>STAI Trait</td>
<td>-.20</td>
<td>0.42</td>
<td>.68</td>
</tr>
<tr>
<td></td>
<td>STAI State</td>
<td>.02</td>
<td>0.06</td>
<td>.96</td>
</tr>
<tr>
<td></td>
<td>OASES-T:S3</td>
<td>-.20</td>
<td>0.56</td>
<td>.59</td>
</tr>
</tbody>
</table>

Note. FNE = Fear of Negative Evaluation; STAI = State and Trait Anxiety Inventory; OASES-T:S3 refers to section three of the Overall Assessment of Speaker’s Experience of Stuttering; %WPWR = Percentage of word and part word repetitions. %SS acted as a control variable in %WPWR correlations.

4. Discussion

The results obtained in this study demonstrate significant differences between anxiety and communication attitude in adolescents who do and do not stutter. Adolescents who stuttered reported statistically significantly higher levels of state and trait anxiety, a greater fear of being negatively evaluated and greater difficulty with functional communication than those who did not stutter. The measures of trait and state anxiety were significantly correlated with perceived difficulty with functional communication for the adolescents who stutter, but these same measures were not correlated for controls. The findings, however, failed to confirm any association between both anxiety and the degree of difficulty with functional communication and the surface features of stuttered speech behaviour as measured by stuttering severity and typography. Further replication of these results with a larger sample size is recommended. The following discusses the theoretical and practical implications of these findings.

4.1. Anxiety in adolescents who stutter

The finding that adolescents who stuttered displayed significantly higher trait, state and social anxiety than did control participants is consistent with results obtained by Blood et al. (2007), whereby significant differences were reported on a generalised anxiety scale between adolescent participants who did and did not stutter. This suggests that adolescents who stutter are at risk of developing higher levels of anxiety than their fluent peers. One important finding
in the present study is that increased levels of anxiety in adolescents who stutter may stem from a generalisation of speech-associated negative emotion due to the significant associations found between communication difficulty and anxiety in this study.

These findings obtained during adolescence contribute toward an important developmental period for individuals who stutter, especially with regards to trait anxiety. It has been suggested that trait anxiety is a permanent personality characteristic (Endler et al., 1991). Craig and Hancock (1996) failed to find trait differences between children who stuttered relative to control participants, however it has been reported that adults who stutter do exhibit such differences (Craig et al., 2003). Trait anxiety may therefore be dynamic and age-dependent in individuals who stutter, and perhaps it is the experience of being chronically negatively evaluated that contributes to this phenomenon (see also, Davis et al., 2007; Messenger et al., 2004). The finding that adolescents who stutter have higher levels of trait, state and social anxiety than their fluent peers has important implications when the developmental path of these anxieties is considered. If the results of this study in adolescents were found to be robust in younger children, it would be incautious to assume that anxiety and a fear of being negatively evaluated only apply to chronic stuttering (Messenger et al., 2004).

4.2. Attitude toward communication in adolescents who stutter

It was hypothesised that, if adolescents who stuttered demonstrated greater anxiety than those that did not stutter, this greater anxiety would be positively associated with a reported difficulty in functional communication due to the chronic negative evaluation of speech that has occurred over time. This was confirmed by the finding that levels of state, trait and social anxiety were significantly higher in adolescents who stuttered and, in addition, that trait and state anxiety measures were statistically significantly and positively correlated with self-reported difficulty with functional communication amongst the adolescents who stuttered. There was no similar association between anxiety and self-reported difficulty with functional communication amongst the controls. A negative attitude toward communication is thought to perpetuate social anxiety among people who stutter (Blood et al., 2001; Davis et al., 2007; Kraaimaat et al., 2002; Messenger et al., 2004). It has been posited that a poorer attitude to communication may be the result of conditioning that occurs when a neutral communication activity is associated with negative and aversive consequences (Daly, McCraksey, Ayres, Hopf, & Ayres, 1997). Given the negative evaluation that has been associated with stuttering over time, it is not surprising that results from this current study indicate that adolescents who stuttered reported higher levels of social anxiety and therefore greater difficulty with functional communication.

4.3. Communication attitude and trait anxiety

Given the results of this study, it is possible that trait anxiety plays a particularly significant role in the stuttering disorder. Trait anxiety was the only measure deemed above average in comparison to normative data, and the relationship between functional communication difficulty and anxiety presented particularly strongly with trait anxiety amongst adolescents who stutter in comparison to their fluent peers. The positive correlation obtained supports an association between communication attitude (potentially related to stuttering) and intrinsic anxiety levels amongst adolescents who stutter. Trait anxiety has been found to be significantly higher in adults who stutter than those who do not (Craig et al., 2003). Given the many factors that impinge on anxiety levels, this relationship may be a worthwhile focus for future research.

4.4. Fear of being negatively evaluated

Menzies et al. (1999) suggest that it is essential to include expectancy of harm measures in studies of the role of anxiety in individuals who stutter. However, results from this current study suggest that the fear of being negatively evaluated does not contribute uniquely to the profile of adolescents who stutter because it correlates significantly with trait anxiety measures. There was no significant correlation between FNE, state or OASES-T:S3 measures in adolescents who stuttered. In addition, the effect size reported for the FNE was lower than the effect sizes obtained for state and trait anxiety measures. Thus, results do not support the argument that FNE may be a more focussed way of measuring anxiety in adolescents who stutter (as opposed to traditional trait or state anxiety measures) and suggest that an interaction between different components of anxiety contributes to its manifestation (Endler et al., 1991).
The lack of significant correlation found between the FNE, state anxiety and OASES-T (section three) might also be related to the sensitivity of the FNE scale used. Participants responded to the FNE using a binary true/false response method, whereas Likert-style scales were used for the other measures providing a greater range for responses. Increased sensitivity may, therefore, arise from using Likert-style rather than dichotomous response options (Collins, Westraa, Dozoisb, & Stewart, 2005).

4.5. The role of social anxiety in severity and typography

Although it is incalculable to assume the results of this study can be extended to address whether anxiety mediates stuttering or vice versa, results are of interest clinically and suggest further experimental research is needed in this area. The finding that anxiety and attitude toward communication were independent of severity or typography in correlation and regression analyses does not support the mediating role of anxiety in exacerbating stuttering behaviours (Conture et al., 2006; Davis et al., 2007; Messenger et al., 2004). It is possible that rather than playing a mediating role in stuttering, increased anxiety among adolescents who stutter is, in fact, a by-product of the stuttering disorder regardless of its surface manifestation. Blood et al. (2007) also found no significant correlation between a standard anxiety measure and stuttering severity. The present study therefore supports their findings and suggests that an association is not observed even when stuttering typography is taken into account.

It is also possible, however, that a relationship exists between these variables that was not found in this study (see, e.g., Blood et al., 2001). For example, what adolescents focus on in terms of the surface manifestation of their own speech, and what may therefore impact on their attitude toward functional communication and/or level of anxiety, may not relate directly toward the surface symptomatology of stuttering as reflected in %SS and %WPWR. The context in which stuttering occurs, and how well that can be managed, for example, was not considered in the present study and may have greater significance for adolescents than simple measures of stuttering frequency and typography. It is possible that speech-related anxiety suppressed a true representation of stuttering surface features. Investigation of alternative approaches to obtaining representative measures of stuttering severity and typography, perhaps in more ecologically valid conversational contexts than the clinic and of greater syllable length, would also be of value to further examine potential relationships between psychosocial variables and stuttered speech (as suggested by Block, Onslow, Packman, Gray, & DaCakis, 2005). More detailed speech analyses of stuttering rates and/or other methods of evaluating severity are needed to explore the relationship between stuttering and anxiety more closely.

4.6. Anxiety and treatment status

Craig et al. (2003) suggest that individuals who stutter who have sought speech pathology treatment have higher levels of anxiety when compared to those who have not. Alternatively, however, Craig (1994) proposes that even moderately successful treatment may reduce anxiety levels and negative expectancies. Menzies et al. (1999) propose the inclusion of both treated and untreated participants in a single sample may be confounding. Given that only adolescents who had been enrolled in treatment for their stuttering participated in this study and 68% were currently enrolled, the results allow for examination of anxiety in the clinical population of adolescents who stutter. If, as suggested by Craig (1994), this current sample has lower anxiety due to treatment effects, it is important to consider the potentially greater prevalence of anxiety in the wider population of adolescents who stutter who are both treated and untreated. Conversely, results may be overestimating the anxiety levels in this population. An accurate examination of treatment-related factors in individuals who stutter (such as type, length and frequency) should be considered in future research to account for possible treatment effects and to examine this relationship more precisely.

4.7. Clinical management of adolescents who stutter

The primary interests of speech pathologists who manage the stuttering disorder include its aetiology, treatment and prognosis. The finding that adolescents who stutter have higher levels of trait, state and social anxiety and greater difficulty with functional communication associated with this anxiety has potential implications for each of these. The current results suggest a place for anxiolytic treatments (such as desensitisation) in the management of adolescents who stutter, particularly for speech-specific difficulties or in individual cases where anxiety is debilitating. Cognitive-behavioural procedures for stuttering need to be examined more thoroughly in light of the current view of the construct.
of anxiety and these results (see also, Menzies et al., 1999). In addition, the significant correlation found between the communication attitude and anxiety measures argues for the use of anxiety-reduction therapy as a way of minimising functional communication limitations. Lincoln, Onslow, and Menzies (1996) suggest that, in Australia, the majority of speech-language pathologists regularly include anxiety management strategies in the treatment of their adult clients. The findings from this current study suggest that a multidisciplinary approach to intervention is encouraged for the adolescent who stutters, such as the behavioural-cognitive treatment developed by Blood (1995). The finding that stuttering severity and typology were independent of anxiety and communication attitude also challenges the current clinical practice whereby individuals with more severe stuttering are given a preference in therapy. It is recommended that a flexible and holistic view to treatment priority and choice be adopted in management of adolescents who stutter, as it is clear that clients may intrinsically differ in their symptoms and needs regardless of the surface features of their speech.

In summary, adolescents who stutter were found to have greater trait, state and social anxiety associated with greater difficulty in daily or functional communication than their fluent peers. These results are both clinically and theoretically significant and advocate the need for a multidisciplinary perspective when managing adolescents who stutter. The results highlight stuttering as a disorder that potentially features psychosocial conflict regardless of its surface features.

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Appendix A. CONTINUING EDUCATION

Social anxiety and the severity and typology of stuttering in adolescents.

QUESTIONS

1. In the past, stuttering has been associated with:
   a. suppressed anger
   b. approach–avoidance conflicts
   c. anxiety
   d. all of the above
   e. none of the above

2. Surface symptomatology of stuttering behaviour in this paper includes:
   a. frequency and typology
   b. typography
   c. severity and frequency
   d. self-perceived attitude towards communication
   e. all of the above

3. According to current research, anxiety in adolescents who stutter may be more directly manifested in:
   a. trait anxiety
   b. state anxiety
   c. fear of being negatively evaluated
   d. fear of communication
   e. none of the above

4. The results of the current study showed that, in adolescents who stutter:
   a. increased levels of anxiety may stem from speech-associated negative emotion
   b. communication in daily situations is difficult due to anxiety
   c. the more anxious you are, the worse your stuttering is
d. none of the above
e. all of the above

5. The clinical implications of this study include:
   a. treatment priorities should be based only on the severity of a client's speech
   b. there is a role for treatment of anxiety in managing adolescents who stutter
   c. stuttering will reduce by treating anxiety in adolescents who stutter
d. none of the above
e. all of the above

References


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Paper 3

The Influence of Parenting Styles and Attachment in School-Aged Children who Stutter.

Parenting styles and attachment in school-aged children who stutter

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ABSTRACT

Parental input has been described as influential in early childhood stuttering yet the exact nature of this influence remains equivocal. The present study aimed to examine whether quantitative measures of parenting styles, parent and peer attachment patterns, and parent- and self-reported child behavior could differentiate between school-aged children who stutter (CWS) (n = 10) and their fluent peers (n = 10). In addition, qualitative individual semi-structured interviews with all CWS were conducted to gain insight into their life experiences and reflections in relation to stuttering. The interviews were classified into ancillary themes of school, peers and parents. Quantitative findings revealed that CWS perceived their parents with significantly lower attachment, particularly in relation to trust, and parents of CWS perceived their children with significantly higher maladjustments than fluent counterparts. Qualitative themes emerged pertaining to attitudes, perceptions and relationships with teachers, peers and parents, with consistent experiences of teasing and bullying reported as a consequence of the stutter. The majority of participants recounted frustration with the nature in which their parents attempted to remediate their stuttering. Collectively, these findings highlight imperative management considerations for school-aged CWS and their parents. The usefulness of quantitative and qualitative research paradigms is also emphasised.

Learning outcomes: The reader will be able to: (1) identify themes associated with the impact a childhood stutter has on parent and peer relationships; (2) identify how the quality of the parent–child relationship is influenced by parenting styles and attachment; and (3) discuss the clinical implications of the results for children who stutter and their families.

1. Introduction

The development of a stuttering disorder is viewed as complex and multi-factorial, and is increasingly perceived to be influenced by environmental, genetic and constitutional factors (Guitar, 2003; Yaruss & Quesal, 2006). Parents have been recognised as influencing stuttering in some way; however the nature of this influence remains equivocal. Johnson's (1942) diagnostroglyphic theory proposed stuttering to be caused by parents’ abnormal reactions to, and inaccurate labelling of normal dysfluencies (Bloodstein & Bernstein Ratner, 2008). As a result, therapy was aimed at modifying the interactions and responses of parents of children who stuttered (CWS) (Siegel, 1998). While this notion of causality is debatable, parental input is often considered an essential component in the amelioration of stuttering (Bernstein Ratner, 2004; Finn & Cordes, 1997). Speech pathologists working with paediatric clients often rely on parents to actively engage in the therapeutic process, in order to facilitate successful fluency outcomes.

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1.1. Parenting styles and parent–child attachment concepts

1.1.1. Parenting styles

Parenting style and parent–child attachment (PCA) are two discrete, but closely related concepts. Parenting style refers to patterns of childrearing evolved from parents’ reactions towards their child. Conversely, PCA is concerned with the dyadic emotional bond that emerges between parent and child (Bell & Calkins, 2000; Desjardins, Zelenski, & Coplan, 2008). Parenting style is commonly viewed along two dimensions: responsiveness and demandingness (e.g., Desjardins et al., 2008; Gullone & Robinson, 2005; McGarvey, Kryzhanovskaya, Koopman, Walte, & Canterbury, 1999; Wilhelm, Niven, Parker, & Hadzi-Pavlovic, 2005). Responsiveness, or care, refers to the degree of warmth between parent and child, while demandingness, or control, refers to the extent of disciplinary practice and behavioural standards parents set for their child (Carlo, McGinley, Hayes, Batenhorst, & Wilkinson, 2007). Based on these two dimensions, a taxonomy of four main parenting styles has been identified which include: authoritarian (high demandingness, low responsiveness), authoritative (high on both constructs), permissive (low demandingness, high responsiveness) and neglectful (low on both constructs) (e.g., Luther, 2007; McGillicuddy-De Lisi & De Lisi, 2007; Slicker, 1998).

1.1.2. Parent–child attachment

According to Bowlby’s (1969) ethological-evolutionary attachment theory (e.g., Bowlby, 1969, 1970, see also Ainsworth, 1979) human beings possess an adaptive system in which infants seek proximity with their caregivers for survival and protection. When danger recedes, infants explore their environment freely to gain new knowledge and experiences. Over time, an “internal working model” (Leveridge, Slootenberg, & Bessley, 2005, p. 578) is formed so that the child develops knowledge about self and attachment figures. This model forms the foundation from which the child interprets and anticipates the behaviours of others. This inner representation is thought to be flexible in childhood, but becomes increasingly resistant to change in adulthood (Leveridge et al., 2005).

Four main attachment styles, based on infants’ responses to their caregivers, have evolved from Ainsworth’s Strange Situation Assessment (Ainsworth, Blehar, Waters, & Wall, 1978; Ainsworth, 1979). These include: secure, avoidant, ambivalent-resistant and disorganised/disoriented. Secure attachment results when the child is able to use significant attachment figures as a safe base to explore their environment, yet are comforted by physical contact when upset. Avoidant attachment figures are characterised by the child’s lack of distress when separated from the attachment figure. The child also avoids interacting with the caregiver. Ambivalent-resistant infants tend to cry when separated from their caregivers, yet continue to cry and are unlikely to be easily soothed even when comforted. Disorganised/disoriented infants do not respond systematically to their caregiver. These infants tend to seek proximity yet lean away from their attachment figure at the same time (Ainsworth, 1979; Waters, Hamilton, & Weinfield, 2000; Yoo, Kim, Shin, Cho, & Hong, 2006).

Motivated by the research into infant attachment, Mary Main and colleagues (1985) addressed adult attachment which led to the development of the Adult Attachment Interview (AAI). The language and coherence of recounted relationships reflected by the adult in the interview is said to reveal mental representations of attachment experiences (Van Ijzendoorn, 1995). Building on Bowlby’s theory, Bartholomew and Horowitz (1991) derived a two-dimensional model to systematically describe adult attachment. The two dimensions are models of self (degree of positivity towards self) and models of others (degree of positive towards others), giving rise to four attachment patterns: secure, anxious, preoccupied, dismissive, and unresolved/disorganised. Autonomous adults view their attachment experiences as influential and have a positive viewpoint of others. Disorganised/disoriented adults view their attachment experiences as problematic and have a negative viewpoint of themselves and others. These adults are comfortable with intimacy. Preoccupied attachment results when adults hold positive viewpoints of others, but not of themselves. These individuals are confused about their past experiences and they tend to strive for self-acceptance through continuous efforts to please others such as their parents. Dismissive adults are characterised by positive viewpoints of themselves, however, are dismissive of others and tend to avoid intimacy by maintaining independence. Lastly, unresolved or disorganised attachment is characterised by negative viewpoints of both self and others. Such adults are fearful of intimacy and tend to avoid social situations (Bartholomew and Horowitz, 1991; Griffin & Bartholomew, 1994; Yoo et al., 2006). These terminologies have also been described in Target, Fonagy, and Shmueli-Goetz (2003) Child Attachment Interview, an attachment measure in middle childhood (8-13 years), derived from the AAI.

Previous research in stuttering disorders has emphasised facets of PCA, such as temperament, parental speech characteristics, communicative styles, attitudes and knowledge regarding stuttering (e.g., Crowe & Cooper, 1977; Fowlie & Cooper, 1978; Langlois, Hanrahan, & Inouye, 1988; Meyers & Freeman, 1983). These facets of PCA may reflect complex interactions between the stuttering behaviours and PCA constructs (Seery, Watkins, Mangelsdorf, & Shigeto, 2007).

1.2. Nature and evidence of current research for children who stutter

School-aged children (typically aged 6-12 years old) have unique psychosocial, affective and behavioural developmental patterns that are distinct from preschoolers and adolescents. Moving towards adolescence, these children show increasing independence from their parents, and simultaneously, increasing dependence on their peers for social, emotional and academic development (Conture & Guitar, 1993). School-aged children also begin to demonstrate preliminary notions about their sense of self and personal identity, as a reflection of their growing awareness of future socialisation roles. To achieve this successfully, social competence, or skilled communication in social behaviours, plays a substantial role (La Greca & Lopez, 1998). Consequently, the disruptive nature of stuttering may encumber the way some school-aged CWS participate in
social discourse. The duration of the experience that the school-aged CWS has had with stuttering is longer than that for a preschooler, but not as chronically advanced as those experiences for adolescents who stutter (Conture & Guitar, 1993; Schwartz, 1993). The growing demands placed on the school-aged CWS, with expectations for increasingly adult-like social, communicative and academic competence, may exacerbate communication anxiety for some. Therefore, the quality of parent–child relationships might play an important role in providing the child with models of social competence, coping strategies and motivational orientation (Bukatko & Daehler, 2004).

Evidence from psychology and psychiatry has suggested that optimal parenting equips children with effective social adjustment and coping resilience, amongst other facets of positive development (Engels, Finkenauer, Dekovic, & Mees, 2001; Hoeckma, Oosterlaan, & Schipper, 2004; McGillivray-De Lisi & De Lisi, 2007; Padilla-Walker, 2007). A hallmark longitudinal study found that securely attached children emerged as more enthusiastic and with better problem-solving skills than other children without the same degree of attachment (Ainsworth, 1979). Dismissively attached children were found to be more easily frustrated and less persistent in problem-solving skills. Yet, despite the pervasive influence of parenting, no previous research into attachment construct in relation to school-aged CWS and their parents could be found. A preliminary study by Woods, Shearsby, Onslow, and Burnham (2002) examined attachment and outcomes of the Lidcombe program (an operant-based stuttering therapy program) in preschool children. No systematic relationship was detected and the Lidcombe program was concluded to be safe with no adverse psychological effects. The degree of influence of parent-child relations on school aged children who stutter remains uncertain.

In light of these findings, the question remains as to whether distinctive parenting patterns and PCA exist within a population of school-aged CWS compared to their fluent peers; and whether qualitatively, further insights can be gained regarding the attitudes, perceptions and relationships that CWS have with their teachers, peers and parents. Specifically, this study aimed to determine if: (a) particular parenting styles (care and control constructs) differentiate between CWS and their fluent peers; (b) particular parent and peer attachments differentiate CWS and fluent children; (c) self-reported child social behaviour can differentiate CWS from fluent children; (d) parent-reported child social behaviour can differentiate CWS from fluent children; and (e) qualitative interviews can provide further insight with respect to the perceptions, attitudes and social relationships of CWS to parents and peers.

2. Method

2.1. Participants

Twenty school-aged participants between the ages of 8 and 14 years and their parents were participants in this study. Participants who stuttered were 10 CWS, 9 males and 1 female (ranging from 8; 6–14; 2 years, M = 11.5 years, SD = 1.9) and were age matched as a cohort to a normally fluent control group of 10 participants, 9 males and 1 female (ranging from 8; 9–12; 10 years, M = 11.7 years, SD = 1.9). Parents of CWS and those of the fluent cohort were 8 mothers and 2 fathers respectively for each group.

Participants who stuttered were invited from the Curtin University Stuttering Treatment Clinic (Perth, Western Australia). One of the 10 CWS lived in a rural area approximately 150 km away from Perth, Western Australia, while all other participants resided in the Perth metropolitan region. Fluent control participants were recruited through staff and students contacts in the School of Psychology and Speech Pathology, Curtin University.

All 20 families reported English as their first language. Caregivers of CWS reported onset of stuttering in their child between the ages of 2 and 4 years. All caregivers of CWS also reported the stutter as a priority of concern with no comorbidity issues, based on parental reports from case history taken by the examiners.

2.2. Measures

2.2.1. Quantitative

2.2.1.1. Stuttering severity. The clinical diagnosis of stuttering and the stuttering severity measures for the 10 CWS were determined by rated speech samples obtained from digitally recorded interviews within the clinic setting. The criteria for participant eligibility for the CWS group included the facts that participants had a reported stuttering disorder by both participant and examiner as well as demonstrated a minimum of at least 3% syllables stuttered in speech samples obtained by the examiner. A ZOOM H4n audio recording device was used to record the interviews. Two experienced speech pathologists rated the interviews based on a minimum of 2000 syllables with at least 15 min of real time accrued speech. An Easy Rater Intelligent Instrument was used to calculate the percentage of syllables stuttered (%SS), with a higher %SS reflecting more severe stuttering behaviours. Guitar (2006, p. 191) classified stuttering on a severity rating scale with mild (0–2%), moderate (2–12%), severe (12–25%) and very severe (>25%). Four CWS demonstrated mild-moderate stuttered behaviours and the remaining six who stuttered demonstrated moderate-severe stuttered behaviours (Guitar, 2006). The %SS for the 10 CWS ranged from 3.2% to 13.9% (M = 8.1; SD = 4.5).

All ten recorded interview samples were analysed to determine intra- and inter-rater reliability. Pearson's product-moment correlation coefficients were then calculated. Pearson's r was found to be .96 between raters, while Pearson's r was reported .97 within raters, demonstrating satisfactory inter- and intra-rater reliability.
Rated speech samples for the fluent control participants were analysed by the primary researcher with no examples of stuttered speech or abnormal dysfluencies identified for any participant. In addition, parental reports were obtained for each control participant with no fluency concerns outlined.

2.2.1.2. Parental Bonding Instrument. The Parental Bonding Instrument (PBI; Parker, Tupling, & Brown, 1979) has been administered to individuals 16 years and over to evaluate retrospectively the subjective experience of being parented. Participants evaluate their mother (Mo) and father (Fa) separately. The PBI is consistently used to evaluate parenting style across clinical and non-clinical populations (Wilhelm et al., 2005). Participants are required to respond to a series of 25 statements, measured on a 4-point Likert scale ranging from very like to very unlike (Hertz & Gullone, 1989). Two dimensions of perceived parental factors, care and control, are evaluated by tabulating then classifying the scores into four different parenting style quadrants in accordance to the cut off scores obtained (Parker et al., 1979). The four quadrants are affectionate constraint (high care and high control), affectionless control (low care and high control), optimal (high care and low control) and neglectful (low care and low control). Recent studies have demonstrated the PBI to be successful with younger children with the wording of the statements changed from retrospective reflections to the present (Gullone & Robinson, 2005; Hertz & Gullone, 1989). The modified instrument was administered in this study.

2.2.1.3. Inventory of Parent and Peer Attachment – Revised. Each child completed the Inventory of Parent and Peer Attachment – Revised questionnaire (IPPA-R; Gullone & Robinson, 2005). Based on Bowlby’s (1969) attachment theory, the IPPA-R measures a child’s psychological security from measurements of their reported relationship responses regarding parents and peers. Originally developed by Armsden and Greenberg (1987) for adolescents, the IPPA-R has been adapted by Gullone and Robinson (2005) for use with children and adolescents aged 9–15 years. This age range was deemed appropriate for the age range of the children in this study of between 8 and 14 years. This 53-item questionnaire consists of a 3-point Likert response scale (scored 1–2–3) in which 30 questions have been simplified to promote comprehension (see Gullone & Robinson, 2005 for more details). The three constructs entitled trust, communication and alienation are calculated to form a total score for parent and peer attachment separately, with a higher score reflecting more optimal attachment. The IPPA-R has been found to have adequate to good internal consistency across its three subscales (Cronbach’s alpha coefficients of .60 to .88), with significant correlations to the PBI (Gullone & Robinson, 2005).

2.2.1.4. Strengths and Difficulties Questionnaire. Each participant also completed a Strengths and Difficulties Questionnaire (SDQ; Goodman & Scott, 1999). The SDQ-Parent and SDQ-Self consist of 25 items designed to assess for a child’s (aged between 4 and 17 years) internalising and externalising behaviours, as well as social adjustment.

The SDQ has been found to reliably identify high-risk children within the community (Goodman & Scott, 1999). Several versions currently exist for parents, teachers and child to report on a child’s behaviour, with only parents completing the SDQ on children aged 4–10 years of age. However, recent studies have confirmed children as young as 7 years can successfully and reliably complete the Parent of Teacher4–10 version to rate themselves (Mellor, 2004).

In this study, different versions of the SDQ were used dependent on the child’s age. Children between 8 and 10 years completed the Parent4–10 version, while children aged 11 years and above completed the Self11–17 version. The parents of each child also completed the SDQ Parent version. All versions consisted of 25 items. The cut off scores in which children are distinguished between normal, borderline and abnormal adjustment vary across the parent (SDQ-Parent) and self reported (SDQ-Self) versions (Mellor, 2004). A higher total difficulties score reflects greater difficulties with adjustment. The test–retest reliability coefficients (measuring total difficulties) of the Parent version have been reported as .81 and the Self11–17 version, as .79. The long-term stability of the Parent and Self11–17 versions has been reported as .72 and .62, respectively (Achenbach et al., 2008).

