NOTICE: this is the author's version of a work that was accepted for publication in Journal of Fluency Disorders. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in Journal of Fluency Disorders, Vol. 38 (2013). DOI: http://dx.doi.org/10.1016/j.jfludis.2012.12.001

Manuscript Title: The Impact of Stuttering on Adults Who Stutter and Their Partners

Article Type: Research Articles

Keywords: Stuttering, partners, relationships, impact of stuttering, quality of life

Corresponding Author: Dr Janet Beilby Corresponding Author's

Institution: Curtin University of Technology

First Author: Janet Beilby PhD

Order of Authors: Janet M Beilby, PhD; Michelle L Byrnes, PhD; Emily L Meagher, BSc (Hons); J. Scott Yaruss, Ph.D.

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 program for adults who stutter that includes the fluent partner as an agent of change in their treatment. Findings also support the utilisation of qualitative and quantitative research techniques to elucidate relevant psychosocial life themes and experiences for those who live with a stutter.

Janet M. Beilby is a Lecturer and Clinical Educator in Stuttering Disorders in the School of Psychology and Speech Pathology at Curtin University, Perth, Western Australia. Her current research interests include parent-administered early treatment initiatives, adolescent and adult stuttering treatment programs and the psychosocial impact of stuttering disorders across the life-span.

Michelle L. Byrnes is Research Fellow and Head of the Clinical Psychology Research Unit at Australian Neuromuscular Research Institute, Perth, Western Australia. Her current research interests include the use of holistic multidisciplinary child, adolescent and adult stuttering treatment programs which assist in alleviating the psychosocial impact of stuttering disorders across the life-span.

Emily L. Meagher is a Speech Pathologist who works in the Western Australian Country Health Service. Her current clinical interests include management of paediatric and adult stuttering disorders, developmental and acquired speech sound disorders and dysphagia.

J. Scott Yaruss, Ph.D., CCC-SLP, ASHA Fellow, is an associate professor in Communication Science and Disorders at the University of Pittsburgh. He teaches classes regarding stuttering disorders and is co-author of the Overall Assessment of the Speaker's Experience of Stuttering (OASES). Yaruss' research is aimed at improving the diagnosis and treatment of children and adults who stutter.

#### \*Educational Objectives

Educational Objectives: The reader will be able to: 1) identify the life themes associated with having a partner who stutters; 2) identify the perceived impact of stuttering for adults who stutter compared to their partners; and 3) discuss the clinical implications of the results with regards to working with adults who stutter.

Keywords: Stuttering, partners, relationships, impact of stuttering, quality of life

# Acknowledgements

The authors would like to thank the participants and their families. This study was supported by Project Grants from the Neurotrauma Research Program (Government of Western Australia) and the Research Centre for Applied Psychology at Curtin University. The authors would also like to thank anonymous reviewers for their helpful comments in improving this manuscript.

# Research Highlights - Beilby et al 2012

- Stuttering has a holistic impact on family members including partners
- A mixed methods research design explored the experiences of the people who stuttered and their fluent partners
- Key aspects of the stuttering disorder were perceived similarly by adults who stutter and their partners
- Partners share life experiences such as anxiety and reactions by others to stuttering
- Findings lend support to involvement of partners in stuttering treatment

\*Title Page

Title Page

The Impact of Stuttering on Adults Who Stutter and Their Partners

Janet M. Beilby<sup>a</sup>, Michelle L. Byrnes<sup>b</sup>, Emily L. Meagher<sup>a</sup>, & J. Scott Yaruss<sup>c</sup>

a School of Psychology and Speech Pathology, Curtin Health Innovation Research Institute, Curtin

University, GPO Box U 1987, Perth, Western Australia, 6845, Australia.

b Australian Neuro-Muscular Research Institute, CNND, University of Western Australia, Crawley,

Western Australia, 6009, Australia.

c Department of Communication Science and Disorders, University of Pittsburgh, Pittsburgh,

Pennsylvania, 15260, United States of America.

Correspondence to: Janet M. Beilby, School of Psychology and Speech Pathology,

Curtin University.

Email: J.Beilby@curtin.edu.au

Running Head: Impact of Stuttering on Adults and Partners

Table 1
Participant Information and Descriptive Summary

Couple & Code	PWS	Age	Gender	PPWS	Age	Gender	Years in Relationship
1PWS 1PPWS	1	29	Male	1	29	Female	10 years
2PWS 2PPWS	2	35	Male	2	35	Female	12 years
3PWS 3PPWS	3	40	Female	3	37	Male	8 years
4PWS 4PPWS	4	33	Male	4	35	Female	5 years
5PWS 5PPWS	5	36	Male	5	35	Female	10 years
6PWS 6PPWS	6	43	Male	6	35	Female	10 years
7PWS 7PPWS	7	39	Male	7	37	Female	14 years
8PWS 8PPWS	8	61	Male	8	60	Female	42 years
9PWS 9PPWS	9	52	Male	9	52	Female	32 years
10PWS	10	29	Male	10	28	Female	2 years

## Table 2

# Adapted Boberg and Boberg (1990) Interview Questions for Fluent Partners

- 1. How did you meet your partner?
- 2. Did he/she stutter at the time?
- 3. What was your first impression?
- 4. Have you known any other people who stutter?
- 5. How did the speech problem affect your courtship?
- 6. How did the speech problem affect your decision to marry?
- 7. How did the speech problem affect the marriage ceremony?
- 8. How does the speech problem affect your day to day lives together?
- 9. How have you reacted to your partner's stuttering'?
- 10. Do you have children and if so how many?
- 11. How do your children react to their mother/father's stuttering?
- 12. What have you **done** to help your partner with their speech?
- 13. What role did you play in them obtaining any help for their speech?
- 14. How did/does the therapy affect your relationship?
- 15. What advice would you offer to someone contemplating marrying a person who stutters?