2.2.2. Qualitative

2.2.2.1. Interviews. All 10 CWS were invited to attend an interview with the primary author. The focus of each semi-structured interview was based around the topic of stuttering, with broader questions aimed at eliciting information on ancillary themes such as school, peers and parents. Standardized questions and probes were prepared ‘a priori’, however there was flexibility in questioning throughout the interview. These questions were derived from narrative therapy research, which encouraged the participants to use their own words to describe their life experiences (Di Gallo, 2003; Semmler & Williams, 2000). Each interview ranged from 30 to 75 min and averaged 40 min in duration.

2.2.2.2. Transcript analysis procedure. Each recorded interview was transcribed verbatim by the principal author of this study and analysed using QSR NVivo 8 qualitative analysis software. The interview transcripts were analysed and sub-themes identified which were broadly based around the themes of school, peers and parents (Strauss & Corbin, 1990). The process of analysis included open, axial and selective coding to develop a set of comprehensive themes and sub–themes (Liampitpong & Ezzy, 2005). Multiple sub-themes were assigned to each transcription and after these initial sub-themes were agreed upon, a subset of text was selected for analysis of inter-rater reliability. Three researchers agreed on coding of themes and sub-themes in 91 percent of the passages. Reiterative comparisons within and across groups were made. Emergent themes and sub-themes were examined and agreed upon by all three researchers.
Table 1
Descriptive statistics for the parent bonding instrument care and control constructs for children who stutter and fluent controls.

<table>
<thead>
<tr>
<th></th>
<th>CVS</th>
<th>Fluent</th>
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<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Mo care</td>
<td>31.1</td>
<td>2.3</td>
</tr>
<tr>
<td>Mo control</td>
<td>13.2</td>
<td>5.4</td>
</tr>
<tr>
<td>Fa care</td>
<td>28.8</td>
<td>5.2</td>
</tr>
<tr>
<td>Fa control</td>
<td>13.0</td>
<td>5.9</td>
</tr>
</tbody>
</table>

Note. Mo, mother PBI ratings; Fa, father PBI ratings.

To promote credibility and reduce the possibility of researcher bias, several procedures were adopted (Heine, Packman, Osmolow, & Quine, 2008). Interview facilitators familiarised themselves with the purpose of the study and a priori questions. Regular debriefing and member checking was also conducted between the interviewers to identify biases regarding stuttering and to discuss alternative data interpretation. This was aimed at reducing the likelihood of the interviewers sharing similar biases of their experiences with the stuttering population and ensuring the valid interpretation of findings (Heine et al., 2008; Mlexico, Manning, & DiLolo, 2005).

2.3. Procedure

Ethics approval was obtained through Curtin University Human Research Ethics Committee. All children and their parents provided informed consent prior to participation. All 10 CWSs were initially interviewed and then completed the SDQ, PBI Mo and Fa and IPPA-R questionnaires while their parents completed a case history form and the SDQ-Parent in a separate room. The order of the questionnaires was randomly presented to control for order effects.

3. Results

3.1. Quantitative analysis

3.1.1. Parenting styles

The scores for the care and control constructs were analysed separately using two-way mixed design analyses of variance (ANOVA), with group (CWS vs. fluent controls), as a between groups factor, and parental figure (mother vs. father) as a within groups factor. An alpha level of .05 (two tailed) was applied to all tests.

For the care construct, there was no main effect of participant group, F(1,18) = 1.05, p = .32, η²_p = .06, and no main effect of parental figure (mother vs. father), F(1,18) = 3.20, p = .09, η²_p = .15. The interaction between group and parental figure was also non-significant, F < 1, η²_p < .01.

For control, there was no significant difference between participant groups, F < 1, η²_p < .01; no significant difference between parental figures, F < 1, η²_p = .01, and no interaction between group and parental figure, F < 1, η²_p < .01. Table 1 provides a summary of the mean ratings for the PBI care and control constructs for both mothers and fathers.

3.1.2. Parent and peer attachment

Overall attachment scores were analysed using a two-way mixed design ANOVA with group (CWS vs. fluent controls) as the between-groups factor, and scale type (parent vs. peer focus) as the within-groups factor. The IPPA-R scores for the three subscales for both parents and peers (i.e., trust, communication and alienation) were compared between CWS and fluent controls using independent samples t-tests.

The two-way ANOVA revealed a significant main effect of scale, F(1,18) = 42.51, p < .05, η²_p = .70. When the overall attachment scores were collapsed across both groups, parents were rated significantly higher (mean M = 32.58) than peers (mean M = 31.50). In contrast, no statistically significant difference was found for the main effect of group, when collapsed across scale type, F < 1, however, there was a significant interaction between scale and group, F(1,18) = 12.96, p < .05, η²_p = .42. Simple effect contrasts revealed that CWS rated their parents with significantly lower attachment compared to the fluent controls, F(1,18) = 9.03, p = .01, η²_p = .33. In contrast, when rating their peers, the difference between the CWS and the fluent controls in terms of attachment was not statistically significant, F(1,18) = 1.40, p = .252, η²_p = .07.

Follow up t-tests showed CWS rated their parents with significantly lower perceived trust compared to their fluent peers, t(18) = 2.81, p = .01, η²_p = .30. In contrast, the CWS did not rate their parents significantly differently compared to their fluent peers on alienation, t(18) = 1.82, p = .09, η² = .16, or communication, t(18) = 1.43, p = .17, η² = .10. On the IPPA-R peer scale, the CWS rated their peer attachment significantly higher on the communication subscale, t(18) = 2.13, p = .05, η² = .20, however, there was no group difference on the trust subscale, t(18) = .88, p = .39, η² = .04, or the alienation subscale, t(18) = .95, p = .36, η² = .05. Table 2 summarises the mean scores, standard deviations and ranges obtained for the overall IPPA-R parent and peer scales and the subscales trust, communication and alienation, for both CWS and fluent controls.
3.1.2. Parent- and self-reported child behaviour

A two-way mixed design ANOVA was used to analyse the average SDQ-Parent and SDQ-Self scores with group (CWS vs. fluent controls) as the between groups factor, and scale version (parent vs. self) as the within groups factor.

A statistically significant main effect of group was found, $F(1, 18) = 15.87, p < .01, \eta^2_{\text{partial}} = .47$. Collapsed across both versions of the SDQ, CWS rated significantly higher ($M = 12.2$) when compared to their fluent peers ($M = 6.3$). There was, however, no main effect of scale version, $F(1, 18) = .52, p = .44, \eta^2_{\text{partial}} = .03$, and no interaction between group and scale version, $F < 1, \eta < .01$.

Planned contrasts revealed a significant difference between the parent of CWS and the parents of the fluent peers on the SDQ-Parent scores, $F(1, 18) = 14.36, p < .01, \eta^2_{\text{partial}} = .44$. There was no significant difference found between the CWS and their fluent peers on the SDQ-Self, $F(1, 18) = 3.30, p = .09, \eta^2_{\text{partial}} = .16$. This suggests the main effect of group is carried mostly by the SDQ-Parent ratings. See Table 3 for the means for each group.

3.2. Qualitative analyses

Transcription of the interviews revealed three themes of interest, which were reported consistently by CWS, namely: school, peers and parents. Within these three broad topics, three main sub-themes emerged from each topic.

3.2.1. School themes

Each participant described their individual experiences and perceptions of school. The following three main sub-themes that related to schools emerged from the qualitative data and described facets of schooling experiences.

3.2.1.1. Attitude towards school. Under this sub-theme, conversation topics that arose included the CWS' favourite subjects, and the different aspects of school they enjoyed, as well as subjects they disliked. Participants were able to identify and provide insights regarding their individual strengths and difficulties.

S01: It's (school) boring, hard... just work, work, work.

S08: ... we do hard math and we do hard work and I hate it.

There were also a number of strengths described by the participants.

S05: ... in Science I'm doing pretty well... Have always been interested in debating for example... I've never had any interest whatsoever in sport.

S10: Writing... coz that's where I got my principal's award, and art... I really like my art... and drama.

In addition, there were a variety of reactions expressed by participants who were transitioning from primary education to secondary education at new schools. Some participants described fear, while others felt sadness, but also acknowledged support given that their current friends were also going to attend the same new school.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Descriptive statistics for children who stutter and fluent controls on the Inventory of Parent and Peer Attachment – Revised (IPPA-R).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CWS</td>
</tr>
<tr>
<td>Parent scale</td>
<td></td>
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<tr>
<td>Overall score</td>
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<tr>
<td>Trust</td>
<td>26.1</td>
</tr>
<tr>
<td>Communication</td>
<td>25.2</td>
</tr>
<tr>
<td>Alienation</td>
<td>12.3</td>
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<tr>
<td>Peer scale</td>
<td></td>
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<tr>
<td>Overall score</td>
<td>33.3</td>
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<tr>
<td>Trust</td>
<td>27.6</td>
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<tr>
<td>Communication</td>
<td>20.8</td>
</tr>
<tr>
<td>Alienation</td>
<td>12.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Descriptive statistics for the strength and difficulties questionnaire parent (SDQ-Parent) and self version (SDQ-Self) for children who stutter and fluent controls.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CWS</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>SDQ-P</td>
<td>12.7</td>
</tr>
<tr>
<td>SDQ-S</td>
<td>11.8</td>
</tr>
</tbody>
</table>
S03: Yeah pretty scary... just like tons of older kids and like tons of homework and all the other stuff like that.
S08: ... but we'll make new friends coz other people are coming in... (I'm) happy to make new friends (but) will miss friends in school now.

3.2.1.2. Attitude towards communicatively demanding situations. Participants described their attitude towards communicatively demanding situations during school activities, such as oral presentations and school assemblies. While there was a general consensus that the school environment presented many challenging communicative situations in light of the stutter, there were diverging coping mechanisms. Many disclosed they did not enjoy these communicative situations and some engaged in situation avoidance. Conversely, some participants discussed that they did not avoid participating in these situations, because they felt it would not be fair to their friends to use their stutter as an excuse not to participate in the task.

S02: I've always had a bad experience...the only thing that gets me...is show and tell. I just talk but I have no idea what I'm saying. I can't do talks coz once... I had my speech all planned out. And when I talked right in front of the whole class, you should have seen my hands like (imitated shaking hands) shaking. I don't know (if other children find talking as difficult), but I'm the worst one there coz they replay the videos and I'm like (look of disgust) because I keep on stuttering.
S03: No, coz (because) all my friends are like doing it, so I feel kinda [sic] left out if I don't, and then I kinda [sic] feel a bit... selfish, because they like, had to do a speech then I just got off easily.
S07: I get nervous and I stutter (if required to do a speech), yeah coz you know even before I go up, I get nervous you know...and when I get up there, I start...my first few sentences is a bit stutter [sic].

3.2.1.3. Relationship with teachers. Another sub-theme that emerged through the interviews was the different experiences and relationships participants encountered with their teachers. One participant in particular, recounted a difficult relationship with his classroom teacher, while another reported enjoying a particularly positive relationship with his teacher.

S01: They (the teachers) don't even say your first name. They say (last name), and make you feel bad.
S05: I have a pretty nice teacher... Year 8 is pretty good. I tend to actually get along quite well with the teachers of my school.

Another aspect of the teacher–child relationship sub-theme that emerged was the teacher's awareness or lack of awareness about stuttering. In a majority of cases where the teacher was aware of the child's stutter, participants reported that it was their mothers who informed the teacher. There were a number of occasions identified when participants would have preferred more autonomy in the decision making process as to whether or not their teachers were informed of their stuttering difficulties.

S03: One lady I had once, she like didn't know (that I stuttered). And then I said something, for like to put my hand up for answer, and I said all the stutter, and she said don't like, be like nervous.
S09: I think it was in Year 3, the teacher kept on like yelling at me...because she wanted me to sound a word out loud but I can't...(I) always sound the word out in my head...(she) kept yelling at me.

Although the teacher–student relationship may not have an obvious relation to stuttering, the quality of the relationship appeared to influence the schooling experience. Given that the teacher is in a position of authority, and the CWS had acknowledged that the school environment was a communicatively demanding situation, the quality of the teacher–student relationship may have shaped the ways in which the CWS coped with stuttering in school, and the CWS' overall schooling experience.

3.2.2. Peer themes

The three main sub-themes that emerged from the qualitative data which related to peers included; relationship to peers, peers' perceptions of stuttering and bullying. A recurring sub-theme that emerged through the interviews regarded social networks in which the participants engaged.

3.2.2.1. Relationship with peers. In general, participants reported having enjoyable friendships, but the extent and number of friends participants had within their networks was variable. Three participants for example, reported having a limited number of friends and feeling lonely in school.

S01: Just three friends... Last year I had one friend. I don't play at school coz no one plays with me. I just walk around the school, that's all I do.
Most of my friends are actually from other schools. I have one friend... at the moment so yeah it's kinda [sic] hard... now there's no one to talk to.

3.2.2.2. Peers' perception of stuttering. A common sub-theme reported in the experiences of participants was that their friends were aware of their stutter, but most were not unduly bothered by it. In addition, some participants reported how their friends attempted to assist them when stuttering episodes occurred.

S04: No one really cares coz there's other people who do it (stutter) at our school.
S08: With my friends I can talk to other people... They (my friends) try to help me with all different suggestions.
S09: Yeah my friends all know about the stutter, sometimes they get annoyed I think because I can't speak.
I don't worry about it. If I'm stuck on a word, he will say fill in the word. It helps.

The general consensus from participants was that not only did they not object to help from their friends but that a significant number were relieved when their friends assisted them in achieving their fluency. This dependence on peers also suggested a degree of trust within friendships formed.

3.2.2.3. Teasing and bullying. A predominant sub-theme that emerged from the interviews was the shared experiences of teasing and bullying encountered especially in school by participants in relation to their stutter. The most common forms of teasing and bullying encountered by the children, included inappropriate mocking and imitation of their stuttering. Some participants also encountered physical forms of bullying and described how they felt and reacted towards these bullies. Teasing and bullying emerged as predominant in the CVR'S schooling experience.

Participants demonstrated a range of reactions and coping strategies they utilised to cope with these unwarranted behaviours. Some participants reported feeling upset when they experienced teasing and bullying, while others reported frustration at the lack of empathy and understanding displayed by peers generally. One participant disclosed that the bullying and teasing affected him emotionally to the point where he applied physical means as retaliation. Participants also described the support of friends as a factor in protecting them when the teasing and bullying occurred.

S03: They just go j-j-j and stuff like that. I just sit there like quietly and just wait till like they walk off.
S07: Some make fun of it, sometimes, coz they don't see how hard it is to control it... See stuttering is a big thing.
you need to take step by step by step to get over it and you get kind of discouraged.
S09: He teased me every day of the week so I just wanted to punch him... I actually cried about it. I just put up with it to a point I got so sad and so angry that I accidently kind of hit one person.
S10: They (the bullies) started copying me bye-bye-bye. They just kind of leave me out that's all... just makes me feel upset... They (my friends) go like hey she's not weird, she's actually a good person.

3.2.3. Parent themes
During the interviews, there were three main sub-themes that emerged from the qualitative data relating to parents. These included the CVR's relationship with their parents, their parents' attitudes towards stuttering and perception of their parents' approaches towards stuttering.

3.2.3.1. Relationship with parents. Participants were asked to describe their relationships with their mother, father or both parents. The participants often described the quality of their relationships within the context of their hobbies and daily lives.

S02: My stepdad is like a very generous person. I'm very close to him like we basically do everything with each other.
S09: Mum... she like handled it (bullying incident) really well.

Other participants described negative characteristics of their relationships with their parents, including a perceived lack of care and affection, as well as high disciplinary standards.

S09: Oooh he's (father) a bit of a tricky one because he yells at me. For like not doing something right and that of... makes me feel like I wanna say f--- off to him. But I can't coz that would make me get into serious (trouble).
I can't even say shut up to him because he gets so angry that I can't say anything to him.

One participant in particular, described his parents as "really nice parents" and he felt "lucky coz I'm so close to my parents". However, he also described difficulties and anxiety when separated from his parents.

S10: I had troubles in the past where I can't sleep over at someone's house because I either miss my mum or dad.
And before I used to miss my dad coz my mum was always at home and dad was at work and I never used to see him a lot... And now that mum works, I miss her now instead of dad.
3.2.3.2. Parents' attitudes towards stuttering. Participants were asked to describe how they felt their parents viewed their stuttering. They were also asked to describe what their parents did to assist with fluency, if applicable. Examples of parental input to helping with fluency included managing their child's speech directly and sometimes offering advice or asking them to repeat the utterance again. The CWS indicated that some parents had collective mutual strategies, while others had mothers and fathers who had different perceptions, and thus approaches towards stuttering.

S03: ...when I've got a stutter, they go breathe.
S06: ...they tell me to start a sentence again. Like when I ask dad can I have a drink, and I have bumpy talking again, dad tells me to start again.
S09: My dad yells at me...of [sic] my stutter...mum says to take a deep breath and slow down and stuff.

3.2.3.3. Perceptions of parents' approaches towards stuttering. There was significant variation in how participants felt in relation to the approaches their parents adopted in assisting them to manage their stuttering episodes. Some participants reported they felt it was frustrating and highly disruptive when their parents intervened.

S05: Sometimes she (mother) brings it up nowadays... before she used to bring it up all the time. But then that got a bit irritating so now she brings it up sometimes, but other times she'll try and finish my sentence.

At the same time, participants also perceived stuttering to be a large part of their self-identity. They appeared self-motivated to increase fluency and many reported positive actions in working towards this goal. A common sub-theme that emerged was also the internalised self-belief that stuttering hindered future career options, especially occupations that involved high communication demands. As such, it manifested in the notion that their capabilities at future aspirations were determined by the presence of the stutter.

S05: I joined that (debating team) to help work on both my stutter as well as public speaking and things confidence wise.
S08: I won't be a footie player or cricket player (if stutter continues into adulthood). I'll just have to be an inventor...invent something...so I'll stop stuttering.
S09: I wish there was a pill to make me stop stuttering. It's controlling my life, basically I can't do anything.

4. Discussion

Quantitative results from this study demonstrated that CWS reported significantly lower parental attachment compared to fluent peers, particularly, in terms of perceived trust. In addition, parents of CWS perceived their children to have significantly more difficult behaviours than did parents of normally fluent children. Qualitative themes and individual experiences were reported embracing school, peers and relationships with parents. The complexities of the stuttering disorder and its impact on life relationships were reported by every participant and their parents alike.

4.1. Parenting styles

There were no significant differences found between the parenting styles of the parents of children who stuttered and parents of normally fluent children. The separate evaluation of particular parenting styles, by mothers and fathers, also yielded no statistically significant results. However, significantly lower parental attachment scores were found for the CWS when compared to the normally fluent group.

Qualitative recounts by participants, on their unique relationships with their parents, highlighted different degrees of care and control, perceived both in the context of daily lives and in relation to stuttering. In particular, the majority of participants reported feeling frustrated, e.g., 'I find it...annoying' with the nature in which their parents attempted to assist in managing stuttering episodes. These experiences may have been interpreted by CWS as their parents being controlling given that parents of children with communication difficulties have been reported as having higher disciplinary standards. The assumption is that these standards are reinforced as parents assume greater responsibilities for their children's communication (Hammer, Tomblin, Zhang, & Weiss, 2001). Combined with the current findings that CWS are perceived by parents to have more difficult behaviours, it is likely the exposure to, and manifestation of stuttering over time may impact or possibly alter parenting styles. These parents work harder to engage their children and compensate for difficulties, especially in relation to their child's communication.

4.2. Parent attachment

The current study found CWS perceived their parents with significantly lower attachment, compared to fluent children. In addition, the Parent Trust subscale revealed CWS perceived lower parental trust compared to their fluent peers. The large effect sizes obtained on the IPPA-R and Parent Trust subscale highlights the clinical magnitude of this significance.
Qualitative recounts from participants reported frustration not only in the ways their parents attempted to shape their fluency but also in how the parents interfaced with the community in managing intimate information regarding their stuttering in general. When discussing their teachers’ awareness of the stutter, most participants recounted it was their mother who informed the teacher. Subsequently, there was general consensus that the CWs would have preferred more autonomy in this decision-making process. This included being consulted whether they would like information regarding stuttering to be shared with the teachers and how much information to share, e.g., receiving speech pathology services.

4.3. Peer attachment

The CWs rated their peers significantly higher on the Communication subscale. School-aged children in general, demonstrate increasing utilisation of peers to develop their social competence and sense of self-identity (Evans, Heasley, Kawai, & Rowland, 2008). When examined in conjunction with parental attachment results, it is plausible these CWs perceived their peers to be a more secure social base, in which trust and, particularly, communication was considered more mutually balanced. Such trust and tolerance was borne out during the qualitative recounts. The majority of CWs reflected that their friends were aware of the stutter, but were not unduly bothered by it. The CWs also reflected that they were not opposed to, and some even appreciated their friends’ attempts to help shape their fluency. This is in contrast to the annoyance the same CWs expressed when reflecting on their parents’ hyper vigilance in their stuttering management attempts.

4.4. Parent- and self-reported child behaviour

The quantitative finding that parents of CWs perceive their children with significantly more difficult general behaviours, than parents of fluent children, supports the contemporary notion that stuttering is more than just its surface behaviours. While speech dysfluency is an essential feature, the disorder of stuttering is intertwined with other psychosocial, emotional and environmental behaviours, (Karass et al., 2005; Yalari, 2007).

The SDQ is designed to measure child behavioural difficulties along constructs including emotional symptoms, conduct and peer problems (Achenbach et al., 2008). These constructs are said to contribute towards temperament, which may be defined as “biologically based individual differences in behavioural characteristics” (Anderson, Pellowski, Couture, & Kelly, 2003, p. 1221). Current findings suggest school-aged CWs possess more susceptible temperaments than their fluent peers and although relatively stable, temperament is also heavily influenced by social development (Anderson et al., 2003). As the SDQ relates to overall behaviour, and is not specific to stuttering, it is possible that the development and presence of stuttering further exacerbates or maintains increased vulnerability in CWs. Individuals who stutter have been reported to be more socially anxious, sensitive and insecure than their fluent peers (e.g., Anderson et al., 2003; Blood, Blood, Telles, & Gabel, 2001; Fowlie & Cooper, 1978; Mulcahy, Hennessey, Beilby, & Byrnes, 2008).

Qualitative results endorsed how stuttering imposed a moderating effect on CWs’ global experiences. Participants consistently described themes of situation avoidance and dislike of communicatively demanding situations. Further, there were reports of ineffective coping strategies (e.g., physical retaliation) towards conflict situations such as bullying and teasing at school.

4.5. Qualitative paradigm

Given the multidimensional facets of stuttering, it is argued that the use of only quantitative methods is problematic when attempting to elucidate relationships between factors in stuttering (Teinowski & Damico, 2001). It is also acknowledged that the use of only qualitative analyses does not sufficiently represent the wider population at large (Heame et al., 2008). The combination of quantitative and qualitative methods adopted in this study was complementary to both paradigms. Quantitative methods enabled the overall comparisons between groups while the qualitative methods assisted in locating thematic data within the context of each participant’s life (Fokkens et al., 2005).

In light of the various attitudes and perspectives of school, peers and parents of the CWs interviewed in this study and comparing these to the quantitative differences of the stuttering and normally fluent groups, it is argued that the incorporation of qualitative orientations in clinical research domains is valuable in expounding the complex disorder of stuttering.

4.6. Limitations and future directions

Several limitations of the study were acknowledged. Firstly, the cross-sectional nature of the study limited the interpretation of results, especially in understanding the evolving and dynamic nature of parenting and PCA. Adopting a longitudinal study that examines the trajectory of parenting styles and PCA across the developmental span would allow further exploration of the moderating influence of stuttering.

Secondly, while qualitative and quantitative paradigms were applied in an attempt to capture to multi-faceted condition of stuttering, data measured may have been underestimated. Given the expectation on school-aged children to demonstrate adult-like communication competencies, the years of stuttering may have generated affective and emotional changes, such
as anxiety during the interviews. True speech dysfluency may have been underestimated due to the possible use of compensatory strategies such as circumlocution and word avoidance. It would also be of interest to conduct interviews with fluent school-aged children to compare aspects of the qualitative data particular only to the CWS. Some of the themes that emerged in the interviews with the CWS, such as attitudes towards school and relationships with teachers are likely to be characteristics of the general school-aged population.

It is also acknowledged that the sample size of the study does not adequately represent the school-aged CWS population at large. While the results of this study suggest lower parental attachment and more perceived difficult behaviours in CWS, it is difficult to ascertain if attachment issues were present regardless of the stuttering. Given that stuttering often presents in an overt fashion, it can generate significant distress and impact significantly on familial interactions. Therefore, it is suggested the presence of the stuttering moderates the communication styles of the dyad, and thus attachment pattern.

Although separate constructs, parenting style and PCA interact continuously to influence the parent–child relationship. The amount of warmth demonstrated and disciplinary standard a parent sets contributes to the quality of the emotional bond between parent and child. Yet, the quantitative inventories (PBI, IPPA-R) adopted in this study were based on the assumption that these constructs existed within discrete quadrants, or along a singular dimension derived from a single score (Fouladi, Moller, & McCarthy, 2006). The PBI allocates scores into four categories of best fit based on responses, and the Care construct is said to only evaluate the general affective tone of parental relationship. The IPPA-R is based on a single secure-insecure dimension, and does not allow evaluation of different forms of insecurity (Fouladi et al., 2006). Given the heterogenous nature of CWS, combined with the considerations of other constellations of relationships (e.g., parents’ marital relations, emotional regulation mechanisms, cultural and social expectations) that are said to contribute to the quality of parenting and attachment (Karaas et al., 2006; Morris, Silk, Steinberg, Myers, & Robinson, 2007), the conceptualisation of parent–child relationships requires further attention in order to better understand its complex associations to stuttering.

4.7. Clinical management of school-aged CWS

In arguing for a broader conceptualisation of stuttering, the collective findings from this study highlight a need to address the epiphenomena that accompany stuttering (e.g., in terms of social, physical, mental health domains) (Francis & Bothe, 2008). While the importance of stuttering severity and typology is an essential outcome of successful fluency, there is a need to extend therapy effectiveness beyond these observable notions. Environmental factors, including attachment, contribute towards motivational orientation. Quality attachment may include a CWS’ resiliency and inherently promote intrinsic motivation to improve communication fluency (Morris et al., 2007; Siefert & Hoffnung, 2001). The findings that CWS perceive their parents with significantly lower attachment than fluent counterparts, demonstrates clinical management in CWS needs to extend to include interactions between parent and child. Given the pervasive influence parents have on their children, empowering a parent to recognise the potential impact their affective state has on their child is an important aspect of the therapeutic process (Millard, Nicholas, & Cook, 2008).

Acknowledgements

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Appendix A. Continuing education

Questions

1. In the current study, what types of research methodologies were adopted?
   (a) Qualitative interviews by the experimental group only
   (b) Quantitative questionnaires by the control group only
   (c) Qualitative questionnaires by the experimental group and qualitative interviews by the control group
   (d) Quantitative questionnaires by the experimental and control group, and qualitative interviews by the experimental group
   (e) Qualitative interviews by the control group and quantitative questionnaires by the experimental group

2. In the current study, how are the concepts of parenting style and parent–child attachment viewed?
   (a) Parenting style refers to patterns of childrearing and parent–child attachment refers to the dyadic emotional bond between parent and child
   (b) Parenting style and parent–child attachment are similar terms that refer to patterns of child rearing
   (c) Parent–child attachment refers to patterns of childrearing and parenting style refers to the dyadic emotional bond between parent and child
   (d) Both concepts refer to a style of dysfluency management.
   (e) Parenting style and parent–child attachment refer to dyadic physical bonds between parent and child
3. The results from the inventory of Parent and Peer Attachment (IPPA-R) questionnaire revealed that CWS rated which significant findings compared to those of the fluent group?
(a) Lower overall parental attachment, lower overall peer attachment
(b) Lower overall parental attachment, higher perceived parental trust, lower perceived peer communication
(c) Higher overall parental attachment, higher perceived parental communication, higher overall parental attachment
(d) Lower overall parental attachment, lower perceived parental trust, higher perceived peer communication
(e) Higher perceived parental alienation, higher perceived parental communication, lower perceived peer alienation

4. In the qualitative interviews, CWS revealed several sub-themes around the ancillary topic of parents. Which of the following best captures the sub-themes revealed?
(a) Relationships with parents and relationships with siblings, parents’ attitudes towards stuttering
(b) Parent’s attitudes towards teasing and bullying, parents’ attitudes towards stuttering, relationships with parents
(c) Relationships with parents, relationships with grandparents, perceptions of parents’ approach towards stuttering
(d) Parents’ perceptions of stuttering, parents’ attitudes towards stuttering, relationship with siblings
(e) Relationships with parents, parents’ attitudes towards stuttering, perceptions of parents’ approach towards stuttering

5. The present study adopted a combination of research methodologies. Which reasons below best explains the reason for this?
(a) A quantitative method allows for comparison across groups
(b) A qualitative method allows for comparison between groups
(c) Quantitative methods allow for overall comparison across groups and qualitative methods allow for locating data within each participant’s life
(d) Qualitative methods allow for comparison between participants and quantitative methods allow for locating data within each participant’s life
(e) Quantitative and qualitative methods allow for comparison between participants

References
Paper 4

The Experiences of Living with a Sibling who Stutters.

The experiences of living with a sibling who stutters: A preliminary study

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ABSTRACT

Stuttering impacts on the child in a variety of ways, notably in terms of communicative impairment and psychosocial impact. In addition, the stuttering disorder has a holistic impact, affecting those with whom the child who stutters lives. Within the family constellation, the closest person to the individual who stutters often is their sibling. This study investigated the experiences of fluent siblings of children who stutter to examine the impact that stuttering may have on their lives. A mixed methods research design incorporated qualitative semi-structured interviews and quantitative questionnaires. The results of the qualitative investigation revealed four aspects of children’s lives that were affected by having a sibling who stuttered: the relationship between siblings, the impact on the fluent sibling, the impact on the parent relationship with both children, and the impact on the sibling’s relationship with others. Findings revealed that siblings of children who stutter exhibited strongly negative emotions, and differing levels of responsibility associated with their involvement in the actual stuttering management programme. Furthermore, for the fluent sibling, secondary to having a brother or sister who stuttered, communication with and attention from their parents was variable. The results of the quantitative component of the study revealed children who stutter and their siblings demonstrated significantly greater closeness, and concurrently, increased conflict and status disparity than did the control fluent sibling dyads. The parents of the experimental sibling dyads also demonstrated significantly greater partiality towards a child, namely the child who stuttered, than did the parents of the control sibling dyads.

Educational objectives: The reader will be able to: (1) identify the themes associated with having a sibling who stutters; (2) identify how the quality of the sibling relationship differs between sibling dyads that do and do not consist of a sibling who stutters; and (3) discuss the clinical implications of the results with regards to working with children who stutter and their families.

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1. Introduction

Children who stutter (CWS) experience more than just the observable typographical features of part word repetitions, whole word repetitions, sound prolongations, inaudible blocks, or audible blocks (Manning, 2010; Ward, 2006). Their stuttered speech can be viewed in terms of several interacting components: presumed etiology, impairment in body function, affective, behavioural, and cognitive reactions to stuttering, the environment, limitations in communication activities, and restrictions in participation (Yaruss & Quesal, 2006). The stuttering disorder is also likely to have an even more holistic impact, affecting those with whom the CWS interacts, such as parents, siblings, friends, extended family and teachers.

Treatment approaches for young children who stutter usually necessitate a significant amount of family involvement. Therapy strategies are provided by the clinician in the clinical setting; however, the suggested therapy techniques are implemented at home in the context of the family environment (Millard, Nicholas, & Cook, 2008; Yaruss, Coleman, & Hammer, 2006). Efficacy data supportive of a beyond-clinic parent–child interaction therapy (Millard et al., 2008), comprised of six sessions of clinic-based therapy and six sessions of parent-led home-based therapy, yielded significantly reduced stuttering frequency in preschool children (Millard et al., 2008). In addition, experimental data for early stuttering treatment compared two treatment approaches which both employed parent-administered procedures (Franken, Kielstra-Van der Schalk, & Boelens, 2005). Results indicated that the stuttered behaviour frequencies and overall stuttering severity ratings decreased for both treatment groups. Franken et al. also showed that therapy positively affected parents, given that treatment acceptance and satisfaction were rated positively by the parents themselves (Franken et al., 2005).

The impact of stuttering and stuttering therapy on the siblings of CWS and the subsequent quality of the sibling relationship has to date not been thoroughly explored. It has been suggested by Bank and Kahn (1982) that siblings follow a particular relationship life cycle. In early childhood, they provide a constant source of companionship; during the school years, they extend themselves to others external to the immediate family; and during adolescence, siblings demonstrate ambivalence regarding their relationship but still confide in and advise each other to a considerable extent (Seligman & Darling, 1997). Siblings, in general, share the majority of time with each other, especially during childhood, and siblings often spend greater time with each other than with their parents (Dodd, 2004). It has been suggested that the emotional ties between siblings are second only to those between children and their parents (Furman & Buhrmester, 1985), and that these sibling relationships are unique in terms of their power and dynamism (Young, 2007). Despite these findings, there has been more research and more clinical focus on the relationship between the parents and the CWS than on the sibling relationship (Young, 2007).

The impact of living with a sibling with a health condition has been explored in the context of other disabilities such as autism (Rivers & Stoneman, 2003; Wolf, Fisman, Ellison, & Freeman, 1998), Down's syndrome (Cuskelly & Gunn, 2006; Wolf et al., 1998), diabetes (Hollridge, 2001), epilepsy (Mims, 1997; Rossiter & Sharpe, 2001), cerebral palsy (Pitt-Ten Cate & Loots, 2000), and spina bifida (Bellin, Kovacs, & Sawin, 2008). Concerns of non-disabled siblings have included: over-identification, embarrassment, guilt, isolation, loneliness and loss, resentment, increased responsibilities, pressure to achieve (Russell, Russell, & Russell, 2003), social stigmatization (Moore, Howard, & McLaughlin, 2002) and bullying (Boer & Dunn, 1992). Furthermore, there have been reported difficulties in the development of self-identity (Moore et al., 2002), as well as frustration at the lack of education and information regarding the disabled sibling's needs (Harris, 1994). Positive implications have also been described by siblings, including such attributes as increased maturity and insight, tolerance, pride, advocacy, and shared social experiences and shared life impact.

Barr et al. (2008) explored the experiences and impact of a speech impairment on siblings in the context of a family-centred practice therapy. One of the key tenets of family-centred practice is the focus on the family as the collective client, in contrast to the singular child. This form of therapeutic practice incorporates the interconnected nature of family relationships and therefore proposes that therapeutically the focus is not exclusively on the child, but may be on the entire family. Findings from the qualitative interviews conducted with the siblings of the child with the speech impairment and their parents during the family-centred therapy identified four areas of impact. These areas included the impact on the sibling relationship, the impact on the sibling's relationships with others, the impact on the sibling themselves, and the impact on the relationship between the parent and sibling. A positive relationship was found between the sibling and the child with the speech impairment. Specifically, when others were present, the sibling tended to interpret and speak for the child with the speech impairment in order to protect them from being misunderstood and potentially embarrassed. Siblings described several personal difficulties including jealousy and concern about their sibling with the speech impairment. In addition, the current study sought to add to the literature with respect to the experiences of siblings of children with communication disorders by exploring these areas of impact from the point of view of the siblings of children who stutter. To place these sibling reactions in the context of the entire family system, the perspectives of parents and the child who stutter were also examined. Specifically, the purposes of the present study were to investigate: (a) the themes which exist regarding
the impact of living with a sibling who has a clinically diagnosed stuttering disorder, (b) whether a significant difference exists in relation to the quality of the sibling relationship, between experimental sibling dyads (i.e., sibling pairs including a child who stutters) and control dyads (i.e., sibling pairs not including a CWS), (c) whether a significant difference exists in experimental families, between the perceptions of the sibling relationship by parents and by the siblings themselves, and (d) whether a significant difference exists in control families between the perceptions of the sibling relationship by parents and by the siblings themselves.

2. Method

2.1. Design

A mixed methods research design incorporating qualitative semi-structured interviews and quantitative questionnaires was implemented in this study. This design assisted the researchers to gain an in-depth understanding of the experiences of the siblings whilst simultaneously assessing the perspectives of the CWS, and parents using quantitative assessments. This mixed methods research design has been demonstrated as worthwhile in the field of stuttering disorders research (Hughes, Gabel, Irani, & Schlageck, 2010).

2.2. Participants

Twelve experimental sibling dyads with their parents and 12 control sibling dyads with their parents were participants in this study. The 12 experimental sibling dyads consisted of the CWS and their fluent sibling living at home in the same family constellation. Information pertaining to the sibling constellation of the experimental and control groups is shown in Tables 1 and 2.

The clinical diagnosis of stuttering and the stuttering severity measures for the CWS were determined by rated speech samples obtained from digitally recorded interviews within the clinic setting. Two experienced speech pathologists with no less than 10 years clinical experience in the assessment and management of stuttering disorders determined the diagnosis of the stuttering disorder. They rated the interviews based on a minimum of 2000 syllables with at least 15 min of accrued real speaking time. An Easy Rater Intelligent Instrument was used to calculate the percentage of syllables stuttered (KSS). Seven children who stuttered demonstrated mild–moderate stuttered behaviours and the remaining 5 children who stuttered

<table>
<thead>
<tr>
<th>Participant code</th>
<th>Gender of CWS</th>
<th>Age of CWS (years; months)</th>
<th>Gender of sibling</th>
<th>Age of sibling (years; months)</th>
<th>Age difference (years; months)</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
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<td>Female</td>
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<tr>
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<td>Female</td>
<td>11; 4</td>
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<td>7; 5</td>
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<tr>
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<td>8; 4</td>
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<td>Male</td>
<td>16; 4</td>
<td>7; 8</td>
</tr>
<tr>
<td>S12</td>
<td>Female</td>
<td>8; 4</td>
<td>Male</td>
<td>9; 10</td>
<td>1; 6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant code</th>
<th>Gender of sibling 1</th>
<th>Age of sibling 1 (years; months)</th>
<th>Gender of sibling 2</th>
<th>Age of sibling 2 (years; months)</th>
<th>Age difference (years; months)</th>
</tr>
</thead>
<tbody>
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<td>Female</td>
<td>11; 11</td>
<td>1; 6</td>
</tr>
<tr>
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<td>Female</td>
<td>12; 4</td>
<td>1; 10</td>
</tr>
<tr>
<td>C03</td>
<td>Female</td>
<td>12; 0</td>
<td>Male</td>
<td>14; 5</td>
<td>2; 5</td>
</tr>
<tr>
<td>C04</td>
<td>Female</td>
<td>11; 2</td>
<td>Female</td>
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<td>2; 0</td>
</tr>
<tr>
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<td>Female</td>
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<td>Male</td>
<td>11; 5</td>
<td>2; 4</td>
</tr>
<tr>
<td>C06</td>
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<td>11; 1</td>
<td>Male</td>
<td>15; 3</td>
<td>3; 2</td>
</tr>
<tr>
<td>C07</td>
<td>Female</td>
<td>11; 6</td>
<td>Male</td>
<td>12; 0</td>
<td>2; 6</td>
</tr>
<tr>
<td>C08</td>
<td>Female</td>
<td>10; 6</td>
<td>Male</td>
<td>11; 1</td>
<td>6; 3</td>
</tr>
<tr>
<td>C09</td>
<td>Male</td>
<td>5; 3</td>
<td>Female</td>
<td>6; 1</td>
<td>2; 10</td>
</tr>
<tr>
<td>C10</td>
<td>Female</td>
<td>5; 3</td>
<td>Male</td>
<td>11; 10</td>
<td>6; 6</td>
</tr>
<tr>
<td>C11</td>
<td>Female</td>
<td>5; 3</td>
<td>Male</td>
<td>6; 0</td>
<td>2; 0</td>
</tr>
<tr>
<td>C12</td>
<td>Female</td>
<td>8; 5</td>
<td>Male</td>
<td>6; 0</td>
<td>2; 0</td>
</tr>
</tbody>
</table>
demonstrated severe stuttered behaviours (Guitar, 2006). The X5S for the 12 children who stuttered ranged from 2.5% to 15.1% (M = 5.4; SD = 4.0; Table 3).

Speech samples for the fluent sibling and fluent control participants were analysed by the primary researcher, with no examples of stuttered speech or abnormal dysfluencies identified for any participant. In addition, parental reports were obtained for each control participant, with no fluency concerns in the child’s development identified.

All 12 recorded interview samples were analysed to determine intra- and inter-rater reliability of the speech measures. Pearson’s product–moment correlation coefficients were then calculated. Pearson’s r was found to be .94 between raters, whilst Pearson’s r was reported .95 within raters, demonstrating satisfactory inter- and intra-reliability. Eleven out of the 12 (92%) of the children who stuttered were currently receiving stuttering therapy. Eight out of the 12 sets of parents stated that the female caregiver was the main provider of therapy within the home, with the remaining four sets of parents reporting equal responsibility.

The older or younger fluent siblings of the CWs were the participants for the qualitative component of the study. None of these siblings had a clinical diagnosis of stuttering according to parent report and informal conversation evaluation by the experienced speech pathologists. The experimental sibling dyads were selected from the clinical database of a large metropolitan stuttering treatment clinic. Fluent control participants were recruited through staff contacts in the same metropolitan region. The fluent control participants were selected specifically to control for gender, age, age ranking, and age difference matched as closely as practicable to the experimental sibling dyad. Independent sample t-tests demonstrated no statistically significant differences between the experimental and control groups in terms of age, (t(42) = -1.79, p = .09, d = .54 and age difference, (t(20) = -.023, p = .89, d = .01).

2.3. Qualitative procedure

The 12 siblings of the children who stuttered attended a semi-structured interview with one of the authors, all of whom had received specialised training in qualitative interviewing and analysis techniques. Each interview took place in a private quiet room and lasted, on average, 30 min. Each of the interviews consisted of a series of standardised questions and probes which were prepared ‘a priori’ and designed to elicit the participants’ personal experiences (see Table 4). In keeping with the principles of semi-structured interviewing, there was flexibility in questioning throughout the interview. The participants were allowed as much time as required to respond to each of the questions. The participants’ responses were recorded on a high quality digital audio recording device which allowed for verbatim transcription of the interviews.

The qualitative methodology used within this study was derived from the framework of grounded theory which provides a flexible set of inductive strategies for collecting and analysing qualitative data (Glaser & Strauss, 1967; Pesho, Manning, & Levitt, 2009). This methodology emphasises building inductive theories through data analysis which allow for theoretical categories that are directly ‘grounded’ within the data (Charmaz, 2008).

The digital recordings were transcribed verbatim and analysed using the QSR Nvivo 8 qualitative analysis software. The process of analysis included open, axial and selective coding to develop a set of themes (Liampittong & Ezzy, 2003; Pesho, Manning, & Levitt, 2009). Each of the interview transcripts was read and segmented into units of text containing one main meaning. Each (et al., 2009). Each of the interview transcripts was read and segmented into units of text containing one main meaning. Each (et al., 2009). Each of the interview transcripts was read and segmented into units of text containing one main meaning. Each (et al., 2009).

After initial themes were stimulated, a subset of text was selected for inter-rater reliability analysis. The three researchers agreed on the coding of themes and subthemes in 91% of the passages. Reiterative comparison within and across groups was made. Emergent themes and subthemes were examined and agreed upon by all three authors.

In grounded theory qualitative research, saturation is the point at which the addition of new interviews does not lead to new themes or understandings and it appears that the data collection is truly reflective and complete. In this study, the final two interviews did not result in identification of any additional themes; all of the topics identified within these two
Table 4
The open-ended questions and standard probes asked of each participant.

<table>
<thead>
<tr>
<th>Open-ended questions:</th>
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<tbody>
<tr>
<td>1. Tell me about your brother/sister.</td>
<td></td>
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<tr>
<td>2. Tell me what’s going on with his/her talking.</td>
<td></td>
</tr>
<tr>
<td>3. What do you like about your brother/sister?</td>
<td></td>
</tr>
<tr>
<td>4. What do you like doing together?</td>
<td></td>
</tr>
<tr>
<td>5. How do you feel when your brother/sister has these difficulties (stutters)?</td>
<td></td>
</tr>
<tr>
<td>6. Tell me about your mum/dad.</td>
<td></td>
</tr>
<tr>
<td>7. What do you like about your mum/dad?</td>
<td></td>
</tr>
<tr>
<td>8. What do your parents do to try and help your brother/sister with their talking?</td>
<td></td>
</tr>
<tr>
<td>9. What do you do to try and help your brother/sister with their talking?</td>
<td></td>
</tr>
<tr>
<td>10. Tell me about your friends.</td>
<td></td>
</tr>
<tr>
<td>11. What do you like about your friends?</td>
<td></td>
</tr>
<tr>
<td>12. What don’t you like about your friends?</td>
<td></td>
</tr>
<tr>
<td>13. Has anyone said anything at school about his/her talking?</td>
<td></td>
</tr>
<tr>
<td>14. How easy is it to speak to your parents about your brother/sister’s talking?</td>
<td></td>
</tr>
<tr>
<td>15. Who in your family do you think understands your brother/sister’s talking difficulties?</td>
<td></td>
</tr>
<tr>
<td>16. How do you think your brother/sister’s talking difficulties affect how well you get along?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Standard probes:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me more about that.</td>
<td></td>
</tr>
<tr>
<td>2. Do you agree with that?</td>
<td></td>
</tr>
<tr>
<td>3. Can you clarify that for me?</td>
<td></td>
</tr>
</tbody>
</table>

interviews had previously been identified in prior transcripts, which indicated that there was adequate saturation (Glaser & Strauss, 1967).

In this study, a range of additional procedures were followed to improve the credibility and reliability of the findings (Hughes et al., 2010; Flexico et al., 2009). Each of the interviews was transcribed verbatim prior to analysis. A range of techniques was used to ensure that the results and conclusions drawn from the qualitative data were not biased. The professional biases of the three authors regarding stuttering, sibling relationships and the expected findings were examined before the interviews and as the various themes emerged. Each researcher was encouraged to suspend their expectations, expectations, and hypotheses about the themes and phenomena of interest. All three investigators had backgrounds in fluency disorders and one investigator (second author) had a background in qualitative research. Each of the authors collaboratively developed the codes that ultimately became the themes detailed in the results section. In addition, the second author periodically met with the other two authors to review the use of grounded theory and receive ongoing feedback on the interviewing process and the creation of the themes.

2.4. Quantitative measures

The Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985) was completed by the CWS, the fluent sibling, and the two parents from each family in the experimental group, and two children and two parents from each family in the control group. The SRQ examines 16 different domains of the sibling relationship; intimacy, prosocial attributes, companionship, similarity, admiration by sibling, admiration of sibling, affection, nurturance of sibling, nurturance by sibling, dominance of sibling, dominance by sibling, quarrelling, antagonism, competition, maternal partiality, and paternal partiality (Furman & Buhrmester, 1985). Specifically worded questions on the differing child and adult questionnaires allowed for contrasting perspectives. One questionnaire was completed by a member of the sibling relationship whereas the other questionnaire was completed by each parent. The questionnaires consist of 48 questions, 3 for each of the 16 domains of the sibling relationship. Most of the items are scored on a 5-point Likert scale ranging from “hardly at all” to “extremely much”. Responses associated with maternal and paternal partiality range from “X almost always gets treated better gets more attention/ is favoured” to “Y almost always gets treated better gets more attention/is favoured”. The SRQ has an average internal consistency coefficient of .77 for participants aged 8–17 years of age (Buhrmester & Furman, 1990). The average Cronbach’s alpha reliability coefficient has been reported as .84 for the parent scale (Storch et al., 2008). Therefore, it is judged to be a valid measure of the many aspects of the sibling relationship.

Ethics approval was obtained for this study through the requisite Human Research Ethics Committee. Informed consent was obtained from all members of the sibling and parent dyads for both the experimental and control families. The qualitative interviews were conducted in a quiet room in the homes of the individual families. The SRQ was mailed out to control and experimental families following the interview component of the study and completed and returned within 2 weeks.

3. Results

3.1. Qualitative analyses

A large quantity of data was accumulated from the interview transcripts. Four main themes and various subthemes emerged and are summarised in Table 5.
Table 5
Themes and subthemes regarding the impact of stuttering on the siblings of children who stutter.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on the sibling relationship</td>
<td>Acceptance</td>
</tr>
<tr>
<td></td>
<td>Power</td>
</tr>
<tr>
<td></td>
<td>Perception of stuttering</td>
</tr>
<tr>
<td></td>
<td>Negative emotions of the CWS</td>
</tr>
<tr>
<td></td>
<td>Personal relationship</td>
</tr>
<tr>
<td>Impact on the sibling</td>
<td>Negative emotions</td>
</tr>
<tr>
<td></td>
<td>Positive emotions</td>
</tr>
<tr>
<td></td>
<td>Responsibility</td>
</tr>
<tr>
<td>Impact on the parent–sibling relationship</td>
<td>Communication with parents</td>
</tr>
<tr>
<td></td>
<td>Attention from parents</td>
</tr>
<tr>
<td>Impact on the sibling’s relationship with others</td>
<td>Protection of the CWS and educating others</td>
</tr>
</tbody>
</table>

It is important to note that although the themes and subthemes are discussed separately, the themes described were not experienced in isolation rather, many were experienced in conjunction with others.

3.1.1. Theme 1: impact on the sibling relationship

3.1.1.1. Acceptance. Seventy five per cent (N = 9) of the siblings referenced the subtheme of acceptance. Within these nine references, four tolerable aspects of the stuttering disorder were reported. These aspects included being used to the stuttering, being used to the notion of their sibling stuttering when they get older, being used to less parental attention, and being used to their own emotions associated with having a brother or sister who stuttered. This subtheme was illustrated by S02, a 7-year old sibling whose younger sister has a severe stutter:

“It’s okay because she’s little and I’m big and they [parents] need to help her with her talking” (S02).

In contrast, S04, a 12-year old sister of a 10-year old boy with moderate stuttering, detailed several emotions she experienced:

“I feel a bit frustrated and annoyed because you have to wait for him to finish talking, and then you kind of get used to it after a while” (S04).

3.1.1.2. Power. The notion of power encompassed the fluent sibling’s involvement in the CWS treatment, such that the fluent sibling was able to exert some form of control over the CWS. The majority (N = 8) of the fluent siblings reported being naturally and inevitably involved in the treatment process in some way simply because they shared family life and the interactions therein with their sibling. Topics of involvement included; identifying the stuttered speech, providing emotional support and positive reinforcement to the CWS, implementing structured speech activities and providing reminders regarding the treatment strategies. This subtheme can be illustrated as follows:

“We have a bumpy word chart. When [CWS] does really bad talking he loses points, but if he does good talking he gets points” (S08, 7 year old sister of a 4 year old boy with mild stuttering).

“Sometimes I make him happy when he is sad and I say don’t worry and it will be okay and you know how to fix it and just repeat it again” (S10, 10 year old sister of a 6 year old brother with moderate stuttering).

3.1.1.3. Perception of stuttering. Despite the majority of children stating that their parents understood the stuttering disorder and the impact it has on the CWS more than they did, considerable heterogeneity existed regarding the fluent siblings’ perception of stuttering. This occurred at a number of levels, from perception of the disorder itself, to perception of how the fluent sibling is impacted upon, and also their perception of the future implications of stuttering for the CWS. This subtheme was reported by S11 and S08 who were describing their younger brothers who had moderately severe stutters:

“I think with his stuttering, it’s more when he’s speaking a lot and he’s more excited with what he’s saying and he gets worked up a bit and he talks very fast” (S11).

“Well, what happens when [CWS] is an adult and people can’t understand him and he might say ‘hello, I want to buy this house’ and he might have bumpy words and they can’t understand him so he might not get a house? And a job, he can’t get a job because if he is selling a toy then people won’t understand him and they won’t know what he said” (S08).

3.1.1.4. Negative emotions of the CWS. Fluent children described their siblings who stuttered as demonstrating a variety of negative emotions including being annoyed, being upset when asked to repeat, becoming frustrated when interrupted, and demonstrating anger during a stuttered speech episode. The fluent sibling often acknowledged that the CWS was bullied and teased by others. The negative impact of the presentation of emotions on the fluent sibling was best portrayed by S06 and S03 who were older sisters of brothers who had moderately severe stutters:
"Once you understand what he’s saying it’s alright but I think he just gets really annoyed at himself because he can’t do it" (S05).
"He just said they were picking on him because he stuttered and stuff, and sometimes they wouldn’t do anything about it, so that’s why he had to move (school)" (S05).

3.1.1.5. Personal relationship. Approximately 50% of the siblings stated that having a sibling who stuttered affected how positive their relationship was, whilst the remainder indicated no impact at all. One reason stated for the stutter impacting on their relationship was frustration towards the CWS, when the fluent sibling became annoyed with the stutter and embarrassed by their sibling’s speech. These contrasting personal relationships are portrayed in the following quotes obtained from S05 who was a younger sister close in age to her 11-year old sister who stuttered, and also from S012 who was a 9-year old boy whose younger sister had a severe stuttering disorder.

"Sometimes I get upset that [CWS] is making mistakes when she is talking" (S05).
"No, we are normally really close and we are always going places together and we help each other and we like each other" (S12).

3.1.2. Theme 2: impact on the sibling
Proportionally more negative emotions than positive ones were described by the fluent siblings. Analysis using the QSR NVivo 8 qualitative analysis software demonstrated 39 references to negative emotions and 18 references to positive emotions. Interestingly, emotions described by the fluent sibling appeared independent of the stuttering severity ratings of their siblings, with children with mild stuttering generating the same reactions as those with severe stuttered speech.

3.1.2.1. Negative emotions. Participants reported a range of negative feelings and experiences about having a sibling who stuttered including anger, annoyance, frustration, jealousy, sadness and boredom. The predominant negative emotion referred to throughout the interviews was annoyance. Reported reasons for the fluent siblings feeling annoyed included comments pertaining to the CWS not talking properly, needing help from the sibling throughout the treatment process, and requiring extra time to be heard. These variable negative emotions were reflected by the following quotes from S03 and S10 who were both older sisters describing their emotions regarding their younger brothers’ speech problems:

"Sometimes I get like annoyed because like I just wanted him to talk properly and sometimes it would make me feel really sad because he used to say that the kids would bully him" (S03).
"I am sad when he is sad because he does a bump" (S10).

3.1.2.2. Positive emotions. Positive emotions, feelings and experiences described by the fluent siblings, included respect, pride, understanding, feeling good, hope, interest and having fun. The predominant positive emotion referred to in the interviews related to the sibling feeling constructive about being able to help. Further positive reactions were reported when the sibling saw improvement in the CWS’ stuttering disorder. This was exemplified by S08 and S06, older sisters of brothers who both had moderately severe stutters:

"The good things are when [CWS] is not frustrated, he corrects himself and that makes me feel quite happy with his talking" (S08).
"It’s getting much better because before he would always stutter and he’d get really annoyed at himself and he’d cry because he couldn’t get it right but it’s getting much better because yesterday we were in the car and he talked for 40 minutes without stammering and he was happy" (S06).

3.1.2.3. Responsibility. The majority of siblings (N = 8; 66%) reported a level of involvement in the therapy programme. Reasons put forward by the fluent siblings for wanting to be more involved in the CWS’ therapy included wanting to understand more and wanting to help. Some siblings attributed their importance in the therapy programme to their perception that they were ‘looked up to’ by the CWS. Reasons stated for not wanting to be involved in the therapy process included not wanting the responsibility and the belief that it was easier for parents to conduct the therapy. These subthemes were portrayed by the following quotes provided by S12 who was the older brother of a sister who had a severe stuttering disorder and also by S06 who was the older sister of a brother with a moderately severe stutter:

"I help [CWS] a little bit with his bumpy talking" (S12).
"I think I wish I was more involved because then I could really understand how to do it [therapy]" (S06).

A significant pattern was found with respect to involvement in therapy.
If the fluent sibling had no involvement in therapy, they generally did not have any desire to be involved. However, if they were slightly involved in therapy, they had a desire to be more involved. If they were heavily involved, they commonly did not have any aspiration to be more involved. Significantly, the duration of the CWS’ involvement in therapy was not related to their sibling’s stuttered speech severity.
Table 6: Descriptive statistics for the domains of the sibling relationship (collapsed across family members).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closeness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>2.41</td>
<td>.64</td>
</tr>
<tr>
<td>Control</td>
<td>3.16</td>
<td>.64</td>
</tr>
<tr>
<td>Conflict</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>2.70</td>
<td>.77</td>
</tr>
<tr>
<td>Control</td>
<td>1.76</td>
<td>.88</td>
</tr>
<tr>
<td>Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>2.82</td>
<td>.35</td>
</tr>
<tr>
<td>Control</td>
<td>2.64</td>
<td>.33</td>
</tr>
<tr>
<td>Rivalry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>1.17</td>
<td>.24</td>
</tr>
<tr>
<td>Control</td>
<td>1.04</td>
<td>.21</td>
</tr>
</tbody>
</table>

Note: higher scores indicate lower closeness, greater conflict, greater status disparity and greater rivalry.

3.1.3. Theme 3: impact on the parent–sibling relationship

3.1.3.1. Communication with parents. Although the majority (N = 8; 75%) of the interviewees reported discussing their sibling’s stuttering with their parents, only one child explained that their feelings about this disorder were ever discussed. Most of the other discussions with parents focused on ways to help the CWS, indicating that the considerations were not directed towards the fluent sibling. This was reflected in quotes obtained from S10 and S08 who were the older sisters of brothers who had significant problems with their communication:

"Mum tells us everything she has learned to help [CWS] and then we all try to help" (S10).
"We talk about ways that we can help [CWS]" (S08).

3.1.3.2. Attention from parents. Approximately half of the interviewees who were asked about parental attention stated that they received less parental attention as a result of having a brother or sister who stuttered. The other half stated that the amount of parental attention they received was not affected by having a sibling who stuttered. This subtheme was epitomised by S01, an older female sibling of a brother who had a moderate stutter:

"It gets a little frustrating sometimes because I want to say something and [CWS] kind of butts in and Mum says, 'Okay [CWS]' and pays attention to him because she wants him to speak more" (S01).

3.1.4. Theme 4: impact on the sibling’s relationship with others

3.1.4.1. Protection of the CWS and educating others. Approximately half of the fluent siblings identified positively their role as a protector of their sibling or as a person who could help to educate others. Two quotes which represented this subtheme were provided by S12 and S10 who were older siblings of a sister and brother who both had severe stuttering disorders:

"I can just tell them to leave [CWS] alone and that she was born with this and leave her alone" (S12).
"I don’t let them tease him. I protect him" (S10).

3.2. Quantitative analyses

An alpha level of .05 (two-tailed) was applied in all statistical tests of the quantitative data from the questionnaires. As a measure of effect size, Cohen’s d (d) was used for the independent samples t-tests, and eta squared (η²) was used for the independent design analysis of variance (ANOVA) tests.

3.2.1. Comparison of the domains of the sibling relationship

The mean scores on the four domains of closeness, conflict, rivalry and status were compared between experimental and control groups, collapsing across family members. Further, the mean scores on the four domains were compared between parents and children in both the experimental and control groups.

Table 6 displays the descriptive statistics pertaining to the four domains of the sibling relationship in the experimental and control groups, collapsed across family members.

A one-way independent design ANOVA of the domains of closeness, conflict and status, and a Mann–Whitney U test (due to the violation of the normality assumption) on the rivalry domain were conducted to test for differences between the experimental and control families.

The experimental sibling dyads demonstrated significantly greater closeness, F(1,94) = 30.63, p < .01, η² = .26; greater conflict, F(1,94) = 37.45, p < .01, η² = .30; greater status disparity, F(1,94) = 6.12, p = .02, η² = .07; and greater rivalry (through parental partiality), U = 570, p < .01, d = .57 than the control sibling dyads.

Further analysis of the data revealed that within the experimental group there were 51 responses (from eight different families) that demonstrated a degree of parental partiality, as opposed to 12 responses within the control group. Forty-eight
Table 7
Descriptive statistics for the domains of the sibling relationship (parents and children).

<table>
<thead>
<tr>
<th></th>
<th>Experimental Mean</th>
<th>Experimental Standard deviation</th>
<th>Control Mean</th>
<th>Control Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closeness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>2.38</td>
<td>.58</td>
<td>3.02</td>
<td>.59</td>
</tr>
<tr>
<td>Children</td>
<td>2.44</td>
<td>.71</td>
<td>3.31</td>
<td>.66</td>
</tr>
<tr>
<td>Conflict</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>2.71</td>
<td>.79</td>
<td>1.59</td>
<td>.53</td>
</tr>
<tr>
<td>Children</td>
<td>2.69</td>
<td>.77</td>
<td>1.92</td>
<td>.78</td>
</tr>
<tr>
<td>Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>2.82</td>
<td>.32</td>
<td>2.62</td>
<td>.34</td>
</tr>
<tr>
<td>Children</td>
<td>2.83</td>
<td>.39</td>
<td>2.57</td>
<td>.33</td>
</tr>
<tr>
<td>Rivalry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>1.18</td>
<td>.28</td>
<td>1.00</td>
<td>.00</td>
</tr>
<tr>
<td>Children</td>
<td>1.17</td>
<td>.19</td>
<td>1.09</td>
<td>.26</td>
</tr>
</tbody>
</table>

Note: Higher scores indicate lower closeness, greater conflict, greater status disparity and greater rivalry.

out of the 51 responses demonstrated parental partiality in favour of the CWS. In the experimental and control groups, there was an equal proportion of occurrences of maternal and paternal partiality.

3.2.2. Comparison of the perception of the sibling relationship

Table 7 displays the descriptive statistics pertaining to the four domains of the sibling relationship for the parents and children within the experimental and control groups.

A one-way ANOVA was conducted to determine whether, in each of the experimental and control groups, there was any difference between how parents and children perceived the sibling relationship.

There was no statistically significant difference between the parent and child perceptions of closeness when both the experimental and control groups were evaluated, $F(1,46) = .09, p = .77, \eta^2 = .02$ and $F(1,46) = 2.28, p = .14, \eta^2 = .05$ respectively. For both the experimental and control groups, there was no statistically significant difference between the parent and child perceptions of conflict, $F(1,46) = .004, p = .95, \eta^2 = .01$ and $F(1,46) = 2.80, p = .10, \eta^2 = .06$ respectively. In addition, there was no statistically significant difference between the parent and child perceptions of status when both the experimental and control groups were evaluated $F(1,42) = .001, p = .97, \eta^2 = .00$ and $F(1,46) = 2.1, p = .15, \eta^2 = .05$ respectively. Finally, in both the experimental and control group, there was no statistically significant difference between the parent and child perceptions of partiality, $U = 230, p = .76, d = .06$ and $U = 220, p = .15, d = .44$ respectively.

4. Discussion

This study investigated the experiences of fluent siblings of children who stutter to examine the impact that stuttering may have had on their lives. The study used a mixed methods research design incorporating qualitative semi-structured interviews and quantitative questionnaires. In light of the emergent qualitative themes and subthemes, and the significant quantitative findings, the framework for integration of results is summarised in Fig. 1 (adapted from Furman and Buhrmester 1985). Reprinted by permission).

This model describes how the impact factors may influence one another, and how each of the factors may be influenced by the stuttering disorder and family constellation variables. The model integrates the impact themes between the stuttering disorder and the sibling relationship, the sibling, the parent-sibling relationship and the sibling’s relationship with others factors.

The heterogeneous qualitative results of this study underpin Lobato, Faust, and Spirito’s (1988) perspective that “the impact of a child’s impairment on siblings may be best conceptualised as a risk factor, the significance of which is mediated by socio-demographic features, individual and family adaptive and functional patterns, sibling constellation variables, and impairment characteristics” (as cited in Pit-Ten Cate & Loots, 2000, p. 399). This study demonstrated the overarching impact of living with a sibling who stutters. A hallmark message is how the impact upon each child in the family unit needs to be evaluated by both parents and professionals in a discreet and judicious manner to ensure that each child’s needs are accounted for in the therapy process. The following is a discussion of the main themes that emerged from the conversations with the siblings.

4.1. Acceptance

During the qualitative interviews, the majority of the siblings used expressions such as “I’m used to it” or “It’s his time” as a means of justifying specific perceived inequities in living with a sibling who stutters. These insights were offered voluntarily and were not probed for in the interview per se. On the surface, acceptance appears to be a positive attribute. However, if
communication with parents regarding their feelings is inadequate, there may be dissonance regarding inward feelings and outward expression on the part of the fluent sibling.

4.2. Power and responsibility

In terms of stuttering treatment, it is widely acknowledged that parents are imperative in the therapy process. Whilst family-centred interventions are often deemed useful, such dependence on parents-as-clinicians may produce increased pressure on parents (Bar et al., 2008; Pratt, Botting, & Conti-Ramsden, 2006). This is of particular significance considering the fact that parent stress levels have been found to be a strong predictor of sibling adjustment difficulties (Pratt et al., 2006).

The interviews revealed different levels of sibling involvement in therapy, however, quantitatively, no trends emerged pertaining to any specific impacts on the fluent sibling. In fact, in several instances, siblings described positive emotions associated with having the control to assist in the therapeutic process.

The entire pattern of sibling involvement in therapy and siblings' feelings about their level of responsibility emerged as interesting and unique. The finding that if the sibling was slightly involved in therapy, they generally had a desire to be more involved suggests that once the opportunity to help is offered, the desire to help increases. When the fluent sibling had no involvement in therapy, they did not desire to be involved and, further, siblings who were significantly involved in therapy generally did not have any aspiration to be more involved. Communication regarding participation and responsibility for all family members emerged as an important clinical objective. Sibling involvement in therapy contributed to the occurrence of some positive emotions, but being provided with too much responsibility in the stuttering management programme contributed to negative emotions on the part of the fluent sibling. Delicate negotiation seems prudent in optimally utilising the resources that siblings are naturally extending in the home environment.

The age of the sibling constellation appeared to contribute to involvement in therapy, such that younger fluent siblings were more involved in therapy than older fluent siblings. It may be assumed that young children spend more time with each other conversing and interacting than do older sibling pairs.

Management of impairments and difficulties almost always means increased responsibility for someone in the family, at least in the short term (Damiani, 1999). It is crucial to understand how responsibility is distributed amongst family members in order to consider the implications for family dynamics and to plan appropriate intervention programmes (Damiani, 1999). If responsibility is naturally offered and borne, at least in part, by the sibling, early education and support in their understanding of stuttering disorders would be beneficial. Secondly, the expectations for therapy involvement should be discussed between the parents, clinicians, the CWS and siblings. In terms of practical involvement, respect for the possibility of some negative impact on the sibling needs to be monitored.
4.3. Negative emotions and communication with parents

A consistent finding was the fact that every sibling mentioned at least one negative emotion associated with having a brother or sister who stutters. It needs to be recognised that, due to the way the questions were framed, these were not simply emotions associated with having a brother or sister. The number of references to negative emotions and the type of negative emotions were not linked to the involvement in therapy, or to family constellation variables. This finding suggests that siblings’ discussions with their parents focused on ways to help the CWS, rather than on their own personal feelings or experiences. The findings within this study are consistent with Sellman and Darling (1997) who concluded that parents perceived that their nondisabled children were coping much better than the children themselves believed they were coping.

4.4. Protection of the CWS and education of others

A number of siblings engaged in the role of protector and educator, by reporting responsibility for their sibling’s stuttered behaviours in day-to-day social routines and in the company of peers or extended family. This protection provided by the siblings was not imposed upon them by parents, nor was it reported by parents. Rather it arose by the very nature of the sibling relationship and it predisposed them to naturally accept such a role. This is important considering the strength of the finding that there was no difference in protective roles associated with the relative ages of the siblings.

4.5. Sibling relationship

The responses to the quantitative questionnaires revealed that experimental sibling dyads had a closer bond, but simultaneously experienced greater conflict and disparity in status than control sibling dyads. Furthermore, the parents of experimental sibling dyads demonstrated significant partiality towards the CWS.

Of significance is the fact that the quality of the sibling relationship was perceived similarly between parents and children in both control and experimental families. Overall, the results of the quantitative questionnaires provided strong support for the themes which emerged in the qualitative interviews.

The strength of the relationship between fluent siblings and the CWS which emerged in the quantitative results mirrors some of the positive emotions articulated by the fluent siblings in the interviews. It is suggested that involvement in the treatment process and the protective role adopted by the fluent sibling may strengthen the underlying bond between the siblings. However, the greater amount of conflict experienced by the siblings also suggests a negative impact associated with having a sibling who stutters, which was also reflected in the interviews. It would appear that a link between conflict and parental partiality is likely. In two thirds of the experimental families, results indicated that the CWS was favoured, received more attention and was treated more positively than the fluent sibling. Furthermore, the disparity in status, which entailed dominance of and nurturance by the fluent sibling, correlated closely with the notion of power and responsibility that emerged in the interviews. It appears that nurturance, when the sibling assists in the treatment process, is a significant contributor to a positive sibling relationship, but dominance in which the power extends beyond assisting in treatment, has the potential to negatively affect that relationship.

The fact that parents and children perceived the sibling relationship similarly indicates insight on the part of parents regarding the impact of stuttering on their children’s relationship. However, despite this level of awareness, parents in the experimental families had a potential undesirable influence on the sibling relationship, specifically through parental partiality. Ultimately, these findings underline the importance of awareness and education regarding the potential impact of stuttering on the sibling relationship.

4.6. Strengths, limitations and future research

A key strength of this study was the fact that it asked some novel questions that may ultimately have value for enhancing treatment and addressing the needs of the whole family. There was rich data collected from a young population of participants and the nature of the research design was broad with layered quantitative and qualitative findings. This approach provided the opportunity to investigate the impact on and explore the experiences of fluent siblings of CWS in their own words in addition to whether a difference existed in relation to the quality of the sibling relationship compared to siblings with no CWS. Each of the qualitative interviews focused on the perceptions of the fluent sibling from their own frame of reference. Finally, the qualitative analysis reached saturation, indicating that the study was robust in representing the experiences of fluent siblings of CWS.

The combined mixed methods research design of this study reduced the respective limitations of using a single qualitative or quantitative approach (Hughes et al., 2010). Future studies may use a more diverse population of siblings of CWS to replicate or extend the findings of this study. Research on a larger cohort with a greater number of contributions from younger siblings, that is fluent siblings who are younger than the CWS, may provide further insights regarding particular emotions younger siblings experience as distinct from those of older siblings. Furthermore, this may elucidate at what age sibling relationships begin to be impacted upon by the presence of a CWS in the family. Considering that the average age of the siblings interviewed in this study was 9 years and 4 months, benefit may also be gained from more in depth and
comprehensive interviews with an older age group. Adult siblings for example, would be able to offer a lifelong perspective on the implications of living with someone with the stuttering disorder.

In order to increase the statistical power of the quantitative findings, further research could address the impact of the stuttering disorder on the sibling relationship using a greater sample size. In addition, further psychosocial investigations could address underlying features of the fluent sibling’s acceptance, given that indications of acceptance may in fact be representative of maladaptive coping mechanisms (Bellin et al., 2008).

5. Summary

In summary, the family unit, and specifically the fluent sibling, was impacted upon in a diverse number of ways by living with a CWS. Qualitatively, there was impact on the sibling relationship, the sibling him- or herself, the parent-sibling relationship, and the sibling’s relationship with others. Quantitatively, experimental sibling dyads experienced greater closeness and greater conflict and disparity in dyad status than did control sibling dyads. Furthermore, sibling rivalry due to significant parental partiality toward the CWS was greater in the experimental sibling dyads. Such results advocate holistic family centred practice as a means of minimising the negative impact of living with a sibling who stutters. Such impact was communicated most powerfully by one of the children who lived with a younger sibling who stuttered when they stated:

“Well sometimes I get annoyed at him but other times you just have to wait for him to finish. You can’t just fluently talk with him”.

A better understanding of the impact of stuttering on siblings may lead to a healthier integration of the entire family in the treatment process and even enhanced support from siblings in the clinical process.

CONTINUING EDUCATION

QUESTIONS

1. In the current study, what methodologies were employed?
   (a) Quantitative questionnaires completed by the experimental group
   (b) Quantitative questionnaires completed by the control group and the experimental group
   (c) Qualitative interviews conducted with the experimental group, and quantitative questionnaires completed by the control and experimental groups
   (d) Qualitative interviews conducted with the control group, and quantitative questionnaires completed by the control and experimental groups
   (e) Qualitative interviews conducted with the control and experimental groups, and quantitative questionnaires completed by the control and experimental groups

2. The results of the current study revealed which theme(s) regarding the impact of stuttering on the siblings of children who stutter?
   (a) Impact on the sibling relationship
   (b) Impact on the sibling
   (c) Impact on the parent–sibling relationship
   (d) Impact on the sibling’s relationship with others
   (e) All of the above

3. From the results of the experimental group’s quantitative questionnaires, there were 51 responses (from eight different families) that demonstrated a degree of parental partiality. How many of these 51 responses demonstrated parental partiality in favour of the child who stutters?
   (a) 0
   (b) 12
   (c) 24
   (d) 36
   (e) 48

4. The results of the current study revealed what percentage of fluent siblings discussed their role as one of protection and responsibility for educating others about their sibling’s stuttering disorder?
   (a) Less than 10%
   (b) Approximately 10%
   (c) Approximately 25%
   (d) Approximately 50%
   (e) 100%

5. The quantitative results of the current study revealed that the sibling dyads consisting of a child who stutters experienced which significant findings compared to those of the control group?
   (a) Greater closeness, greater conflict and greater disparity in status
(b) Greater closeness, less conflict and less disparity in status 
(c) Greater closeness, greater conflict and less disparity in status 
(d) Less closeness, greater conflict and greater disparity in status 
(e) Less closeness, less conflict and less disparity in status

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References


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Paper 5

The Impact of Stuttering on Adults who Stutter and their Partners.

The impact of stuttering on adults who stutter and their partners

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ABSTRACT
This study explored the impact of the stuttering disorder on perceived quality of life, with emphasis on the individual's relationship with their partner or spouse. Specifically, the purposes were: (a) to investigate what personal experiences and themes exist for both members of a couple dyad when one member of the couple stutters and (b) to examine whether the partners have different experiences with respect to the impact of stuttering on their lives.

A mixed method research design was used. Participant dyads (adults who stutter and their fluent life partner) each completed one semi-structured qualitative interview and two questionnaires: the Overall Assessment of Speakers' Experience of Stuttering (OASES), and the Medical Short Form 36 (SF-36).

Interviews were analysed qualitatively and significant themes evaluated. Quantitative results of the OASES and SF-36 were analysed, and scores correlated to determine the strength of any clinically significant relationships.

Results indicated that people who stutter and their fluent partners reported similar experiences in reactions to stuttering and perceived difficulties in communication. However, no relationship was seen between the two groups in perceived impact on quality of life. Qualitative results indicated that the participants shared life experiences including reactions to stuttering treatment undertaken and support. Such findings lend support to a broad-based clinical programme for adults who stutter that includes the fluent partner as an agent of change in their treatment. Findings also support the utilization of qualitative and quantitative research techniques to elucidate relevant psychosocial life themes and experiences for those who live with a stutter.

Educational objectives The reader will be able to: (a) identify the life themes associated with having a partner who stutters; (b) identify the perceived impact of stuttering for adults who stutter compared to their partners; and (c) discuss the clinical implications of the results with regards to working with adults who stutter.

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1. Introduction

1.1. The perceived life impact of stuttering

People who stutter (PWS) often view their speech as an obstacle to developing relationships with potential partners (Hayhow, Cray, & Enderby, 2002; Van Borsel, Brepoels, & De Coene, 2011). In part, this may be due to anxiety that some people who stutter develop about speaking in social settings. A meta-analysis of the literature conducted by Craig and Tran (2008) revealed chronic levels of anxiety experienced by those who stutter and their subsequent fear and avoidance of social interactions. Petrunk and Shearing (1983) explored these experiences regarding social interactions and suggested that underlying behaviours include avoidance, circumvention, voluntary disclosure and denial. A recent article by Van Borsel et al. (2011) found that adolescents and young adults perceived their peers who stuttered to be less attractive than those who were fluent. Further, these fluent young people were less likely to engage in a romantic relationship with someone who stuttered. There are a number of studies that have investigated the prevalence of avoidance behaviours and coping strategies in PWS (Daniels, 2007; Daniels, Hagstrom, & Gabel, 2006; Klein & Hood, 2004; Messenger, Onslow, Packman, & Menzies, 2004). However, there is a gap in the literature exploring the impact and prevalence of such behaviours on the personal support networks of people who stutter.

Klopas and Ross (2004) investigated the impact of stuttering on key psychosocial aspects of the PWS's life. Measures included employment, self-esteem, marital and family status as well as overall emotional functioning. The study found that 43.7% of participants identified that stuttering did have a negative influence on their marital and family life; however, the research did not explore how the quality of life of the partner of the PWS was also affected.

1.2. Quality of life

The concept of quality of life (QoL) for individuals who stutter is inherently complex and the empirical literature is not unambiguous. Patrick and Erickson (1993) recognised QoL as being "a comprehensive construct that encompasses the emotional, mental and physical functioning, life satisfaction and overall well-being" (p. 377).

It has been demonstrated that the features pertaining to QoL impacted upon for individuals who stutter may include vitality, social functioning, emotional functioning and mental health (Craig, Blumgart, & Tran, 2009; Yaruss, 2010). These features have been evaluated using both qualitative and quantitative assessment measures. People who stutter do not often report difficulties across the more physical areas within standard QoL instruments, such as pain, general health, vitality or sexual function. However, they do report difficulties often with social interactions, perceived ability to reach potential in education and vocational opportunities and general activities of daily living (e.g., Craig, 2010; Craig et al., 2009; Klein & Hood, 2004; St Louis, 2001; Yaruss & Quesal, 2006).

The clinical potential for measuring QoL provides a broader understanding of the clients' experiences and life impacts that the speech disorder may potentially pose. Yaruss (2010) suggests that it is, in fact, the essence of the speech pathologist's job to address their clients' quality of life and explore their life experiences. Further, the American Speech-Language-Hearing Association recognise this role to be one of "improving quality of life by reducing impairments of body function and structures, activity limitations, participation restrictions, and barriers caused by contextual factors" (ASHA, 2007, p. 4).

1.3. Other disorders

A number of studies have investigated the QoL of patients who live with adults with serious disabilities. Such studies have been conducted with partners of stroke survivors experiencing aphasia and partners of people who have suffered spinal cord disability (Angermeyer, Killan, Wiks, & Wittmund, 2006; Kershaw et al., 2008; Kim et al., 2008). These studies have found that spouses of people affected by a variety of communication-specific disorders or general sudden-onset chronic disabilities demonstrate significantly reduced and impaired QoL ratings. For example, literature specific to spinal cord injury has found that the spouse emerges as a key facilitator in their partner's rehabilitation. Further, it has demonstrated how the partner can embody a positive support system which in turn directly affects the level of therapeutic gain achieved following the sudden onset of the impairment (Kershaw et al., 2008; Kim et al., 2008; Vargo & Stewin, 1984).

1.4. Impact on partners of people who stutter

Previous research has explored others' perceptions of people who stutter from the point of view of teachers, students, professionals, parents, employers and peers (Crowe & Cooper, 1977; Crowe & Walton, 1981; Dorsey & Guenther, 2000; Fowlie & Cooper, 1978; Sass et al., 1992; St Louis & Sass, 1981; St Louis, Reichel, Yaruss, & Luber, 2009; White & Collins, 1984; Woods & Williams, 1976; Yeakle & Cooper, 1986). The impact that the speech disorder potentially poses has also been investigated from the perspective of the speech-language pathologists, vocational rehabilitation counsellors, special educators, relatives and family members (Cooper & Cooper, 1996; Cooper & Rustin, 1985; Craig, Hancock, Tran, Craig, & Perry, 2002; Doody, Kalinowski, Arman, & Stuart, 1993; Gunupalli, Kalinowski, Nambudrieswaran, Saltzkarogiu, & Erik Everhart, 2006; Hurst & Cooper, 1978; Kalinowski, Arman, Stuart, & Lerman, 1993; Lass, Ruscello, Pannbacker, Schmitt, & Everhart, 1984; Neals, Kalinowski, Stewart, & Rastatter, 2009; Turnbaugh, Guitel, & Hoffman, 1979; Woods & Williams, 1988; Rami, Kalinowski, Stewart, & Rastatter, 2000).
1976; Vail & Williams, 1970; Zhang, Saltuklaroglu, Hough, & Kalinowski, 2009). Despite the copious amount of research into others' perceptions of stuttering, the most intimate relationship of all, that with the partner, remains relatively unexplored.

Close relationships are believed to improve the overall physical and emotional domains within the individual's self-rated QoL (Myers, 1999). The social need for intimacy and companionship is an underlying driving force that sustains human beings in day-to-day living. Accordingly, the impact of disability on the formation and maintenance of intimate relationships is an important and previously limited theme in stuttering disorder literature. Given that people who stutter have reported concerns about their ability to form relationships (especially intimate relationships, e.g., Hayhow et al., 2002), it seems particularly important to explore how the experience of stuttering may affect partners of people who stutter. Moreover, if individuals who stutter are in some way limited in their ability to communicate with their partners due either to stuttering or to anxieties about speaking, this may lead to problems in the formation of long-term relationships or difficulties with problem-solving within the family unit. On the other hand, if a person who stutters is dependent upon his or her partner for communication, then this may have an adverse impact on the speaker's ability to participate fully in life experiences outside of the home environment.

Boberg and Boberg (1990) devised a hallmark study investigating theimpact of stuttering from the spouse's perspective. The study involved 15 marriage partners of the adults who stuttered who engaged in a series of interviews. Questions examined the diverse ways in which the spouse was affected by the partner's fluency disorder. The study identified a number of issues including: the emotional effects of the partner's fluency, related anxieties during courtship and anxieties on their actual wedding day. Further, Boberg and Kully (1985) raised awareness regarding the pivotal role the spouse could play as an agent for therapeutic change in their spouse's fluency therapy. In conversations between PWS and their fluent partners, fluent partners proved to be primary facilitators ensuring the success of the interactions (Hughes, Gabel, Irani, & Slaghekke, 2010). Boberg and Boberg (1990) also found that speakers achieved greater success when partners were actively involved in their spouses' therapy programmes. Other research has also recognised that supportive relationships serve as a critical benefit compared to the overall experience of therapy (Corcoran & Stewart, 1998). Still, specific issues related to how a stuttering disorder might affect the quality of life of fluent partners, or how the presence of a fluent partner might affect an individual who stutters, have yet to be examined.

1.5. Quantitative and qualitative stuttering research

Yaruss and Quesal (2004, 2006) proposed that existing models within the literature under-represent the complex experiences of PWS. Accordingly, they developed a quantifiable subjective measurement tool which assesses the life perspectives of stuttering: Overall Assessment of the Speaker's Experience with Stuttering (OASES; Yaruss & Quesal, 2006). This assessment evaluates the underlying, implicit effects of stuttering on a client's overall quality of life. Based on the client's self-perceptions, it serves to assess personal reactions in terms of affective, behavioural and cognitive reactions to stuttering, as well as functional communication difficulties and adverse impact of stuttering on quality of life. An important component of the speaker's experiences involves environmental factors, including interpersonal influences and the reactions of those with whom speakers interact, such as partners, family members or peers. To assess these interactions from the perspective of the speakers' partners, this study used an adapted version of the OASES specifically designed for use with the fluent partners of people who stutter.

An additional quantitative assessment that assesses the impact of disability across physical and emotional domains is The Medical Short Form 36 (SF-36) (Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 has been shown to possess good reliability and validity across a broad range of clinical populations (Craig et al., 2009). Craig et al. (2009) outlined how quantitative studies have assessed key areas that contribute to a person's happiness and how more recent qualitative research has extended the insights beyond that obtained through the predetermined categories found in traditional QoL measures.

Specifically, qualitative research has contributed interesting and clinically valid findings augmenting the previous reliance on quantitative measurement of stuttering (Boberg & Boberg, 1990; Corcoran & Stewart, 1998; Hughes et al., 2010; Klopman & Ross, 2004; Pexico, Manning, & DiLollo, 2005; Pexico, Manning, & Levitt, 2009a, 2009b). Qualitative research methods study the experience of living with a stutter and as such, provide opportunity to explore interconnections between participants' experiences which might otherwise be underestimated or lost (Tetnowsky & Damico, 1999).

To fully explore the perceptions of all participants and to capture detailed, representative data, the present study adopted a mixed methods approach. Tashakkori and Teddlie (2003) identified how a mixed method approach is most beneficial when the researcher wishes to answer questions that would be difficult utilizing an exclusive qualitative or quantitative approach. These authors further advocate a mixed methods design as a most legitimate means of exploration within social and psychological investigations.

1.6. Research aims

This study aimed to explore the impact of stuttering on perceived quality of life, with specific emphasis on the impact on the individual's interpersonal and most intimate relationship, that is, with his or her partner or spouse. Specifically, the purposes of the present study were to investigate: (a) quantitatively, what personal experiences and themes exist for the both members of a couple dyad regarding forming and maintaining personal relationships when one member of the couple stutters; (b) quantitatively, whether the individual who stutters and the fluent partner have significantly different

experiences with respect to the impact of stuttering on their lives. It was hypothesised that a finding of similarities in PWS and their fluent partners would provide further qualitative and quantitative support for stuttering research regarding personal experiences and the psychosocial impact of stuttering. This may in turn lead to a more comprehensive integration of the entire family in the treatment practice and even enhanced support from partners in the clinical process.

2. Methodology

2.1. Participants

Ten dyad couples constituted the 20 participants in the study. Nine males and one female formed the group of PWS. This group had a mean age of 39.7 years. The group of fluent partners consisted of one male and nine females. Their mean age was 38.3 years. Participant information is summarised in Table 1.

The following inclusion criteria for the PWS were applied when determining participation eligibility: (i) a clinical diagnosis of stuttering confirmed by a speech and language pathologist with no less than ten years of experience in assessment and treatment of fluency disorders; (ii) a relationship with their fluent partner for no less than one year; (iii) experienced no central nervous system trauma or in situ post puberty; (iv) no concurrent medical issues or co-morbidities that might confound the validity of their quality of life evaluations; (v) a confirmed age older than 21 years; and (vi) English as their primary language.

The spouse/partner (PPWS) had: (i) no history of speech dysfluency, communication, speech or language disorder; (ii) a relationship with their partner for no less than one year; (iii) no concurrent medical issues or co-morbidities that might confound the validity of their quality of life evaluations; (iv) a confirmed age older than 21 years; and (v) English as their primary language.

2.2. Qualitative procedures

In order to successfully investigate and analyse the qualitative component of the study, data were collected and analysed in concordance with the standards of a phenomenology qualitative research approach (Starks & Brown Trinidad, 2007). The 10 PWS and their fluent partners attended a semi-structured interview with one of the authors, all of whom have received specialised training in qualitative interviewing techniques. The PWS and their partners were provided with the choice to complete interviews separately or in the presence of one another. All of the dyads chose the latter. The qualitative interviews were conducted in a quiet room in the homes of the participants and lasted between 1 and 2 h. Interviews consisted of a set of questions adapted from the Bobberg and Bobberg (1990) research protocol, which was designed to elicit the participants’ personal experiences (see Tables 2 and 3). The questions were directed to both participants starting with one partner then checking the same question with the other until all the questions had been covered. In keeping with the principles of semi-structured interviewing, there was flexibility in questioning throughout the interview. The participants were allowed as much time as required to respond to each of the questions. Potential support and psychology services were organised prior to the interviews for the contingency that additional assistance may be needed as complex or sensitive topics arise. The participants’ responses were recorded on a high-quality digital audio recording device that allowed for easy transcription of the interviews.

Table 1
Participant information and descriptive summary.

<table>
<thead>
<tr>
<th>Couple &amp; code</th>
<th>PW</th>
<th>Age</th>
<th>Gender</th>
<th>PPWS</th>
<th>Age</th>
<th>Gender</th>
<th>Years in relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>1PWS</td>
<td>1</td>
<td>29</td>
<td>Male</td>
<td>1</td>
<td>29</td>
<td>Female</td>
<td>10 years</td>
</tr>
<tr>
<td>1PPWS</td>
<td>2</td>
<td>35</td>
<td>Male</td>
<td>2</td>
<td>35</td>
<td>Female</td>
<td>12 years</td>
</tr>
<tr>
<td>2PWS</td>
<td>3</td>
<td>40</td>
<td>Female</td>
<td>3</td>
<td>37</td>
<td>Male</td>
<td>8 years</td>
</tr>
<tr>
<td>3PWS</td>
<td>4</td>
<td>33</td>
<td>Male</td>
<td>4</td>
<td>35</td>
<td>Female</td>
<td>5 years</td>
</tr>
<tr>
<td>4PWS</td>
<td>5</td>
<td>36</td>
<td>Male</td>
<td>5</td>
<td>35</td>
<td>Female</td>
<td>10 years</td>
</tr>
<tr>
<td>5PWS</td>
<td>6</td>
<td>43</td>
<td>Male</td>
<td>6</td>
<td>35</td>
<td>Female</td>
<td>10 years</td>
</tr>
<tr>
<td>6PWS</td>
<td>7</td>
<td>30</td>
<td>Male</td>
<td>7</td>
<td>37</td>
<td>Female</td>
<td>14 years</td>
</tr>
<tr>
<td>7PWS</td>
<td>8</td>
<td>61</td>
<td>Male</td>
<td>8</td>
<td>60</td>
<td>Female</td>
<td>42 years</td>
</tr>
<tr>
<td>8PWS</td>
<td>9</td>
<td>52</td>
<td>Male</td>
<td>9</td>
<td>52</td>
<td>Female</td>
<td>32 years</td>
</tr>
<tr>
<td>9PWS</td>
<td>10</td>
<td>29</td>
<td>Male</td>
<td>10</td>
<td>28</td>
<td>Female</td>
<td>2 years</td>
</tr>
</tbody>
</table>

The digital recordings were transcribed verbatim and analyzed using the QSR Nvivo 9 qualitative analysis software. The process of analysis included open, axial, and selective coding to develop a set of themes (Liampittong & Ezzy, 2005; Plexico et al., 2005). Each of the interview transcripts were read and segmented into sections of text containing one main meaning (Giorgi, 1970). Each of the meaning units was then assigned a theme that identified discrete ideas and phenomena (Strauss & Corbin, 1990). After initial themes were stipulated, a subset of text was selected for analysis of inter-rater reliability. The three researchers agreed on the coding of themes and subthemes in 94 percent of the passages. Retrieval comparison within and across groups were made. Emergent themes and subthemes were examined and agreed upon by all three authors.

The final two interviews did not result in identification of any additional themes; all of the topics identified within these two interviews had previously been identified in prior transcripts. This indicated that there was adequate saturation (Glaser & Strauss, 1967) and confirmed the appropriateness of the subject numbers in this investigation. A range of additional procedures were followed to improve the credibility and reliability of the findings (Hughes et al., 2010; Plexico et al., 2009a, 2009b). The professional biases of the authors regarding stuttering, spousal relationships and the expected findings were examined before the interviews and during the study, as the various themes emerged from the analyses. Each researcher involved in the interviews and transcriptions was encouraged to suspend their anticipations, expectations, and hypotheses about the themes and phenomena of interest. All investigators had backgrounds in fluency disorders and one investigator (second author) had a background in qualitative research. The authors collaboratively developed the codes that ultimately became the themes which are detailed in Section 3. In addition, the authors responsible for transcriptions met periodically to review the use of phenomenological research approach and share ongoing feedback on the interviewing process and the creation of the themes.

2.3. Quantitative procedures

In addition to the qualitative interviews, the Medical Outcomes Study Short Form 36 (SF-36; Ware & Gandek, 1998; Ware et al., 1993) was completed by both the PWS and their fluent partners. The OAES (Yaruss & Quesal, 2006) was also completed by the PWS, while an adapted version of this tool was completed by fluent partners. This enabled comparisons
between their respective perceptions regarding the impact of living with the stutter, as well as an examination of similarities and differences in self-rated quality of life measures between the participant groups.

The OASES (Yaruss & Quesal, 2006, 2010) consists of 100 items, each scored on a Likert scale ranging from 1 to 5. For each item, response scales are organized so that higher scores indicate a greater degree of negative impact associated with stuttering and lower scores indicate less negative impact of the disorder. The questionnaire is divided into 4 sections: general information about stuttering and self-awareness of stuttering behaviours (OASES SI); affective, behavioural and cognitive reactions to stuttering (OASES SII); communication difficulties in daily situations (OASES SIII); and impact of stuttering on quality of life (OASES SIV). The OASES questionnaire takes approximately 15 minutes to complete. The parallel version of the OASES was developed specifically for this study, with the permission and support of the 4th author, to assess the experiences of the fluent partners (OASES-P). In this adaptation, the words your speech or you were replaced with your partner's speech or your partner. Raw scores were converted to impact scores using the procedure outlined by Yaruss and Quesal (2010) and these impact scores were used in data analyses.

In addition, the SF-36 questionnaire was given to both the PWS and the fluent partner to assess self-rated quality of life across the dimensions of physical and mental health of both the PWS and their partner. The SF-36 assesses the individual's perceived quality of life on a 5-point Likert response scale, with the obtained score compared to normative data as outlined in the SF-36 manual and interpretation guide (Ware et al., 1993). The questionnaire is scored by summing and transforming raw data for each of the eight domains and a resultant high score suggests a better QoL (Ware et al., 1993). The SF-36 has been shown to possess good reliability and validity across a broad range of clinical populations (Craig et al., 2009) and normative Australian data is available for statistical comparison (Australian Bureau of Statistics, 2006).

Descriptive statistics and effect sizes were computed for each of the OASES and SF-36 questionnaires. Paired t-tests were computed to determine the statistical significance of the PWS and PPWS's responses across the two questionnaires. An overall alpha level of .05 was maintained across the 6 t-test comparisons, with an individual alpha for each comparison of .0083 following the Bonferroni correction. In addition, Pearson product-moment correlations were carried out to determine any relationships in the study variables between people who stutter and their fluent partners. Again, an overall alpha of .05 was maintained, with the individual alpha for each correlation analysis defined as .0083.

2.4. Procedure

Ethics approval was obtained for this study through the requisite Human Research Ethics Committee. Informed consent was obtained from all participants. The OASES and SF-36 questionnaires were provided to the participants following their interview session in order for them to complete the forms separately at home and then return them to an examiner.

3. Results

3.1. Qualitative analysis

A large quantity of data was accumulated from the interview transcripts. In total, 7 main themes and 42 subthemes emerged and are summarised in Table 4.

3.1.1. Theme: advice

One of the most common themes evident in the dyads' responses involved the provision of advice to other people who stutter and their partners. This involved advice about acceptance of stuttering, participation in treatment and general advice for couples where one partner stutters.

3.1.1.1. Acceptance. Twenty per cent of respondents referred to the notion of 'acceptance' during the advice component of their interviews. This subtheme emerged from interview transcripts of both the PWS and their fluent partners. They discussed how being accepting of the stutter, and not regarding it as a limitation, was imperative to the PWS's potential speech recovery. This subtheme was illustrated by quotes obtained from a husband who stuttered and his wife who had been married for 32 years:

PWS

'In every situation you have to deal with stuttering and may hide it in everyday situations. It's something that we both have to work on.'

PPWS

'I'd encourage everyone to work on being more accepting of themselves as a person who stutters and try not to hide in new social situations.'

3.1.1.2. Treatment. A number of participants indicated their preference for treatment including what they perceived was important in the therapeutic process:

PWS

'Both stutterers and their partner, whether supporting them, should be in some pre-treatment workshops and discussions. And the discussions should be completely honest. Honest in that the therapy is not going to cure you. There is no cure. You're starting on a journey that's going to be life-long.'

Thank you for your help in providing the text. If you have any further questions or need assistance, please let me know! 😊
Table 4
Main themes and subthemes of personal accounts of living with stuttering from PWS and PPWS perspectives.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice</td>
<td>Acceptance</td>
</tr>
<tr>
<td></td>
<td>For treatment</td>
</tr>
<tr>
<td></td>
<td>Frustrations</td>
</tr>
<tr>
<td></td>
<td>Openness</td>
</tr>
<tr>
<td></td>
<td>Patience</td>
</tr>
<tr>
<td>Initial impressions</td>
<td>Awareness</td>
</tr>
<tr>
<td>Knowledge of stuttering</td>
<td>Acceptance</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
<td>Denial</td>
</tr>
<tr>
<td></td>
<td>Embarrassment</td>
</tr>
<tr>
<td></td>
<td>Prior experience with stuttering</td>
</tr>
<tr>
<td></td>
<td>Frustration</td>
</tr>
<tr>
<td></td>
<td>Grief and loss</td>
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<tr>
<td></td>
<td>Life impacts for partner</td>
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<tr>
<td></td>
<td>Protection</td>
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<tr>
<td></td>
<td>Reactious</td>
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<tr>
<td></td>
<td>Threatened</td>
</tr>
<tr>
<td>Partnerships</td>
<td>Acceptance</td>
</tr>
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<td>PWS' experience with</td>
<td>Aggression</td>
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<tr>
<td>stuttering</td>
<td>Avoidance</td>
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<td>- Lack of Cultural effects/bilingualism</td>
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<td>- Maltreatment</td>
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<td>Perseverance</td>
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<td>Relationships/dating</td>
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<td>The stutter (history of)</td>
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<td>Withdrawal</td>
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<td>Impact on relationship</td>
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<td>Reduced access</td>
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<td></td>
<td>Personal growth/development</td>
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</table>

3.1.1.3. Openness. Both openness and honesty were prevalent throughout the majority of the interviews. These subthemes were further endorsed by 'partner support', an additional theme that will be discussed under Section 3.1.7. The subtheme of openness was exemplified by the following quotes:

PPWS5: I would say talk to them. Talk about it because we never talked about it for a while. I mean we never sort of said it was a thing to talk about.

PPWS7: I would just be completely open with it. Allow yourselves to be open and honest, tell the other person what bothers you, get it right out from the start and don't let it fester. You should both just discuss it, get it out there.

3.1.1.4. Patience. Patience was referred to by two of the fluent participants over five separate occasions. Both participants reflecting this subtheme advocated for a patient and understanding approach to their partner's speech difficulties. This subtheme was illustrated in the following quotes provided by two fluent spouses:

PPWS6: Be really patient — because it can frustrate me sometimes. Like when I am in the middle of a conversation with him and he can't get that word out, it can frustrate me. But you just need to be patient.

PPWS8: Just be patient you know. Let them say as much as they can and prompt them if they need.
3.1.2. Theme: Initial Impressions
To establish a positive environment in which the participants would share their stories, the researcher asked participants to reflect on when they first met their respective partners and their initial impressions. Below are two reflections:

PW59: We went all the way through school together. I just remember she was always athletic and sports champion and sought after by other boys. So out of my league.

PW55: Made for me. That's what I thought.

3.1.3. Theme: Knowledge of Stuttering
As participants shared their stories, a number of references to their knowledge and/or awareness of stuttering arose. The diverse range of participants meant that there was a broad spectrum of understanding. This extended to the fluent partner's awareness of their partner's speech difficulties as well as general information about dysfluency. The issues discussed also reflected some misconceptions about stuttering as reflected below:

PW52: I knew I stuttered but I never knew it was something you can cure.

PW58: They [family] thought that I would grow out of it.

But I think that if the stutter [is] going to get worse, it will come out through our friction in our family. Well, I think it did.

3.1.4. Theme: Partners' Perceptions of and Reactions to Stuttering
During the accounts offered by the PPWS, 11 subthemes pertaining to perceptions of and reactions to stuttering emerged. These subthemes represented the unique and individual experiences each partner recounted about their experiences of living with a stutter.

3.1.4.1. Acceptance. This theme described both the partners' acceptance of the stutter, and other life aspects on which stuttering potentially impacts. This subtheme is exemplified by the following two quotes:

PW54: He's gone through nearly all his life with this and he works. He's done really well with his stuttering.

PW55: Then I realised what kind of problem [was] for him. For me it's not a big problem, because it didn't affect me much. But professionally, I realised there was going to be a problem for him.

3.1.4.2. Anxiety. The adults who stuttered expressed significant concerns with social interactions and as a result anxiety was a subtheme identified in the majority of the partner interviews as well when discussing their social lives with their partners:

PW54: I become really anxious sometimes when we are out in a social environment and I can see him stuttering. But most of the time I hope that he will be fine.

The quote below details a participant reflecting on her husband's first therapy session, which was recorded and shown to her:

PW59: I found it really distressing to watch it. Really really distressing.

3.1.4.3. Embarrassment. The interviews frequently raised the topic of embarrassment for people who stutter:

PW56: He lives a sheltered life, because he doesn't like interacting with people. Because of the way he talks. And he's obviously quite embarrassed about it, you know.

One participant reflected on an earlier encounter with someone who stuttered during her school days and expressed how she felt during the times when her classmate was dysfluent:

PW57: She was so bad that you'd feel embarrassed for her. It was tough, really really tough. And we were always told to walk on eggshells around her.

3.1.4.4. Prior Experience with Stuttering. Before meeting their partner, most participants had previously met someone who stuttered and the researcher asked them to reflect on this:

PW57: It was painful I have to say. We had a girl in our class and she was terrible. It was painful to watch her. Lovely, lovely girl. But it was hard, you couldn't look because you felt so awful.

PW53: There was a kid at school that had a bit of a stutter. And we teased him?

PW53: Yeah, cos as a kid you would take the piss because you know it was a stutter. But you'd always think why as a kid, they don't talk like us.

3.1.4.5. Frustration. A number of partners revealed that they often became frustrated with their partner's speech and the impact it has on their respective lives:

PW56: It's a bit frustrating on my behalf because he won't use the phone, he won't communicate with people properly. And that's frustrating on my behalf because I like to get out there and meet people and do things with people, and he just doesn't like to do that.

PW59: There are all these things that just keep nagging you in the face in different stages of your life where you reflect back and you think 'Well this isn't how it's meant to be'.

PW59: I remember saying to him 'look you've got to do something about this,' because then I recognised that I couldn't carry everything.

3.1.4.6. Protection. Forty per cent of the partners expressed their concerns towards their partners and described how they protected them when they needed to do so:

PWS5: And I have defended him a lot when he's not been there and people have said things. I've jumped in and said 'that's not right'.

PWS6: No we never really talked about or discussed his stutter. I didn't really want him to feel embarrassed about it.

3.1.5. Theme: partnership

The majority of the partners reflected unity in their partnership and shared experiences:

PWS5: No I don't feel I have a problem. It's our problem.

PWS9: We're both involved, you're starting on a journey that's going to be life-long.

3.1.6. Theme: PWS's experience with stuttering

Several significant themes emerged from the responses of the partners who stuttered as they reflected upon their prior experiences, persistent difficulties and the approaches that they have adopted in order to successfully participate in society.

3.1.6.1. Avoidance. This issue was powerfully conveyed in the interviews of 12 participants and consequently emerged as the most prevalent subtheme of this study. Avoidance was characterised by explicit avoidance of words or sounds that typically evoked a stutter, avoidance of people and social situations, and resistance to discussion about or recognition of the stutter. The subtheme avoidance is exemplified below:

PWS3: I didn't want to go to school. I used to hate that school. Maybe that's why I enjoyed art as a kid I think, because I didn't have to talk.

PWS5: I would not do anything to do with [speaking]. Anything do with speaking, I made sure I'm not there.

PWS8: I just try and avoid things when I can. At times I even avoid people, I think that's why I tend to stick to myself. That's much of what I do.

3.1.6.2. Social anxiety. Following 'avoidance', social anxiety emerged as the next most prevalent theme from the interview data. The stress of living with a stutter and having to deal with the fear of social interactions was reflected in the responses below. The responses of the fluent partners illustrate their perceptions of their partner's struggle and detail how they provided comfort and/or support:

PWS3: When you gotta deal with people and you had to talk with strangers, because you have to control your stutter, that was quite interesting, it's nerve wracking in itself, plus you're trying hard to control your stutter.

PWS4: I think it affects how I learnt and my view of the world as well, in that I think either I'm a very anxious person or it's because I stutter, I'm an anxious person, because, before I even ask something, I'd be 'oh hang on, I gotta ask,' and I'd get worried about something.

3.1.6.3. Embarrassment. In addition to anxiety, embarrassment emerged as a significant experience that occurred during social interactions and discourse:

PWS5: And obviously he's quite embarrassed about it, or you know, embarrassed and...

PWS9: And I used to come home sometimes, with girls' telephone numbers but then I could never ring them. Once I did try to ring up a girl, I really liked and then it didn't really work, so she hung up on me before I even got a word out.

3.1.6.4. Acceptance. Thirty per cent of the adults who stuttered expressed their ongoing personal development and eventual self-acceptance. They highlighted their enduring difficulties and inner conflict but reflected upon their ultimate acceptance and confidence. Two representative quotes are detailed below:

PWS9: I'm in a different phase, so I don't mind. I don't worry when I stutter, because I know that I can. 'Oh it's not the end of the world' and now I can bring it back.

PWS4: [Reflecting on his therapy]. 'Every fibre of me just said 'I don't want to do this anymore' 'I'm just going to do what I do. It's kind of accepting to some extent. And learning that people really don't care as much as you do about it.'

3.1.6.5. Confidence. This theme emerged in both positive and negative contexts as some participants reflected on how the stutter had detrimentally affected their confidence whilst others revealed that therapy had facilitated improvement in their self-esteem:

PWS7: As I got confident, my stutter got less and less.

PWS5: He doesn't have the confidence to try and do it. He wants someone else to do it.

3.1.6.6. Cultural impacts and influences. Issues were raised regarding different communities and the diverse reactions to stuttering:

Interviewer: Was there a lot of knowledge of it [stuttering] in Zimbabwe?

PWS7: No.

PWS5: No, there was nothing.

PWS7: I believe they were very much the old school way of letting the person struggle through it and not interrupt.

PWS5: In Sri Lanka we don't have any kind of speech therapy or anything. They just said 'practice, you'll be right'. On several occasions my father would give me stones to put in my mouth to practice and [would] have my tongue outside, and stay like that for hours, just to practice.
3.1.6.7. Denial. Several participants expressed denial in relation to the severity and extent of speech difficulties:

PWS5: I don't have a problem with fluency, I think. I have problems with situations like...it's not fluency. So it's not to do with fluency.

PWS7: [PWS] was actually in a little bit of denial about the whole thing when it started. He didn't want to believe it was a problem [for their son], he kept saying 'leave it, leave it.'

3.1.6.8. Fear. Several participant dyads, reflected upon a sense of fear that greatly impacted their lives:

PWS9: That [meeting new people] was really scary.

PPWS9: He was so terrified. He could have just about cancelled the wedding.

PPWS3: And [when my son began stammering] my worst fears came to life.

3.1.6.9. Frustration. Both groups expressed frustration arising from situations in which the PWS experienced dysfluency:

PPWS1: It's very frustrating for him. I mean for me as well.

PPWS7: And then he pointed it out to me and said 'look, it really bothers me when you do that,' he was getting very annoyed with me because it was so easy to jump in and finish his sentence.

3.1.6.10. Others' reactions. The participants discussed life impacts and how other people have reacted to their speech.

PWS9: The enrolment clerk just got so frustrated that she threw the pen and paper at me and said 'here you fill it in.' Then I went and confronted my boss and he said 'look, just frankly, be thankful you've got a job. You'll never be manager.'

PPWS7: My father was really concerned about [PWS's] stuttering when we started dating. He wrote to all these organisations over the world and got all this information.

3.1.6.11. Relationships and dating. Participants reflected on the impact of stuttering had on their previous romantic relationships:

PWS9: She was my voice prior to therapy, for a long time.

PWS10: And it was good that my then girlfriend didn't mind [about the stutter], & there are some people who would mind.

3.1.6.12. School-aged experiences. The majority of the PWS reflected upon their school-aged years, which was uniformly described as the most difficult period of their lives:

PWS7: My school life up to that was an absolute hell. I went to 3 schools before I actually made peace with myself.

PWS8: You know at primary school, when you stutter, you just get teased a lot.

3.1.6.13. The stutter. Additional information pertaining to the background of the PWS’s speech difficulties was coded at this level. It describes the individual’s experience and history of their stutter and reflects perceived changes within their speech over time:

PWS10: I feel I can control it a bit better than what I used to before. I just found it really difficult to talk fluently. My facial expressions would be all weird and I just found it really difficult. Over the years, you get to know a bit more about yourself and how to control your speech.

3.1.6.14. Withdrawal. This theme emerged as the participants expressed how the stutter had impacted on their choices to interact with others and how it consequently contributed to feelings of introspection:

PWS8: You go into your own shell, you don’t interact with people.

PPWS9: Looking back, we spent a lot of time as a couple just by ourselves. We didn’t do as much socialising with friends. We probably kept very... quite insular.

3.1.7. Theme: support

Couples reflected upon their relationships and expressed how the fluent partners have facilitated their partners' improvement or success with their speech.

PPWS5: There are times, like when I see him doing it specifically, like if he’s talking to somebody and just in between I try to fill [in] the word for him.

PPWS6: I’d actually help him out. Like if he’s talking to somebody and he can’t get the word out, I’ll help him and say the word for him.

3.1.8. Theme: treatment and relapse

PWS were asked to describe previous and relevant intervention programmes that had been undertaken and there was a wide range of treatments and strategies that were detailed.

PWS7: We had all those old wives tales, peas under the tongue...

PWS9: I went to speech therapy. Came out, thought I was cured... But then I crashed, it was so much harder... I was still hiding my stutter behind my newfound fluency.
Table 5
Means and standard deviations for OASES and SF36 scores for people who stutter (PWS) and their partners (PPWS), T-values, p-values, and effect sizes, as well as Pearson correlations and p-values are shown for t-test comparisons between people who stutter and their partners.

<table>
<thead>
<tr>
<th>Measure</th>
<th>PWS M SD</th>
<th>PPWS M SD</th>
<th>T-test</th>
<th>p-Value</th>
<th>Effect size</th>
<th>Correlation</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>OASES I</td>
<td>2.44 0.60</td>
<td>2.31 0.83</td>
<td>1.41</td>
<td>0.19</td>
<td>0.23</td>
<td>0.88</td>
<td>.0014*</td>
</tr>
<tr>
<td>OASES II</td>
<td>2.25 0.88</td>
<td>2.14 0.86</td>
<td>1.17</td>
<td>0.27</td>
<td>0.16</td>
<td>0.91</td>
<td>.003*</td>
</tr>
<tr>
<td>OASES III</td>
<td>2.15 0.90</td>
<td>2.2 0.85</td>
<td>0.32</td>
<td>0.76</td>
<td>0.06</td>
<td>0.76</td>
<td>.008*</td>
</tr>
<tr>
<td>OASES IV</td>
<td>1.80 0.62</td>
<td>1.46 0.29</td>
<td>1.85</td>
<td>0.10</td>
<td>0.70</td>
<td>0.10</td>
<td>.78</td>
</tr>
<tr>
<td>SF36 - MH</td>
<td>136.11 12.62</td>
<td>138.03 11.98</td>
<td>2.20</td>
<td>0.06</td>
<td>0.16</td>
<td>-0.22</td>
<td>.35</td>
</tr>
<tr>
<td>SF36 - PH</td>
<td>145.72 6.77</td>
<td>127.12 24.46</td>
<td>0.32</td>
<td>0.76</td>
<td>1.03</td>
<td>-0.18</td>
<td>.02</td>
</tr>
</tbody>
</table>

* Significant at Bonferroni-adjusted alpha = .0083; overall alpha = .05.

One adult who stuttered flew to America to participate in an intensive, residential workshop. Financial and emotional consequences were outlined in his attempts to find a 'cure' for his stutter. Such findings are consistent with those reported by Craig, Blumgart, and Tran, (2011) identifying the considerable costs incurred by some adults in obtaining treatments.

PWS10 I went to the states and had therapy there. I did an intensive course for 14 days straight because I really wanted to improve my speech. That was big bucks as well. I heard about it from the Internet. I saw their website and they claimed to have pretty good results from their clients. It worked for me for only a short time.

3.2. Quantitative results

A two-tailed paired samples t-test with an alpha level of 0.05 was used to compare the average scores on the OASES and SF36 questionnaires across the two groups (PWS and PPWS). The data were scanned for univariate and multivariate outliers with no significant outliers identified. Visual inspection of the relevant histograms indicated that there was no violation of the normality of the data or the difference scores. Descriptive statistics were computed for OASES and SF-36 and are shown in Table 5. Effect sizes were calculated using Cohen's d.

3.2.1. Between-group comparisons

3.2.1.1. OASES. For the majority of cases the impact scores reported by the PWS were higher than those reported by the PPWS (see Table 5), but there were no statistically significant differences between the self-reported OASES outcome measures provided by the PWS and the PPWS, OASES I, t(9) = 1.41, p = .19; OASES II, t(9) = 1.17, p = .27; OASES III, t(9) = -3.2, p = .76; or OASES IV, t(9) = 1.85, p = .10.

3.2.1.2. Quality of life SF36. There were no statistically significant differences between PWS and the PPWS on either the physical (PH), t(9) = 2.20, p = .06, or mental (MH) domains, t(9) = -3.2, p = .76, of the SF36 questionnaire.

3.2.2. Correlational analysis

Pearson product moment correlations were computed to compare how people who stutter and their fluent partners responded to the OASES and SF-36 questionnaires. Results, shown in Table 5, revealed strong, positive, significant correlations on the OASES-I, OASES-II, and OASES-III subsections. This indicates that people who stutter and their partners reported similar experiences with respect to their knowledge of stuttering, their personal reactions to stuttering, and the degree to which stuttering affected communication. No significant correlations were found in OASES-IV or either of the SF36 subtests, indicating that people who stutter and their partners did not judge the impact of stuttering on quality of life in the same way.
4. Discussion

This study combined qualitative and quantitative methodologies to investigate participants’ personal narratives and experiences with stuttering, their romantic/personal partnerships and the impact on these relationships. It was anticipated that partners would report quality of life ratings and shared experiences that closely paralleled those of their disfluent spouse. Research regarding personal experiences of partners underpins Sheehan’s (1970) iceberg analogy whereby the hidden portion below the surface of the speech symptoms comprises the interpersonal and psychosocial aspects of the impact of stuttering.

4.1. Qualitative

Interviews within this study evoked rich, multifaceted responses from all participants resulting in a large number of themes that summarised their life experiences. The themes distributed across two domains from the model of stuttering based on the ICF framework: (i) environmental factors and (ii) personal factors/reactions (Yaruss & Quesal, 2006). The environmental aspects of the participants’ experiences pertained to those interactions between the speakers and their partners or the environment (e.g., support, other people’s reactions to stuttering and initial impressions). The personal factors and reactions concerned the delicate experiences for the PWS and their fluent partner, such as acceptance, frustration and fear in life (Table 6).

4.1.1. Environmental factors

The most prevalent themes emerging in this domain were reflections upon prior experiences and the impact of supportive relationships. Many participants from the stuttering group reported intense feelings of social anxiety. Those who reported higher perceived ratings regarding the impact of their stutter consequently described experiences of social anxiety and negative reactions of others towards their stutter. This resulted in a deleterious outlook towards social communication often resulting in avoidance of such situations. These experiences were reiterated in the partners’ responses to questions pertaining to the perceived severity of the PWS’s communication ability and perceived reactions of others.

A qualitative retrospective investigation into the school-aged experiences of adults who stuttered found that vital peer relationships were identified as at risk during this period of life due to the impact of stuttering on successful communication (Daniels, 2007). Many of the adults who stuttered in this study, shared similar stories that evoked painful memories of unsuccessful social interactions during their younger school years. Such reports included social ostracism and teasing from their peers. In addition, the participants testified that during their secondary schooling, they had difficulty forming personal/romantic relationships because they avoided talking with members of the opposite sex. Linn and Caruso (1998) poignantly stated that “speaking/communication plays a major role in the development of interpersonal relationships and people who stutter may experience greater difficulty in such relationships as compared to their fluent counterparts” (p. 13).

The fluent partners also reflected on the perceived impact of the stutter upon communication with their spouse and explained the support that they felt they provided on a regular basis. This type of support varied from explicit provision of a target word, to broader concepts of patience in allowing the PWS to express themselves without pressure. Further, they encouraged their spouse to seek therapy, and described the support they provided regarding the range of decisions their partner made in the pursuit of fluency. Finally, the fluent partners described strong and unflawing acceptance of their spouse and their stutter. Throughout the interviews there evolved a profile of individually tailored and personal approaches to successfully building a secure and supportive partnership.
4.1.2. Personal factors/reactions
This domain encompasses the personal and individual experiences of living with a stutter. The most prevalent themes that emerged from this domain were avoidance and anxiety. Previous research has described the close relationship between anxiety and expectancies of social harm (Messenger et al., 2004). This expectancy is the anticipation of stuttering in a social context that ultimately adversely affects the public interaction and increases the PWS’s negative self-perceptions. Both the PWS and their partners in this study reported these feelings of anxiety and stress evoked during such situations. The close parallel of the psychosocial aspects reflected in the responses by both individuals within the couple dyads supports the notion of the shared experiences of living with a stutter proposed by Boberg and Boberg (1990). Couples reflected almost identical psychosocial features within their interviews as they demonstrated feelings of acceptance, anxiety, avoidance, denial, embarrassment and frustration.

The most poignant insights emerging from the interviews pertained to those relating to psychosocial influences on stuttering. The participants openly and honestly shared their experiences with the primary investigator and responses were abundant and diverse. Corcoran and Stewart (1998) proposed that “It is critical that speech-language pathologists obtain the story or narrative of the client’s experience of stuttering in order to learn the personal meaning given to this experience” (p. 261). The sensitive narratives of participants within this study provided insight into their individual experiences of living with a stutter. Incorporating such unique perceptions, expectations and support would in turn lead to a healthier integration of the partner in the treatment process. The partner responses in this study were congruent with those observed by Boberg and Boberg (1990) who found that successful therapy resulted from encouragement and involvement of the spouse and that a more complete understanding of the therapy process was achieved by involving the spouse from the outset.

4.2. Quantitative

The current study compared the quantitative perceptions of the PWS and their partners and found no statistical differences between the responses of adults who stutter and their partners in addition to the strong correlations of the study responses for knowledge about stuttering, negative reactions to stuttering, and functional communication difficulties associated with stuttering. This suggests that fluent partners shared accurate and overall congruent perspectives of the impact of stuttering on their partners who stuttered. Interestingly, however, speakers and their partners did not report the impact of stuttering on quality of life in the same way, as no significant correlations were found for the OQL of the OASES or for the two subscales of the SF-36. This suggests that, even if fluent partners understand the nature of stuttering in the same way as their stuttering partners, they may still not be fully aware of the true extent of the adverse impact that stuttering may have.

4.3. Strengths and limitations and future research

Strengths of this study include the detailed, layered and significant amount of information obtained from fluent partners and adults who stuttered in recounting aspects of their personal relationships. A mixed methods design was chosen so that distinctive trends in partner support might be highlighted while consideration was provided to a layering of personal contexts, opinions and experiences. The adoption of a mixed methodology procedure and analysis enhanced both the validity and implications of these outcomes.

A number of limitations should also be noted. This study attempted to obtain a randomly selected, representative sample of participants, but the recruited sample reflected only 10 couple dyads. A larger cohort may provide different insights regarding diverse life experiences, though analyses revealed that saturation of themes was reached with these 10 dyads. In addition, the treatment histories of the adults who stuttered in the study were not explored. Such background information about the types of treatments attempted, and details regarding the amount of time, money and resources expended in the past may have provided additional context for the responses and reactions described. Another possible concern may also exist in the methodology, given that the parallel form of the OASES develop for partners was not independently validated; however, the strong consistency between the response of people who stutter and the responses of their fluent partners suggests that the assessment accessed the same constructs. Next, it is possible that the results were biased by the fact that all dyads of participants and their partners opted to conduct their interviews together, rather than separately. This could be addressed through the use of independent interviews for speakers and their partners. Finally, future research which includes a larger number of females who stutter and their partners may allow for comparisons regarding the effects of gender on the experiences of living with stuttering.

4.4. Conclusion

This study explored the lives of 10 couples living with stuttering. The mixed methods approach investigated the participants’ personal narratives revealing comparable responses and themes from both partners. The congruent and significant themes of anxiety, avoidance and supportive relationships emerged most strongly. Findings from the OASES and SF-36 identified the holistic impact of stuttering on environmental/reactions and personal domains for the person who stutters and their life partner. The conclusions provide support for a healthier integration of the entire family in the treatment practice with enhanced support from partners in the clinical process.

CONTINUING EDUCATION

The impact of stuttering on adults who stutter and their partners

QUESTIONS

1. In the current study, what methodologies were employed?
   (a) Quantitative questionnaires completed by the experimental group
   (b) Quantitative questionnaires completed by the control group and the experimental group
   (c) Qualitative interviews conducted with the control and experimental groups, and quantitative questionnaires completed by the control and experimental groups
   (d) Qualitative interviews conducted with the experimental group, and quantitative questionnaires completed by the control and experimental groups
   (e) Qualitative interviews conducted with the control group, and quantitative questionnaires completed by the control and experimental groups

2. Which qualitative theme was not reported by the partners of adults who stutter in this study?
   (a) Advice
   (b) Support
   (c) Knowledge of stuttering
   (d) Treatment and therapy
   (e) Other disabilities

3. Quantitative results from the partner's questionnaires revealed which of the following to be correct?
   (a) There were no significant differences in the responses of speakers and their partners in terms of OACES or SF-36 scores
   (b) People who stutter reported significantly more negative reactions to stuttering than their partners
   (c) People who stutter reported significantly less negative reactions to stuttering than their partners
   (d) There was a strong positive correlation between speakers and their partners in perceived quality of life on the SF-36
   (e) There was a strong positive correlation between speakers and their partners in perceived quality of life on the OACES

4. Qualitative results from the adults who stutter revealed which of the following to be correct?
   (a) Self-assurance in social situations
   (b) Anxiety towards reactions of others
   (c) Advantages in terms of occupational opportunities
   (d) Confidence in public
   (e) Benefits of stuttering in general

5. Which of the following participant information in this study is NOT correct?
   (a) Nine females and one male in the PWG group
   (b) Age range from 28 years to 61 years
   (c) Nine males and one female in the PWG group
   (d) One male and nine females in the PWGS group
   (e) 10 dyad couples

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References


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Paper 6

Acceptance and Commitment Therapy for People who Stutter.

Acceptance and Commitment Therapy for People Who Stutter

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Abstract

In contemporary clinical allied health and medical settings, there has been a proliferation of Acceptance and Commitment Therapy (ACT) programs. These clinically effective programs have reduced comorbid anxiety, depression, and stress for individuals suffering from chronic medical and psychosocial issues. However, to date, there has been no published work examining the effectiveness of an integrated ACT program for individuals who stutter. In this review, we will provide a platform from which readers will be able to (a) appraise the literature regarding combined speech pathology and psychology therapeutic programs for people who stutter, (b) appreciate an overview of ACT in the context of stuttering disorders, and (c) understand the relevant psychosocial outcome measures that constitute therapeutic change. This unique review of ACT will distinguish the processes of self-concept, defusion, acceptance, mindfulness, values, and committed action in support for people who stutter who experience psychosocial distress. In the culmination of the review, we advance the integration of ACT into current treatments for individuals who stutter.

Historical Overview of Cognitive Behavior Therapy and Stuttering

Researchers and clinicians from the field of stuttering disorders have conceptualized stuttering as more than the surface behaviors present in a person’s speech. They have embraced the psychosocial impact and consequences that stuttering has on the person’s life as well (Cooper & Cooper, 1996; Gabel, 2006; Quesal, 1989; Rustin, Cook, & Spence, 1995; Yaruss & Quesal, 2004, 2006). There have been numerous propositions to incorporate psychological initiatives in existing stuttering treatment programs that would result in more holistic models of support for individuals who stutter (Andrews & Craig, 1982; Andrews & Feyer, 1985; Blood, 1995; Boyle, 2011; Craig & Andrews, 1985; Craig, Feyer, & Andrews, 1987; Howie, Tanner, & Andrews, 1981; Menzies et al., 2008; Menzies, Onslow, Packman, & O’Brien, 2009; Neilson, 1999; Stein, Baird, & Walker, 1996).

Several treatment outcome studies were published in the 1980s (Andrews & Craig, 1982; Andrews & Feyer, 1985; Craig & Andrews, 1985; Howie et al., 1981; Maxwell, 1982) that documented the use of cognitive behavioral therapy (CBT) for people who stutter (PWS). Maxwell (1982) provided outcome data for a combined therapeutic program that integrated
speech modification techniques with CBT. The CBT components of the program specifically targeted increasing optimistic attitudes and decreasing negative cognitive appraisal. Maxwell (1982) reported that participants demonstrated significant reductions in the severity of their stuttering.

Further hallmark studies also integrated CBT programs for PWS (Andrews, Craig, & Peyer, 1983; Craig et al., 1987) in the 1980s. These initiatives addressed behavior and attitude change and involved both speech retraining and social and assertiveness skills training. In addition to speech management, researchers made a direct attempt to change maladaptive attitudes towards communication and social anxieties by implementing cognitive therapy in unison with behavioral therapy. The integrated cognitive portion of the therapeutic program involved the use of thought stopping and cognitive relaxation to reduce fears, speech anxieties, and social anxieties and enhance feelings of responsibility toward maintaining therapy skills (Andrews et al., 1983; Craig et al., 1987). Collectively, a review of the outcomes of this CBT program (Craig et al., 1987) over a 6-year period (N=191) detailed a significant reduction of stuttering severity achieved immediately posttreatment and maintained 10 to 18 months later.

Following the historic work in the 1980s, there was an expansion of clinical research incorporating CBT with speech management in the next decade (Blood, 1995; Neilson, 1999; Stein et al., 1996). Stein and colleagues (1996) proposed that PWS with concomitant social phobia would benefit from combined CBT programs that specifically targeted social anxiety. Anecdotal support for this proposal was based on reports from three participants who described reductions in social anxiety, avoidance, and overall disability across the 12-week CBT program. In addition, Blood (1995) combined a computer-assisted biofeedback program for reducing stuttering with a CBT component that encompassed problem solving, cognitive restructuring, and nondirective supportive counseling. Notwithstanding a limited sample size of four participants, researchers documented consistent reductions in stuttering severity across the trial and these gains were maintained at 1 year follow-up.

Criticism of the outcome research studies from the 1980s and 1990s included the fact that no participant received a treatment component (speech or psychological) in isolation. Hence, critics deemed it was not possible to determine the relative contributions of the speech restructuring treatment or the psychological intervention (Menzies et al., 2008). In addition, outcome measures documented from these studies were predominantly related to speech measures detailing the severity of the stutter and speech rate with no detailed psychosocial outcome measures.

In 2008, Menzies and colleagues attempted to address these limitations with a research study of CBT and speech techniques that also incorporated some clinical psychosocial measures (Menzies et al., 2008). This study specifically examined the effects of a CBT program addressing social anxiety and stuttering. A sample of 32 PWS were randomly allocated to receive either stuttering treatment following a CBT package for social anxiety or stuttering treatment alone. At 1 year follow-up, PWS who had received CBT showed greater improvements on a range of psychological measures of anxiety and avoidance. However, the CBT package produced no difference to the speech outcomes of those individuals who had social phobia.

More recently, researchers have published several review articles that propose the incorporation of psychological therapies such as CBT and Mindfulness (Boyle, 2011; Menzies et al., 2009) into existing stuttering treatment programs to enable a more holistic model of therapy for PWS. The papers explored the relationships between psychosocial variables and stuttering and provided an overview of CBT and Mindfulness strategies. To date, there are few publications addressing the potential incorporation of ACT programs for individuals who stutter (Belby & Byrnes, 2010a, b; Byrnes, Hart, Belby, Blacker, & Schug, 2010).

Acceptance and Commitment Therapy and Stuttering

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Acceptance and Commitment Therapy programs have proliferated in other clinical and medical settings and have proven to be clinically effective in reducing comorbid anxiety, depression, and stress in individuals suffering from chronic medical and psychological issues (Blackledge & Hayes, 2006; Bohmlejer, Fledderus, Rolx, & Pieterse, 2011; Bricker, Mann, Marek, Liu, & Petterson, 2010; Brinkborg, Michael, Hesser, & Berghund, 2011; Dahl, Wilson, & Nilsson, 2004; Dalymple & Herbert, 2007; Eifert et al., 2009; Flaxman & Bond, 2010; Fledderus, Bohmlejer, Smid, & Westerhof, 2010; Flessner, Busch, Heideman, & Woods, 2008; Forman, Herbert, Moitra, Yomans, & Geller, 2007; Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007; Jackson Brown & Hooper, 2009; Lundgren, Dahl, Melin, & Kies, 2006, 2008; Masuda et al., 2007; Twahig, 2009; Twahig et al., 2010). To date, no one has explored the core processes of ACT in the context of stuttering management or evaluated the effectiveness of an integrated ACT therapeutic program. In this review, we will evaluate the possible benefits of an ACT therapeutic program in facilitating behavioral and psychosocial therapeutic change for PWS. As such, in this unique review we will target the processes of self-concept, defusion, acceptance, mindfulness, values, and committed action, which could assist PWS in making meaningful and valued therapeutic change.

There is increasing empirical evidence for acceptance-based interventions such as dialectical behavior therapy (DBT; Linehan, 1993), mindfulness-based cognitive therapy (MBCT; Segal, Williams, & Teasdale, 2002), and ACT (Hayes, Strosahl, & Wilson, 1999), among others. Of these, ACT is unique in that it focuses directly on values identification, values clarification, and behavioral decisions linked to personal values. It is particularly appropriate for a cohort of individuals who stutter given that their daily struggle often is defined by the value placed on communicating fluently. ACT is often referred to as a third wave of behavioral therapy because it involves approaches that are focused more on awareness, acceptance, and understanding of the context of thoughts rather than on direct challenges or changes to the content of thought per se (Hayes, 2004; Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Acceptance and Commitment Therapy, as described in the remainder of this review, may add a valuable dimension to stuttering management beyond that currently in existence. PWS require treatment that facilitates self-efficacy and self-responsibility (Craig, 1998); ACT approaches could provide a means for PWS to accomplish these goals.

The overarching goal of ACT is to promote psychological flexibility through honing the ability to connect with the present moment more fully. Patients are trained to have increased consciousness which, in turn, changes persistent behavior to more value-based outcomes (Hayes et al., 2006). ACT and the psychological flexibility it promotes could allow PWS to enhance the ability to resolve provocative or evocative private thoughts, accept personal experiences for what they are, stay in touch with the present moment, make valued life outcomes, and build patterns of committed action in pursuit of those ends (Hayes, Strosahl, Bunting, Twahig, & Wilson, 2004). Psychological flexibility fundamentally relates to an expansion of a narrowed behavioral repertoire and researchers have demonstrated that it may lead to improved quality of life, enhanced physical health, reduced emotional reactivity, and improved mental health (Donaldson & Bond, 2004; McCracken & Vowles, 2007; Sloan, 2004). To date, no researchers have volunteered a discussion of stuttering from this perspective of psychological flexibility or inflexibility.

The ACT model addresses experiential avoidance, a process that interferes with psychological flexibility. A PWS experiencing experiential avoidance will be unwilling to come into contact with negative private events (e.g., thoughts, feelings, bodily sensations, memories, etc.). He or she also will embrace any attempt to avoid or control the content and frequency of these experiences (Chawla & Ostafin, 2007; Hayes & Gifford, 1997; Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Within the stuttering literature, there are numerous examples of experiential avoidance, including emotional, behavioral, and cognitive reactions to stuttering. Researchers have documented that PWS experience a variety of emotional reactions to their stuttering (e.g., Cooper, 1993; DeNil & Brutten, 1991; Guitar, 2006; Logan & Yaruss, 1999;
Manning, 2010; Shapiro, 1999; Sheehan, 1970; Vanryckeghem & Brutten, 1996; 1997; Watson, 1988; Yaruss, 1998; Yaruss & Quesal, 2004, 2006). These emotional reactions include feelings of embarrassment, anxiety, fear, shame, guilt, anger, isolation, loneliness, inadequacy, and other negative emotions accompanying stuttered speech (Cooper, 1993; Watson, 1988; Yaruss & Quesal, 2006). PWS also may exhibit behavioral reactions to stuttering including physical tension and struggle as speech is forced through moments of stuttering and effort (e.g., Johnson, 1961; Van Riper, 1982; Wingate, 2002). These behavioral reactions develop from avoidance or escape behaviors in which the PWS attempts to minimize exposure to difficult speaking situations. For example, audience size and perceived status of a conversation partner often generate high levels of avoidant behavior (Siegel & Haugen, 1964). Individuals who stutter can have difficulties with a wide variety of environmental stimuli that have habitually elicited coping mechanisms of avoidance and fear (Manning, 2010).

Although avoidance behaviors may decrease stuttering in the short-term, the PWS who avoids such speaking situations is eventually compromised in the key activities that are important for work or social development (Murphy, Quesal, & Guiker, 2007). Additional cited examples of experiential avoidance include cognitive reactions to stuttering such as negative thinking styles, low self-esteem, diminished self-confidence, and reduced feelings of self-efficacy (Blood & Blood, 2004; Healey & Scott, 1995; Manning, 2010; Ramig & Bennett, 1995; 1997; Ramig & Dodge, 2005; Reeves & Yaruss, 2012; Starkweather & Givens-Ackerman, 1997; Vanryckeghem, Brutten, & Hernandez, 2005; Yaruss, 1998; Yaruss & Quesal, 2004, 2006). Experiential avoidant responses to these reactions might include spending time and energy trying to alter a thought with substituted positive thinking, arguing with or challenging thoughts, or attempts at self-distractions. PWS who spend increasing amounts of time and resources attempting to change their emotions, behaviors, and thoughts may deplete their personal resources and distract themselves from fundamental values such as connecting with others. This is defined by Linn and Caruso (1998), “Speaking/communication plays a major role in the development of interpersonal relationships and people who stutter may experience greater difficulty in such relationships as compared to their fluent counterparts” (p. 13).

Attempts to control undesirable private events may work in the short term and rationalizing thoughts and distraction may even be helpful at times, however, researchers have indicated that efforts to repress undesired thoughts may be unworkable and even counterproductive (Wegner, 1994; Wenzlaff, Wegner, Roper, 1988). When asked to block out certain thoughts, individuals in thought suppression groups reported better immediate results in terms of thinking less about the target stimulus when compared to their counterparts in control groups (Wegner, 1994; Wenzlaff, Wegner, & Roper, 1988). Although these findings appear promising for the effectiveness of suppression, they may result in postsuppression rebound effects (Clark, Ball, & Pape, 1991; Wegner & Gold, 1995; Wegner, Schneider, Knutson, & McMahon, 1991; Wenzlaff, Wegner, & Klein, 1991). Efforts to eradicate unwanted thoughts, in fact, only seem to highlight and reinforce them further, resulting in increases in unwanted thoughts, especially in times of stress (Wegner, 1994; Wenzlaff & Wegner, 2000; Wenzlaff et al., 1988). Considering the chronic environmental stressors in the life of a PWS, these findings are especially relevant and suggest that efforts directed at cognitive avoidance may serve to amplify negative thoughts that might arise for the individual.

Researchers also have observed similar results in relation to another type of experiential avoidance, that of emotion suppression. In a study in which individuals were placed in situations resulting in increased stress, they recounted being unable to control their emotions. Further, researchers reported that emotional swings occurred in an unintended direction (Wegner, Erber, & Zanakos, 1993). Researchers have linked high emotional suppression to increased experiences of negative emotions and fewer experiences of positive emotions (Gross & John, 2003). Emotional suppression is also associated with higher levels of anxiety and affective distress (Feldner, Zvolensky, Eifert, & Spira, 2003; Levitt, Brown, Orsillo, & Barlow, 2004).
higher levels of panic and fear (Karekla, Forsyth, & Kelly, 2004), impaired interpersonal functioning, and a decreased sense of well-being (Gross & John, 2003).

The literature on thought suppression and emotion regulation underscores the futility of experiential avoidant behaviors. Summarizing the body of literature devoted to thought suppression and emotion regulation reveals the futility of control. In fact, control has been demonstrated as the problem, rather than the solution (Hayes et al., 1999). By contrast, ACT proposes a different approach to the management of experiential avoidance and emotional instability. Simply put, patients focus not on attempting to eradicate negative thoughts and feelings, but rather they reduce frustration through acceptance and a focus on valued living. The six core processes that contribute to psychological flexibility in the ACT model are self-concept, defusion, acceptance, mindfulness, values, and committed action.

Self-Concept

The self-concept for a PWS may include perceptions such as “I am a person who stutters” or “I am an inefficient communicator.” If a PWS adopts a self-concept of “I am a person who stutters,” the ACT goal would be to assist the client in gaining awareness that “I am a person who stutters” is a thought about self that triggers certain emotions and is really only a description of their fluency. The goal of the self-concept process is to lead clients away from defining themselves solely by any outstanding idea, emotion, or characteristic and instead to assist them to become more flexible in how they define their self-concept.

Defusion

Defusion is a core process within ACT that targets entanglement that prohibits the person from managing themselves effectively in the present moment. Using ACT, clinicians encourage clients to actively notice their thoughts and reorient them. Clinicians do not attempt to change thought patterns, as seen in a CBT treatment paradigm. To help clients understand the difference between cognitive fusion and defusion, clinicians can demonstrate the difference between saying “Everyone is noticing my stuttering whilst I speak” (cognitive fusion) and “I am having a thought that everyone is noticing my stuttering whilst I speak” (cognitive defusion). Cognitive defusion emphasizes the ability to notice each thought as being a thought, rather than adhering to thoughts as facts. Becoming defused from thoughts enables clients to choose whether they respond to the thought behaviorally or not. In this way, defusion promotes behavioral flexibility.

Acceptance

The process of acceptance embodies a willingness to experience private events fully, without attempting to alter or otherwise control their frequency or form, especially when these attempts cause psychological harm (Pletcher & Hayes, 2005). PWS practicing acceptance embrace feelings, sensations, urges, and emotions, in ACT, this is the fulcrum for giving up old behaviors that are not working. Within the ACT framework, emotional and cognitive discomforts are viewed as normal, unavoidable consequences of being human. Although it is not possible to eradicate the content or occurrence of undesirable private experiences, it is possible to reduce their affect through acceptance. Particularly, clinicians indicate acceptance as a possible treatment when change to external stressors is unlikely (Hayes, Bunting, Herbst, Bond, & Barnes-Holmes, 2006).

Mindfulness

The process of mindfulness promotes a non-evaluative awareness of, and contact with, the present moment and is a means of promoting acceptance. A constant focus of ACT is being in contact with the present moment, even when reflecting on past experiences. It is important for PWS to understand how past experiences have shaped current behavior and influenced their ideas about themselves and how they operate in society. In order to facilitate an awareness of the present moment, clinicians using ACT target the reduction of certain behaviors that reinforce experiential avoidance of certain life circumstances (e.g., evading talking on the phone). PWS tend to give priority to thoughts and experiences of past failed
speaking scenarios. Clinicians can use ACT to help reorient the client to the present moment, reminding them that they can have a new experience now (Kabat-Zinn, 1994).

Values

In the values component of ACT, clinicians ask clients to identify the domains of life most meaningful to them. Clients commonly identify value domains such as work, education, family, intimate relationships, parenting, friendship, recreation, spirituality, citizenship, and physical self-care (Dahl, Plumb, Stewart, & Lundgren, 2009). Once clients identify and clarify values, clinicians can develop goals that lead in the direction of these values (Hayes, 2004). PWS can learn to use personal resources that were previously devoted to the management and avoidance of negative life experiences toward living in accordance with and achieving defined personal values. Values provide a more stable guidance for life direction than thoughts and feelings. In addition, they facilitate motivated, committed action and satisfaction under difficult circumstances (Hayes et al., 2004).

Committed Action

The final core process of ACT is committed action. This constitutes following through with a specific values-based goal or committing to practice mindfulness and acceptance in response to a demanding situation. ACT emphasizes practical goals to match current resources, capabilities, or life situations of individuals. Any traditional behavioral interventions such as goal setting, exposure, behavioral activation, and skills training can be used in this part of the ACT framework. Clinicians can teach any skill that improves quality of life—such as negotiation, time management, assertiveness, and problem-solving—under this process of the ACT model, provided that it promotes valued living and does not reinforce experiential avoidance (Harris, 2009).

Researchers have shown that stuttering is a fluency disorder that has an adverse impact on quality of life (Yaruss, 2010). ACT may provide a novel and useful intervention for managing barriers to and improving aspects of the individual’s tolerance to living with a stutter (Belsky & Byrne, 2010a, b; Byrne et al., 2010). In the third component of this review, we will detail relevant psychosocial outcome measures to evaluate therapeutic change following an ACT intervention.

Assessment of ACT in Therapeutic Change

The various assessment tools that can be used to assess therapeutic change when using the ACT model for people who stutter are detailed below (Baer, 2010).

Acceptance

The Acceptance and Action Questionnaire (AAQ; Hayes et al., 2004) is the most widely used assessment for ACT and is available in several versions. The 9-item version (Hayes et al., 2004) assesses elements of experiential avoidance, including negative evaluation of and tendency to avoid or control aversive internal stimuli and inability to take constructive action while experiencing these stimuli. When reverse-scored, it serves as a measure of acceptance. It has adequate internal consistency (α=.70) and is correlated with many fields of psychopathology (Hayes et al., 2004). A patient’s scores on the questionnaire are predictors of future mental health and researchers have shown that these can be used to mediate the relationship between participation in ACT and improved well-being (Bond & Bunce, 2003; Dalrymple & Herbert, 2007; Forman et al., 2007). The 16-item version of AAQ (Bond et al., 2011) includes two subscales: Willingness and Action. The Willingness subscale reflects openness to experiencing negative thoughts and feelings. The Action subscale reflects the ability to behave consistently with values and goals even while experiencing unpleasant thoughts and feelings. The most recent version, known as the AAQ-II (Bond et al., 2011), consists of 10 items and is a measure of psychological flexibility, the central construct of ACT. Preliminary findings suggest that the AAQ-II has good internal consistency, a single-factor structure, and significant correlations with measures of mental health (Bond et al., 2011).
Cognitive Defusion

Given the internal privacy of cognitive defusion, clinicians must rely on self-report to obtain this information. Although symptom- or disorder-specific measures are still in their infancy, researchers have used the White Bear Suppression Inventory (WBIS; Wegner & Zanakos, 1994) to measure an individual’s inclination to manage aversive cognitive content. This 10-item Likert-type scale has normative data and correlates with treatment effects for individuals with anxiety (Småri & Hermóðsdóttir, 2001). In addition, Eifert and Forsyth (2005) proposed using established measures such as the Automatic Thoughts Questionnaire-B (ATQ-B; Hollon & Kendall, 1980) and the Thought-Action Fusion Scale (TAF; Shafran, Thordarson, & Rachman, 1996) to fully assess defusion.

Mindfulness: Contacting Present Moment and Perspective Taking

The Mindfulness and Attention Awareness Scale (MAAS; Brown & Ryan, 2003) is a 15-item, six-point Likert-type scale that assesses a core characteristic of mindfulness, namely the open or receptive awareness of and attention to the present. This scale demonstrates strong psychometric properties and has strong validation (Carlson & Brown, 2005). The Kentucky Inventory of Mindfulness Skills (KIMS; Baer, Smith & Allen, 2004) is a 36-item, five-point Likert-type scale that is divided into four different factors; observing, describing, acting with awareness, and accepting without judgment. The exploratory and confirmatory factor analyses support the proposed four-factor structure, and researchers have published expected correlations with a variety of other constructs (Baer, Smith, Hopkins, Krietemeyer & Toney, 2006).

Values

The Valued Living Questionnaire (Wilson, Sandoz, Kitchens, & Roberts, 2010) addresses the relative importance of an individual places on each of 10 personal life domains. Questions address consistency regarding the person’s recent behavior with respect to their values imbued in each life area. In addition, values can be assessed using measures delineated by Dahl and Lundgren (2006).

Committed Action

Researchers can use the Overall Assessment of the Speaker’s Experience of Stuttering (OASES; Yaruss & Quesal, 2010) to provide an assessment of the effect of stuttering on the PWS and therefore can be used to reflect committed action post-ACT program. The OASES consists of 100 items, each scored on a Likert-type scale ranging from 1 to 5. The questionnaire is divided into four sections. Section 1 (General Information) contains 20 items pertaining to the speakers' perceived fluency and speech naturalness, knowledge about stuttering and stuttering therapy, and overall perceptions about stuttering in general. Section 2 (Reactions) contains 30 items examining the speakers' affective, behavioral, and cognitive reactions. Section 3 (Communication in Daily Situations) contains 25 items assessing the degree of difficulty speakers have when communicating in general situations, at work, in social situations, and at home. Section 4 (Quality of Life) contains 25 items assessing how much stuttering interferes with the speakers' satisfaction with their ability to communicate, their interpersonal relationships, their ability to participate actively in life, and their overall sense of well-being.

Summary

In this review, we appraised the relevant literature regarding combined speech pathology and psychology therapeutic programs for people who stutter, provided an overview of ACT in the context of stuttering disorders, and presented relevant psychosocial outcome measures that constitute therapeutic change. Specifically, this unique review of ACT detailed the processes of self-concept, defusion, acceptance, mindfulness, values, and committed action in the support for people who stutter who experience psychosocial distress. We propose that the ACT therapeutic model may be beneficial in combination with a variety of fluency.
enhancing and stuttering modification treatment paradigms to enhance quality of life for individuals living with a stutter. Our preliminary outcome data (Beilby & Byrnes, 2010a, b; Byrnes et al., 2010) has demonstrated the effectiveness of an 8-week Acceptance and Commitment group intervention program for adults who stutter. Although initial results are promising (Beilby, Byrnes, & Yaruss, 2012), future research will help further elucidate the potential value of ACT for assisting individuals who stutter.

References


Paper 7

Acceptance and Commitment Therapy for Adults who Stutter: Psychosocial Adjustment and Speech Fluency

Acceptance and Commitment Therapy for adults who stutter: Psychosocial adjustment and speech fluency

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The aim of the present study was to assess the effectiveness of an Acceptance and Commitment Therapy group intervention program for adults who stutter (N = 20). The program consisted of 2-h therapeutic sessions conducted weekly for eight consecutive weeks. It was an integrated program designed to improve: (a) psychosocial functioning, (b) readiness for therapy and change, (c) utilisation of mindfulness skills and psychological flexibility; and (d) frequency of stuttering. The findings provide innovative evidence for Acceptance and Commitment Therapy as an effective intervention with statistically significant improvements in psychosocial functioning, preparation for change and therapy, utilisation of mindfulness skills, and overall speech fluency. Follow-up data collected at three months post-treatment revealed that therapeutic gains were successfully maintained over time. These findings enhance the understanding of the impact of stuttering on psychological wellbeing and offer a new perspective on what might constitute successful stuttering treatment. Further, clinical research support is provided for Acceptance and Commitment Therapy delivered in a group format as a promising and novel intervention for adults who stutter.

Educational objectives: The reader will be able to: (a) appreciate the potential for Acceptance and Commitment Therapy for adults who stutter; (b) identify the improvements participants experienced in psychosocial functioning and frequency of stuttered speech; (c) appreciate the six core processes of Acceptance and Commitment Therapy; and (d) appreciate the differences between an ACT model of intervention for adults who stutter compared to a CBT approach.
and development of friendships (Hayhow, Cray, & Enderby, 2002; Hugh-Jones & Smith, 1999; Yaruss et al., 2002). When recalling the experience of stuttering and its impact, individuals who stutter consistently describe a variety of negative consequences including struggle and avoidance causing restriction on many and varied aspects of their lives (Corcoran & Stewart, 1998; Flexico, Manning, & DiLollo, 2005). Such experiences of stuttering cannot be fully understood without taking into account the cognitive and affective reactions of people who stutter and their global life experiences with the disorder (Flexico et al., 2005).

The ability of an individual who stutters to communicate effectively in a variety of every day speaking situations is not necessarily determined by the amount of stuttering they experience (Beilby, Byrnes & Yaruss, 2012; Blumgart, Tran, Yaruss & Craig, 2012; Kooi, Versteegh, Yaruss, 2011; Mulcahy, Hennessy, Beilby, & Byrnes, 2008). It is affected by how completely the person is able to convey their spoken message in each situation. The level of fluency may be unrelated to the adverse impact the person is experiencing in any given situation.

Communication effectiveness can be diminished if gains in fluency are achieved through avoidance or through the use of speaking techniques that are burdensome and unnatural that the individual has difficulty using them on a consistent basis (e.g., Manning, 2010; Murphy, Yaruss, & Quesal, 2007a; Murphy, Yaruss, & Quesal, 2007b; Murphy, Quesal, & Guikler, 2007; Shapiro, 2011). Thus, many clinicians recommend maintaining an emphasis on effective communication which focuses on emotional support as well as the acquisition of speaking techniques. Managing the speaker’s reactions in terms of functional communication rather than in terms of stuttering frequency represents a significant yet positive challenge for stuttering treatment programs (Frattoli, 1998; Yaruss & Quesal, 2008).

1.2. Psychological therapy and stuttering

There have been numerous propositions to incorporate psychological initiatives in existing stuttering treatment programs which would result in more holistic models of support for individuals who stutter (Andrews & Craig, 1982; Andrews & Feyer, 1985; Blood, 1995; Boyle, 2011; Craig & Andrews, 1985; Craig, Feyer, & Andrews, 1987; Howie, Tanner, & Andrews, 1981; Menzies et al., 2008; Menzies, Onslow, Packman, & O’Brien, 2009; Nielsen, 1999; Stein, Baird, & Walker, 1996). For example, previous treatment studies have documented the use of cognitive behaviour therapies (CBT) to target improving optimistic attitudes and decreasing negative appraisals (Andrews & Craig, 1982; Andrews & Feyer, 1985; Craig & Andrews, 1985; Howie et al., 1981; Maxwell, 1982). Further integration of cognitive components to stuttering therapy has used thought-stopping and cognitive relaxation to reduce fears, speech and social anxieties and enhance feelings of responsibility towards maintaining therapy skills (Andrews, Craig, & Feyer, 1983; Craig et al., 1987). Blood (1995) combined a computer-assisted biofeedback program for reducing stuttering with a CBT component which encompassed problem-solving, cognitive restructuring and non-directive supportive counselling. Menzies and colleagues examined the effects on anxiety and stuttering through a CBT package for social anxiety (Menzies et al., 2008). In addition, several review articles have proposed the incorporation of psychological therapies such as CBT and Mindfulness (Boyle, 2011; Menzies et al., 2009) into existing stuttering treatment programs.

Most recently, a review of Acceptance and Commitment Therapy (ACT) programs has highlighted the potential usefulness of this clinical initiative for individuals who stutter (Beilby & Byrnes, 2012). Findings addressing the potential incorporation of ACT programs for individuals who stutter have to date, been positive (Beilby & Byrnes, 2010a; Beilby & Byrnes, 2010b; Byrnes, Hart, Beilby, Blacker, & Schug, 2010).

Unlike CBT programs, ACT does not focus on control or thought regulation but proposes a different approach to the management of experiential avoidance and emotional instability. The focus of ACT in treatment is not an attempt to eradicate negative thoughts and feelings; rather, frustration is reduced through acceptance and a focus on valued living. The six core processes that contribute to psychological flexibility in the ACT model are self-concept, defusion, acceptance, mindfulness, values and committed action (Beilby & Byrnes, 2012; Hayes, Strosahl, & Wilson, 1999).

Under the ACT auspices, the goal of self-concept is to develop flexibility in how the person views and defines themselves. The core process of defusion promotes behavioural flexibility while acceptance teaches the client to embrace emotional and cognitive events without attempts to change. The mindfulness process teaches perspective on the present rather than dwelling on thoughts and experiences in the past. The values component of ACT clarifies for the client domains of life most meaningful for them and the committed action process follows through with goals and future quality of life priorities (Beilby & Byrnes, 2012). In summary, ACT is unique in that it focuses directly on values identification, values clarification, and behavioural decisions linked to personal values. The authors deemed the proposed ACT treatment to be particularly appropriate for a cohort of adults who stutter given that their daily struggle is often defined by the value placed on communicating fluently. Individuals who stutter require treatment that facilitates self-efficacy and self-responsibility (Craig, 1998), and the ACT approach investigated in this study may provide a means for adults who stutter to accomplish these goals.

1.3. Aims of study

The aim of this study was to investigate the statistical effectiveness of an ACT group program for AWS. Specifically, the study examined whether participants experienced significant improvements in: (a) psychosocial functioning, (b) readiness
for therapy and change. (c) utilization of mindfulness skills and psychological flexibility, and (d) frequency of stuttering. The study also examined whether these improvements were maintained over a 3 month follow-up period of time.

2. Methods

2.1. Participants

Participants were 10 adult males and 10 adult females who stuttered (M = 28.75 years; SD = 11.07 years; range = 18–65 years). The individuals self-referred or were referred to the specialist Curtin University Stuttering Treatment Clinic (CUSTC) by speech pathologists in the community. Each adult had a clinical diagnosis of stuttering confirmed by two speech pathologists with no less than 10 years of clinical experience in the assessment and treatment of fluency disorders. Two of the 10 participants lived in rural areas (ranging from 200 km south-west to 1600 km north-east of Perth, Western Australia). All other participants resided in the Perth metropolitan region. Participants reported an onset of stuttering in early childhood in a manner consistent with developmental stuttering. Eighty per cent (80%) of the adults who stuttered had participated in previous speech pathology treatments for stuttering, and the remaining 20% had not done so. No participant had received treatment within the previous 12 months.

2.2. Integrated ACT Program

The integrated ACT program, which was adapted specifically for individuals who stutter, consisted of 2-h group therapy sessions conducted weekly for eight consecutive weeks. This study reports results for two treatment groups (10 participants per group). Each group was conducted by two group leaders (one speech pathologist and one clinical psychologist) with three undergraduates, final year speech pathology students in attendance. Both group leaders have specialised clinical experience working with adults who stutter. The speech pathology component of the group program was assimilated into the ACT activities in each session. That is, as the ACT activities for each session were practiced, each participant was encouraged and supported to undertake the discussion and conversation about the activities using the individualised speech fluency strategies, negotiated with them based on their pre-treatment assessment. The participants all had individual tasks that were co-designed each week to take home to practice throughout the week. The focus of the speech pathology intervention was to enhance fluency, reduce the severity and occurrence of stuttering behaviors and improve overall communication.

The treatment strategies for stuttered speech were individually tailored to each client's specific fluency needs. At the first session, the speech data were analysed, fluency goals negotiated with each client and a range of different speech management techniques trialled. Speech and stuttering modification strategies included those extensively documented in the literature (Bloodstein & Bernstein Ratner, 2008). Subsequent sessions consolidated the practice and use of the client's individual techniques including typical fluency shaping activities, speech rate control, speech naturalness and self-administered timeout for stuttered moments (Franklin, Taylor, Hennessey, & Beilby, 2008).

The ACT components of the group program addressed all six core processes described above. The goals of the first session were to familiarize the client with ACT and to identify therapeutic goals that were linked to the client's values. For example, the self-concept for a PWS may include perceptions such as "I am an inefficient communicator" and the ACT goal would be to assist the client in gaining awareness that this is a thought about self that triggers certain emotions and is really just a description of their fluency. In identifying this, it leads clients away from defining themselves solely by any outstanding idea, emotion, or characteristic and instead assists them to become more flexible in how they define their self-concept. The second session increased the client's awareness of emotional control as well as the consequences of control efforts. This session also introduced the concepts of willingness and acceptance as alternatives to experiential avoidance. Within the ACT framework, emotional and cognitive distortions are viewed as normal, unavoidable consequences of being human. Although it is not possible to eradicate the content or occurrence of undesirable private experiences, it is possible to reduce impact through acceptance. ACT provides a fulcrum for relinquishing old behaviours that are not working.

The third session involved the identification of private events to target for defusion and acceptance work. This session further introduced acceptance interventions, self-evaluation and the practice of mindfulness skills. With the ACT model, there is no attempt to change thought patterns such as in a CBT treatment paradigm rather cognitive defusion involves the ability to notice each thought as being a thought, rather than adhering to thoughts as facts. The fourth session further extended defusion work and expanded the mindfulness skills into daily life. The fifth session addressed the completion of defusion, extended the mindfulness training and clarified the client's personal sets of values. The sixth session instigated committed action and management of client identified barriers to such action. The seventh session promoted continuation of value-directed activities. In the values component of ACT, clients are asked to identify the domains of life most meaningful to them and personal resources that were previously devoted to the management and avoidance of negative life experiences become directed toward achieving defined personal values. The eighth session processed the reactions of the client to the conclusion of the treatment program, reviewed the ACT strategies and techniques and set goals to promote post-treatment maintenance of therapeutic gains.
2.3. Procedures

Ethics approval was obtained for this study through the requisite Human Research Ethics Committee. Informed consent was obtained from all participants. All participants completed a questionnaire booklet consisting of five qualitative questionnaires (see Section 2.4) at three time points: (a) prior to commencing the ACT program, (b) at the final ACT program session, and (c) at three months post ACT program treatment. In each of the three data-collection sessions, the order of presentation of five questionnaires was counterbalanced to control for order effects.

2.4. Measures

2.4.1. Stuttered speech frequency

Stuttered speech frequency was determined by collection and rating of a representative natural conversational speech sample for each of the 20 participants for each of the three assessment time periods. The speech samples were obtained from a 20 min conversation each person had with an undergraduate student clinician. Each of the person's three assessment samples was obtained by a different student who was not known to the participant. The conversations included topics such as family, work, recreation activities, sporting interests and travel experiences. A minimum of 2000 syllables of speech was obtained and rated by two speech pathologists. The Stuttering Measurement System computer program (Ingham, Bakker, Ingham, Moglia, & Kilgo, 2005) was used to obtain the percentage of syllables stuttered (KSS). Inter-rater reliability, calculated using a one-way independent group random effect model of analyses (Howell, 2007), revealed a correlation coefficient of .91. This indicates that judgements were both satisfactorily correlated and in agreement. Intra-rater reliability was calculated using the same method, and an intra-class correlation coefficient of .89 was obtained, demonstrating satisfactory correlation and agreement.

2.4.2. Overall assessment of speaker's experience of stuttering

The Overall Assessment of the Speaker’s Experience of Stuttering questionnaire (OASES; Yaruss & Quesal, 2010) was used to assess the adverse impact and negative consequences associated with stuttering. These consequences were described in terms of the speaker’s general perception of the stuttering impairment, the speaker’s affective, behavioural and cognitive reactions to stuttering, the impact of stuttering on a speaker’s functional communication in daily situations, and the impact of stuttering on the speaker’s overall quality of life. The OASES consists of 100 items, each scored on a Likert scale ranging from 1 to 5. The questionnaire is divided into four sections. Section I (General Information) contains 20 items pertaining to the speakers’ perceived fluency and speech naturalness, knowledge about stuttering and stuttering therapy, and overall perceptions about stuttering in general. Section II (Reactions) contains 30 items examining the speakers’ affective, behavioural, and cognitive reactions. Section III (Communication in Daily Situations) contains 25 items assessing the degree of difficulty speakers have when communicating in general situations, at work, in social situations, and at home. Section IV (Quality of Life) contains 25 items assessing how much stuttering interferes with the speakers’ satisfaction with their ability to communicate, their interpersonal relationships, their ability to participate actively in life, and their overall sense of well-being. For each item on the OASES, response scales are organised so that higher scores indicate a greater degree of negative impact associated with stuttering and lower scores indicate less negative impact. The OASES has been shown to have strong psychometric properties (Yaruss & Quesal, 2006; Yaruss & Quesal, 2010).

2.4.3. Modified stages of change questionnaire

The Stages of Change questionnaire (SOQ) was originally developed and published by McConnaugha, Prochaska, & Velicer, 1983. The psychometric properties of the original SOQ questionnaire were evaluated and found to have strong concurrent and predictive validity (Blanchard, Morgenstern, Morgan, Labouvie, & Bux, 2003; DIclemente & Hughes, 1990) and good internal consistency (Cary, Purnine, Maisto, & Carey, 1999; Pantalone, Nich, Frankforter, & Carroll, 2002).

Floyd and colleagues modified the SOQ (MSOQ) to measure the four distinct stages of change in therapy for people who stutter: precontemplation, contemplation, action and maintenance (Floyd, Zebrowski, & Flamm, 2007). Participants respond to 32 statements consisting of four, eight-item subscales using a 5-point Likert scale, whereby 1 corresponds to “strongly agree” and 5 corresponds to “strongly disagree.” Floyd et al. (2007) found that confirmatory and exploratory factor analyses of participant responses indicated that the affective, cognitive and behavioural factors characteristic of stuttering discriminate the stages of change for individuals moving through treatment.

2.4.4. Mindful attention awareness scale

The Mindfulness and Attention Awareness Scale (MAAS; Brown & Ryan, 2003) is a 15-item scale which assesses a core characteristic of mindfulness, namely the open or receptive awareness of and attention to the present. Using a six-point Likert scale (almost always to almost never), respondents rate how often they have experiences of being open and receptive to present moment experiences across cognitive, emotional, physical, interpersonal, and general life domains. This scale demonstrates strong psychometric properties and has strong validation (Carlson & Brown, 2005). It has a good internal consistency of .82.
Table 1
Descriptive statistics for outcome measures of AWS at pre-treatment, post-treatment, and follow-up (N = 20).

<table>
<thead>
<tr>
<th>Measures</th>
<th>Pre</th>
<th></th>
<th>Post</th>
<th></th>
<th>Follow-up</th>
<th></th>
<th>F value</th>
<th>p value</th>
<th>Partial $\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>KSS</td>
<td>6.42</td>
<td>4.34</td>
<td>1.39</td>
<td>1.08</td>
<td>1.77</td>
<td>1.05</td>
<td>36.77</td>
<td>&lt;.001</td>
<td>.66</td>
</tr>
<tr>
<td>OASES</td>
<td>3.10</td>
<td>0.32</td>
<td>1.91</td>
<td>0.31</td>
<td>2.00</td>
<td>0.29</td>
<td>147.89</td>
<td>&lt;.001</td>
<td>.89</td>
</tr>
<tr>
<td>OASES – SI</td>
<td>3.55</td>
<td>0.38</td>
<td>2.10</td>
<td>0.22</td>
<td>2.16</td>
<td>0.18</td>
<td>241.02</td>
<td>&lt;.001</td>
<td>.93</td>
</tr>
<tr>
<td>OASES – SII</td>
<td>3.50</td>
<td>0.39</td>
<td>2.12</td>
<td>0.20</td>
<td>2.28</td>
<td>0.23</td>
<td>178.01</td>
<td>&lt;.001</td>
<td>.50</td>
</tr>
<tr>
<td>OASES – SIV</td>
<td>2.88</td>
<td>0.55</td>
<td>1.83</td>
<td>0.31</td>
<td>1.94</td>
<td>0.23</td>
<td>79.58</td>
<td>&lt;.001</td>
<td>.81</td>
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<tr>
<td>PSS</td>
<td>13.95</td>
<td>3.97</td>
<td>10.40</td>
<td>2.01</td>
<td>11.10</td>
<td>1.59</td>
<td>12.37</td>
<td>&lt;.001</td>
<td>.39</td>
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<tr>
<td>Contemplation</td>
<td>38.15</td>
<td>2.13</td>
<td>37.25</td>
<td>3.91</td>
<td>37.30</td>
<td>3.36</td>
<td>0.73</td>
<td>&gt;.05</td>
<td>.04</td>
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<tr>
<td>Action</td>
<td>31.00</td>
<td>5.45</td>
<td>30.00</td>
<td>1.41</td>
<td>29.10</td>
<td>1.07</td>
<td>50.06</td>
<td>&lt;.001</td>
<td>.73</td>
</tr>
<tr>
<td>Maintenance</td>
<td>28.78</td>
<td>4.69</td>
<td>30.90</td>
<td>4.04</td>
<td>34.55</td>
<td>1.60</td>
<td>14.39</td>
<td>&lt;.001</td>
<td>.43</td>
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<tr>
<td>MKAE</td>
<td>3.20</td>
<td>0.44</td>
<td>4.61</td>
<td>0.45</td>
<td>4.18</td>
<td>0.26</td>
<td>115.43</td>
<td>&lt;.001</td>
<td>.38</td>
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<tr>
<td>KIMS</td>
<td>2.68</td>
<td>0.42</td>
<td>4.11</td>
<td>0.23</td>
<td>4.09</td>
<td>0.23</td>
<td>120.38</td>
<td>&lt;.001</td>
<td>.86</td>
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<td>Describe</td>
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<td>0.68</td>
<td>4.16</td>
<td>0.20</td>
<td>4.13</td>
<td>0.15</td>
<td>60.34</td>
<td>&lt;.001</td>
<td>.79</td>
</tr>
<tr>
<td>Acting aware</td>
<td>3.07</td>
<td>0.55</td>
<td>4.66</td>
<td>0.24</td>
<td>4.03</td>
<td>0.18</td>
<td>65.21</td>
<td>&lt;.001</td>
<td>.77</td>
</tr>
<tr>
<td>Accepting</td>
<td>2.59</td>
<td>0.68</td>
<td>4.15</td>
<td>0.36</td>
<td>4.11</td>
<td>0.34</td>
<td>59.09</td>
<td>&lt;.001</td>
<td>.76</td>
</tr>
<tr>
<td>AAQ-I</td>
<td>18.50</td>
<td>5.37</td>
<td>50.40</td>
<td>2.19</td>
<td>50.05</td>
<td>2.20</td>
<td>595.19</td>
<td>&lt;.001</td>
<td>.97</td>
</tr>
</tbody>
</table>

2.4.5. Kentucky Inventory of Mindfulness Skills

The Kentucky Inventory of Mindfulness Skills (KIMS; Baer, Smith, & Allen, 2004) is a 39-item scale that covers four key areas: observing, describing, acting with awareness, and accepting without judgement. This measure was designed to assess the general tendency to be mindful in daily life, to measure various components of mindfulness and to be understood by general and clinical populations. The KIMS uses a five point Likert scale, has high internal consistency (range from .76 to .91) and adequate to good test–retest reliability (Baer et al., 2004).

2.4.6. Acceptance and Action Questionnaire

The Acceptance and Action Questionnaire (AAQ-II; Bond et al., 2011) is a 10-item self-report assessment that assesses psychological flexibility which is the central construct of ACT. Psychological flexibility includes full awareness of the present moment, including thoughts and feelings, while changing behaviour which is consistent with the valued goals (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). It assesses elements of experiential avoidance, including negative evaluation of and tendency to avoid or control aversive internal stimuli and inability to take constructive action while experiencing these stimuli. The AAQ-II has been shown to have good internal consistency, a single factor structure, and significant correlations with measures of mental health (Bond et al., 2011).

3. Results

The data were scanned for any univariate and multivariate outliers with no significant outliers identified. Mahalanobis distances were computed to identify any multivariate outliers with no significant outliers found. Descriptive statistics were computed for the KSS, OASES (SI, SII, SIII, & SIV), SOC, MAAS, KIMS, and AAQ-II, and are shown in Table 1. Results at the three measurement time points (pre-treatment, post-treatment, and at follow-up) are also presented graphically in Figs. 1-6. Results show significant differences across all measures at the three measurement time points.

A repeated measures ANOVA was conducted to compare the outcome measure scores between time-points (pre-treatment, post-treatment and follow-up) in order to investigate the effectiveness of the ACT group treatment program for adults who stutter. The effect size was determined using partial eta squared ($\eta^2$). Results shown in Table 1 reveal

![Fig. 1. Group mean ± SD of % syllables stuttered for participants across each assessment time point.](image-url)
Fig. 2. Scatterplot of % syllables stuttered for participants for the pre, post and follow-up assessments. Note group mean is designated by (—).

Fig. 3. Group mean ± SD of the overall assessment of the speaker’s experience of stuttering subsection items for participants for the pre, post and follow-up assessments.

Fig. 4. Group mean ± SD of the modified stages of change subsection items for participants for the pre, post and follow-up assessments.

Fig. 5. Group mean ± SD of the Mindfulness and Attention Awareness Scale items for participants for the pre, post and follow-up assessments.
significant differences on all measures with large effect sizes (Howell, 2007). An alpha level of .05 (two-tailed) was used for all statistical tests.

3.1. Stuttered speech frequency

Prior to the commencement of the ACT intervention program, half (50%) of AWS demonstrated a stutter frequency rating of <5%S, with the remaining 50% demonstrating stuttered frequency rating of >5%S. The repeated measures ANOVA indicated that frequency of the stuttered speech was reduced and maintained significantly over time (Table 1, Fig. 1).

At the post-treatment time point, three participants (15%) were assessed with a stuttered frequency ratings ranging from 3% to 3.5%, with the remaining participants 85% demonstrating stuttered frequency ratings of <2%S. At the follow-up treatment time point, two participants (10%) were assessed with a stutter frequency rating ranging from 4% to 4.5%, with the remaining participants (90%) demonstrating stuttered frequency ratings of <2%S (Fig. 2).

3.2. Overall assessment of speaker's evaluation of stuttering

As shown in Table 1 and Fig. 3, scores on all four subsections of the OASES improved significantly immediately after the ACT group treatment program, and pairwise comparisons revealed that these psychosocial gains were maintained at 3 months follow-up.

At the pre-treatment assessment time point, mean scores on all four subsections of the OASES were within the moderate or moderate/severe impact ranges. At the post-treatment and follow-up assessment time points, mean scores on all four subsections of the OASES were reduced to the mild/moderate impact range.

3.3. Stages of change questionnaire

The repeated measures ANOVA indicated that participants who registered precontemplation scores pre-treatment, lowered their precontemplation scores post-treatment and maintained these improved lowered scores at follow-up. In addition, the action and maintenance scores increased significantly and were maintained over time indicating that the participants reported that they were engaged in a tangible and deliberate process of therapeutic change in which they were actively maintaining therapeutic effort and attention over an extended period of time. By contrast, the contemplation scores showed no significant difference over time indicating that participants who were involved in this treatment program maintained their behavioural intention to active change (Table 1, Fig. 4).

3.4. Mindful attention awareness scale

As reported in Table 1 and Fig. 5, scores on the MAAS increased and were maintained significantly over time indicating that the participants significantly improved and maintained their mindfulness skills over time.

These results indicate that the participants rated that they were more open and receptive to present moment experiences across cognitive, emotional, physical, interpersonal, and general life domains.

3.5. Kentucky inventory of mindfulness skills

As shown in Table 1 and Fig. 6, score on all four subsections (observing, describing, acting with awareness, and accepting without judgment) of the KIMS improved significantly immediately after the ACT group treatment program and pairwise comparisons revealed that these gains in mindfulness skills were maintained at 3 months follow-up.

These results demonstrate that the participants had a greater tendency to be mindful in daily life through the acquisition and practice of various mindfulness skills.
3.6. Acceptance and Action Questionnaire

Finally, as revealed in Table 1 and Fig. 7, the scores on the AAQ-II improved significantly after the ACT group treatment program and pairwise comparisons revealed that these psychosocial gains were maintained at three months follow-up.

3.6.1. Acceptance and Action Questionnaire

The results provided by this self-report assessment of psychological flexibility indicated that the participants gained a more complete awareness of the present moment, including their thoughts and feelings. At the same time, they modified their unhelpful behaviours to behaviours which were more consistent with their valued goals.

4. Discussion

In the present study, the authors investigated the effectiveness of a novel integrated ACT program on psychosocial functioning, readiness for therapy and change, utilization of mindfulness skills and psychological flexibility, and frequency of stuttering in adults who stutter. The program is unique in that this is the first research to demonstrate the use of ACT as distinct from previously researched CBT approaches in the treatment of stuttering for adults.

ACT involves therapeutic approaches that are focused on awareness, acceptance and understanding of the context of thoughts rather than on direct challenges or changes to the content of thought per se (Hayes, 2004; Hayes et al., 2006). The authors deemed ACT to be an appropriate genre of treatment for adults who stutter because of the psychological flexibility underpinning the basic philosophy. Psychological flexibility relates to an expansion of a narrowed behavioural repertoire and has been demonstrated to show improved quality of life, enhanced physical health, reduced emotional reactivity, and improved mental health (Donaldson & Bond, 2004; McCracken & Vowles, 2007; Sloan, 2004). The results also indicate how the ACT philosophy appealed to the participants given that they attended every session and each person saw the program through to completion and follow-up three months later.

Results from this study showed statistically significant gains across all measures of interest from pre-treatment to post-treatment and continuing on to three months follow-up. This shows that all participants experienced significant reductions in the adverse impact of stuttering on their lives (OASES), an increase in their readiness for change (SOC), an improvement in their mindfulness skills (MAAS and KIMS), and a reduction in overall frequency of stuttering (KSS). Further, these psychosocial and fluency gains were maintained for a three month period after the treatment ceased.

Within the group program, participants identified their avoidance behaviours and then used the ACT strategies to reduce their experiential behavioural, emotional and cognitive avoidance patterns. Significant improvements were found in participants recognising and identifying a need for change, then engaging in and maintaining a commitment to therapeutic effort over an extended period of time.

The fourth aim of the study was to bring about an improvement in fluency and a reduction in the frequency of stuttered speech measured by changes in per cent syllables stuttered. Significant improvements in frequency of stuttering were achieved during the program and maintained by participants for a period of three months post treatment. These results underpin the success and importance of individually tailored speech programs for adults who stutter. Flexibility of speech pathology management was achieved successfully for the participants in the absence of programmed, manualised instruction.

Because the measures selected for assessment in this study have been shown to reflect important aspects of a person's everyday life experience, it seems clear that the ACT treatment program resulted in real and substantive changes that were not only statistically significant but also clinically meaningful for participants. In fact, one interesting aspect of the findings is the fact that all 20 of the participants in the study reported experiencing such changes in their lives. Although no treatment can be said to be effective for everybody, the consistency of the changes reported across participants is notable. This suggests that helping people who stutter focus on their personal values through a flexible treatment paradigm that incorporates both speech changes and psychological changes in an ACT framework, can lead to consistent, positive changes for a wide range of individuals who stutter.
The fact that all participants appeared to benefit from this study’s combination of treatment focused on speech management and treatment focused on acceptance of speaking differences also speaks to another important debate within the field of fluency disorders. Specifically, it might seem paradoxical for clinicians to work toward helping clients modify disfluent speech behaviors to increase fluency while simultaneously helping them increase their acceptance of such behaviors. Throughout the history of the field, various practitioners have debated the relative merits of treatments focused on acceptance versus treatments focused on modification (for a historical review, see Bloodstein, 1993; Bloodstein & Bernstein Ratner, 2006; for a recent discussion, see Nippold, 2011; Yaruss, Coleman, & Quesal (2012)). Results from this study clearly demonstrate that it is possible for individuals who stutter to work toward both of these goals simultaneously and that the results of treatment aimed at acceptance and modification can complement one another. The result is that speakers can speak more fluently and communicate more effectively, all while living their lives with a greater sense of acceptance and a reduced burden from their disorder. Thus, such treatment can result in improved psychosocial functioning as well as improved speech fluency and communication.

This program was adapted specifically for individuals who stutter and constituted an integrated continuous set of activities, strategies, and resources for a mixed gender cohort of adults. Participants demonstrated the value of the program through their attendance and commitment. In addition, all participants made significant progress (statistically and clinically) on all measures. Primary reasons for this consistency and effectiveness may be the non-confrontational nature of the ACT approach plus the importance and focus on acceptance. The emphasis on acceptance, mindfulness, and core values of the client may be likely to promote the therapeutic alliance as well cognitive restructuring by the client resulting in an agentic lifestyle.

An increase in the number of participants is clearly recommended plus a replication to extend these preliminary findings regarding the clinical potential for this treatment package. A further recommendation is to extend the maintenance follow-up period beyond three months. This would permit more detailed consideration of the durability of psychosocial improvements and fluency gains over an extended time frame.

This project is a preliminary evaluation of an integrated ACT program. As such, it advances the integration of ACT into a contemporary vantage point when considering options for effective treatments for individuals who stutter.

CONTINUING EDUCATION

Acceptance and Commitment Therapy for adults who stutter: Psychosocial adjustment and speech fluency

QUESTIONS

(1) In the light of the findings from this study, Acceptance and Commitment therapy improved:
(a) Preparation and change for therapy
(b) Utilization of mindfulness skills
(c) Psychological flexibility
(d) All of the above

(2) What are the six core processes of Acceptance and Commitment Therapy?
(a) Self-content, fusion, avoidance, mindfulness, goals and committed action
(b) Self-concept, fusion, acceptance, mindlessness, goals and committed action
(c) Self-content, defusion, avoidance, mindfulness, values and action
(d) Self-concept, defusion, acceptance, mindfulness, values and committed action
(e) Self-concept, illusion, acceptance, mindfulness, values and committed action

(3) Measures used in the study included?
(a) The Overall Assessment of Speaker’s Experience of Stuttering
(b) Kentucky Inventory of Mindfulness Skills
(c) Stages of Change Questionnaire
(d) Frequency of stuttered speech
(e) All of the above

(4) Compared to Cognitive Based Therapy, ACT does not:
(a) Use thought-stopping
(b) Work on improving optimistic attitudes
(c) Work on decreasing negative appraisal
(d) Use cognitive relaxation
(e) All of the above

(5) Which of the following participant information in this study is NOT correct?
(a) Participants consisted of 10 males and 10 females
(b) All participants were currently engaged in speech pathology treatment for stuttering
(c) Participants came from metropolitan and rural areas in Western Australia
(d) 20% of participants had never received stuttering treatment
Acknowledgements

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References


Discussion
Discussion

Traditionally, a main focus in stuttering literature has been on the symptomatology of the speech characteristics of the disorder. Scientific debate has ensued regarding the definition of stuttering, how to measure the stuttering behaviours and how to treat the stuttered speech severity (Bloodstein, & Bernstein Ratner, 2008). More recently, there has been a shift to address the quality of life in adults resultant from the impact of living with a stutter (Craig, 2010). This thesis extends this contemporary challenge to consider more than the surface speech behaviours and to study the psychosocial and quality of life impact that stuttering has not only on adults but on children and adolescents as well who live with this disorder every day.

This thesis aimed to describe the affective, behavioural, and cognitive impact, in addition to the adverse effect on overall quality of life, arising from living with a stuttering disorder in children and adolescents who stutter. It was also directed at describing the effect that stuttering has on relationships within the family, in particular for the sibling, the parent and the partner of the person who stutters. Finally, it proposed an original integrated therapy direction for managing the psychosocial and fluency needs of individuals who stutter with a novel Acceptance and Commitment Therapy.

A principal outcome of Paper 1 is the finding that children and adolescents who stutter experienced greater adverse impact on their lives as a result of their speech compared to their fluent peers. The young people who stutter showed greater overall concern about their speaking; magnified affective, behavioural, and cognitive reactions to their speaking ability; and significantly compromised communication in
daily situations. Further, findings were underpinned by the fact these young people experienced a reduced quality of life compared to their fluent peers.

Adolescents who stuttered were found to have significantly higher levels of trait, state and social anxiety than their fluent peers in *Paper 2*. These findings highlight some psychosocial concomitants of chronic stuttering in adolescence and strongly suggest that stuttering as a disorder features psychosocial conflict regardless of its surface features. Menzies et al. (1999) suggested that it is essential to include expectancy of harm measures in studies of the role of anxiety in individuals who stutter. However, results from this study do not support the arguments that fear of negative evaluation is a more focused measure. Rather, this study highlighted the usefulness of traditional trait or state anxiety measures for this vulnerable population of adolescents living with a stutter.

The examination conducted in *Paper 3* of parenting styles, parent and peer attachment patterns, and parent and self-reported child behaviour successfully differentiated between school-aged children who stuttered and their fluent peers. The children who stuttered perceived their parents with significantly lower attachment, particularly in relation to trust and at the same time, parents of these children perceived their children with significantly higher maladjustments than fluent counterparts. An additional significant finding was that children who stuttered rated their peers significantly higher than their parents in terms of trust and tolerance and viewed them as important in their development of social competence. Such findings underscore the value of quality attachment which has been demonstrated to improve resilience and motivation and is an important aspect of the therapeutic process (Millard et al., 2008; Morris, Silk, Steinberg, Myers, & Robinson, 2007).
The responses to the quantitative sibling and parent questionnaires in *Paper 4* revealed that sibling dyads including a child who stuttered had a closer bond, but simultaneously experienced greater conflict and disparity in status than fluent sibling dyads. Furthermore, the parents of sibling dyads where one child stuttered demonstrated significant partiality towards the child who stuttered. These findings highlight the importance of awareness and education regarding the potential impact of stuttering on the sibling relationship in a family systems approach to fluency management.

Interviews within the partners' study in *Paper 5* evoked multifaceted responses from all participants resulting in a large number of themes that were distributed across two domains from the model of stuttering based on the ICF framework: i) environmental factors and ii) personal factors / reactions (Yaruss & Quesal, 2006). The environmental aspects of the participants' experiences pertained to those interactions between the speakers and their partners such as support, other people's reactions to stuttering and initial impressions. The personal factors and reactions concerned the delicate experiences for the adult who stuttered and their fluent partner, including acceptance, frustration and fear in life. In both personal reactions to stuttering and perceived difficulties in communication, partners shared similar experiences to those of the adults who stuttered. However, differences were found in perceived impact on quality of life, which suggests that even if partners understand the nature of stuttering, they may still fail to appreciate the extent of the adverse impact of stuttering. The findings highlight the importance of addressing such perceptions in treatment.

The thesis papers thus far have highlighted the need and value for stuttering treatments to include a psychosocial management component. The demonstrated
impacts that stuttering evokes, provides the groundwork for treatments that support psychological flexibility. Such a framework is summarised in the ACT position of Paper 6. This paper appraised the literature regarding combined speech pathology and psychology therapeutic programs for people who stutter while presenting an overview of ACT in the context of stuttering disorders. This paper advocated that ACT provides a novel and useful intervention for managing barriers to and improving aspects of the individual’s tolerance to living with a stutter.

Research conducted in Paper 7 investigated the effectiveness of a novel integrated ACT program on psychosocial functioning, readiness for therapy and change, utilization of mindfulness skills and psychological flexibility, and frequency of stuttering in adults who stuttered. The research, albeit it preliminary in nature, demonstrated how helping people who stutter focus on their personal values through a flexible treatment paradigm that incorporates both speech changes and psychological changes in an ACT framework, can lead to consistent, positive changes for a wide range of individuals who stutter.

Strengths

The thesis directly compared reactions of children and adolescents who stutter to children and adolescents who do not stutter (Paper 1) and is the first research to do so. A further strength of the thesis was the unique focus on the family members who live with the person who stutters (Papers 3, 4 & 5). To date, there has been some research addressing the needs of partners (Boberg & Boberg, 1990) and parents (Conture & Guitar, 1993) but it is of a limited nature. This thesis investigated the impact of stuttering across the lifespan and across all family members with whom the individual has intimate relations. It is the first research to consider the
perspectives of the siblings and the parenting styles and attachments that stuttering influences.

The research findings from Paper 2 have significant original clinical implications for the treatment of stuttering in adolescents. The traditional surface severity of the young person’s stuttered speech does not indicate how much they may be struggling with the impact of the disorder. Clinical assessment regarding the young person’s attitude towards their communication is a priority and psychosocial support to reduce anxiety levels and negative expectancies emerged equally important as strategies for fluent speech.

Further clinical insights emerged from the results of Paper 3 whereby school-aged children who stuttered reported frustration with the nature in which their parents tried to manage their stuttered speech. In addition, they wanted to be present when their stutter was explained to their teachers. Such unassuming yet important practical considerations arose from this research to enhance future family-based interventions.

Paper 6 constitutes the first review of a theoretical model of an integrated ACT program for individuals who stutter. This is the first publication to advance the integration of ACT into current treatments for individuals who stutter. Paper 7 provided positive, preliminary data which demonstrated the usefulness of ACT as distinct from previously researched Cognitive Behavioural Therapy approaches to the treatment of stuttering for adults. The thesis presents the impact of stuttering on the speaker and others in their environment and demonstrates that such impact can be diminished through appropriate treatment.

A final strength of the thesis is that the measurement of fluency change was not discounted; rather it was incorporated as part of the quantitative arm of the
research. Stuttered speech frequency and severity measures throughout the studies were determined by experienced speech pathologists rating a representative natural conversational speech sample from each of the participants who stuttered. The Stuttering Measurement System computer program (Ingham, Bakker, Ingham, Moglia & Kilgo, 2005) was used to obtain the percentage of syllables stuttered (%SS) and inter-rater and intra-rater reliability measures were calculated using a one-way independent group random effect model of analyses (Howell, 2007).

Limitations

The quantitative research in the thesis used self-report measures to assess the adverse impact of stuttered speech. This form of quantitative measurement presents a number of potential concerns, including the operation of response bias and shared variance between the measures. Despite these concerns, self-report methods are currently one of few available methods for the collection of subjective data and questionnaire methodology and remain widely accepted as valid and reliable (Turk & Melzack, 1992). Subsequent research might consider alternate sources of data such as qualitative research methods or information obtained by significant others to verify and cross-validate the self-report responses of children and adolescents who stutter.

Established guidelines for ensuring methodological and interpretive rigor in qualitative research were followed throughout this research; however, there is an element of interpretation inherent to qualitative research. The use of additional independent ‘blind’ researchers for the collection and analysis of data may have enhanced the validity of the results, however, this was not possible as part of this thesis process.
The cohort of children and adolescents in Papers 1 & 2 is a very specific subset of young people who stutter, given that they were drawn from the Wait-List treatment programs specifically run by the Curtin Stuttering Treatment Clinic. Thus the findings cannot be considered representative of all children and adolescents who stutter living in the community. It may be plausible that the level of impact on the psychosocial variables may in part be a reflection of this particular cohort of children and adolescents seeking assistance.

In terms of the findings for Paper 1, the cross-sectional nature of the research limits the interpretation of the results in terms of the impact of potential fluctuations over time. A future recommended longitudinal study evaluating the impact of stuttering in children and adolescents could highlight factors that evolve as prognostic indicators over time during the young person’s development.

A limitation of the sibling research cohort in Paper 4 was the drawback of only one younger sibling in the investigation. A greater number of contributions from fluent siblings who are younger than the child who stutters, may provide insights regarding particular emotions younger siblings experience, which may well be distinct from those of older siblings.

In Paper 5, the treatment histories of the adults who stuttered in the study were not explored thoroughly and any future research studies would benefit from these inclusions. Such background information about the types of treatments attempted, and details regarding the amount of time, money and resources expended in the past, may have provided additional contexts for the responses and reactions described. In addition, this study attempted to obtain a randomly selected, representative sample of participants, but the recruited sample reflected only 10
couple dyads. A larger cohort may provide different insights regarding diverse life experiences.

The research study described in Paper 7 was an effectiveness based research study in which the adult participants within this study were not randomised to a control non-treatment or usual care group. The motivation for this effectiveness based study was clinical in nature. The Curtin Stuttering Treatment Clinic is a centre offering specialised clinical expertise and is respected as a second opinion clinic for previously unsuccessful stuttering treatments. Each adult had formerly been provided with speech pathology therapy intervention, but it had been deemed not to have achieved significant improvement or success.

Based on the presenting history of previously unsuccessful treatment for their stuttering disorder, it was a clinical research decision not to randomise these adults to a non-treatment control group.

Subsequent efficacy based research on a larger cohort of adults who stutter, incorporating a randomised non-treatment control group, would evaluate further the treatment effects and extend the preliminary results obtained in Paper 7. This larger scale work could include a second treatment group incorporating Cognitive Behavioural Therapy as a comparison treatment group. A further recommendation would be to extend the maintenance follow-up period beyond three months. This would permit more detailed consideration of the durability of psychosocial improvements and fluency gains over an extended time frame.

Future Directions

Acceptance and Commitment Therapy and Anxiety

This thesis has investigated and addressed the psychosocial experiences and impact of living with a stuttering disorder across the lifespan. Further, it has provided
theoretical justification and clinically and statistically significant data, to support an integrated ACT treatment approach to the management of this disorder with adults. The next platform for treatment considerations beyond psychosocial issues would be to apply the same integrated ACT therapeutic program to anxiety concerns for individuals who stutter. Considering the relationship between communication difficulties and anxiety, it appears that social anxiety may mediate the surface features of stuttering events in daily communication (Messenger et al., 2004). Hence, from a clinical point of view, inclusion of anxiety management strategies by way of ACT integrated stuttering therapeutic programs for adults who stutter may well prove beneficial. Such a multidimensional interactional agenda would further advance the theoretical knowledge base and drive more effective management of the signs and symptoms of stuttering, including issues pertaining to anxiety.

Acceptance and Commitment Therapy and Children

Children who stutter display significantly more negative communication attitudes and more communication apprehension than their non-stuttering peers (De Nil & Brutten, 1990, 1991; Vanryckeghem & Brutten, 1996, 1997; Vanryckeghem et al., 2005; Vanryckeghem et al., 2001). As indicated earlier in the Introduction of this thesis, children as young as 3 and 4 years of age who stutter, have been found to experience negative attitudes towards speech, and these negative attitudes appear to worsen with age and stuttering severity (De Nil & Brutten, 1990, 1991; Ezraty-Vinacour, Platzky & Yairi, 2001; Vanryckeghem, 1995; Vanryckeghem & Brutten, 1997; Vanryckeghem et al., 2001, 2005). ACT integrates a focus on positive, functional communication with fluency strategies and as such could address negative communication attitudes that children who stutter may bring to the therapy situation. ACT has been used for the treatment of paediatric chronic pain and for body image
problems in adolescent populations and has shown promising results in these areas of youth health (Greco & Hayes, 2008). ACT for children who stutter has the potential to manage psychosocial concomitants of stuttering with a holistic and positive philosophy.

Lifespan Considerations

Longitudinal research examining the trajectory of impact of stuttering across the lifespan of the individual who stutters may be useful in identifying whether psychosocial impact develops on a parallel course or increases with an expanding trajectory with stuttering behaviour. The argument is not whether or not the disorder has a psychosocial impact, but rather when this develops and what might be the optimal time to incorporate treatment support for the individual and their family members.

Conclusions

This thesis is the first series of papers to address the holistic impact stuttering has on the individual and their extended family members. The findings have reinforced that stuttering is indubitably more than just a speech disorder. A mixed methods approach was used in aspects of the research design to outline succinct quantitative information with layered in-depth qualitative background perspectives. The thesis is exclusive in that it investigates the impact of stuttering on psychosocial issues and quality of life and proposes a novel, innovative approach to the treatment of such demonstrated needs. A central challenge to viewing stuttering as a multidimensional disorder is to ensure that integrated programs such as those proposed in this thesis are developed and evaluated in terms of demonstrated outcome and efficacy data. As such, the preliminary success of the proposed integrated therapy is presented with statistically and clinically significant
enhancements in fluency and quality of life for these adults living with a stuttering disorder. This underscores the need for flexible, holistic, integrated treatments that not only address the stuttered speech, but also prevent anguish, promote well-being and improve quality of life across the entire family unit.
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