1. How did you meet your partner? 2. Did you stutter at the time? 3. What was your first impression? 4. Were you anxious about meeting people or have any concerns regarding social interactions? 4. Had you been in a previous relationship? 5. How did the speech problem affect your courtship? 6. How did the speech problem affect your decision to marry? 7. How did the speech problem affect the marriage ceremony? 8. How does the speech problem affect your day to day lives together? 9. How have you perceived your stuttering over the years? 10. Do you have children and if so how many? 11. How do the children react to your stuttering? 12. What have you **done** to work on improving your speech? 13. Have you received therapy since beginning this relationship? 14. How did/does the therapy affect your relationship? 15. What advice would you offer to someone who stuttered if they were contemplating a) beginning a relationship

b) Wanting to get married?

Table 4

Main Themes and Subthemes of Personal Accounts of Living with Stuttering from PWS and PPWS Perspectives

Main theme	Subtheme		
Advice	Acceptance For Treatment Frustrations Openness Patience		
Initial Impressions			
Knowledge of Stuttering	Awareness		
Partners' Perceptions of and Reactions to Stuttering	Acceptance Anxiety Denial Embarrassment Prior experience with Stuttering Frustration Grief and Loss Life Impacts for Partner Protection Reactions Threatened		
Partnership			
PWS' Experience with Stuttering	Acceptance Aggression Avoidance Compensation Confidence - Lack of Cultural effects/Bilingualism Defeated Denial Embarrassment Fear Frustration Others' Reactions - Maltreatment Perseverance Relationships/Dating Respect School Social Anxiety The Stutter (history of) Withdrawal		
Support	Openness		
Treatment and Relapse	Impact on Relationship Reduced Access Personal Growth/Development		

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.

	PWS	PPWS	T-test	Correlation
MEASURE	M SD	M SD	T-test p value effect size	r p value
OASES I	2.45 -0.60	2.31 0.63	1.41 0.19 0.23	0.86 .0014*
OASES II	2.25 -0.68	2.14 0.68	1.17 0.27 0.16	0.91 .0003*
OASES III	2.15 -0.80	2.2 0.85	0.32 0.76 0.06	0.76 .008*
OASES IV	1.80 -0.62	1.46 0.29	1.85 0.10 0.70	0.10 .78
SF36 – MH	136.11 -12.62	138.03 11.98	2.20 0.06 0.16	-0.22 .35
SF36 - PH	145.72 6.77	127.12 24.46	0.32 0.76 1.03	-0.18 .62

<sup>\*</sup> significant at Bonferroni-adjusted alpha = .0083; overall alpha = .05

Table 6

Interpersonal and Psychosocial Domains and Subsequent Themes

Environmental	Personal / Reactions		
Openness	Acceptance		
Patience	Aggression		
Initial Impressions	Anxiety		
Experience with Stuttering	Avoidance		
Reactions	Compensation		
Partnership	Denial		
Support	Embarrassment		
Relationships and Dating	Frustration		
Cultural Impacts and Influences	Grief and loss		
Respect	Protection		
School aged Experiences	Threat		
Social Anxiety			
Support & Supportive Relationships			
Treatment and Relapse			

- 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 OASES 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 OASES
- 4. Qualitative results from the adults who stuttered 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 PWS group
  - b) Age range from 28 years to 61 years
  - c) Nine males and one female in the PWS group
  - d) One male and nine females in the PPWS group
  - e) 10 dyad couples

Answers: 1. C; 2. E; 3. A; 4. B; 5. A.

# 1.0 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, & Do Coeng, 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 & Tran (2006) revealed chronic levels of anxiety experienced by those who stutter and their subsequent fear and avoidance of social interactions. Petrunik & 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, Brepoels and de Coene (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 et al., 2004). However, there is a gap within the literature exploring the impact and prevalence of such behaviours on the personal support networks of people who stutter.

Klompas & 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 (Cummins, 2010). Patrick & 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 partners 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, Kilian, Wilms, & 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 se 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; Lass et al., 1992; St Louis & Lass, 1981; St. Louis, Reichel, Yaruss, & Lubker, 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 et al., 2002; Doody, Kalinowski, Armson, & Stuart, 1993; Guntupalli, Kalinowski, Nanjundeswaran, Saltuklaroglu, & Erik Everhart, 2006; Hurst & Cooper, 1978; Kalinowski, Armson, Stuart, & Lerman, 1993; Lass, Ruscello, Pannbacker, Schmitt, & Everly-Myers, 1989; Rami, Kalinowski, Stewart, & Rastatter, 2003; Turnbaugh, Guitar, & Hoffman, 1979; Woods & Williams, 1976; Yairi & 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 the impact 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 dysfluency, 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, & Schlagheck, 2010). Boberg and Boberg (1990) also found that speakers achieved greater success when partners were actively involved in their

spouses" therapy programs. Other research has also recognised that supportive relationships serve as a critical element beneficial 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 & 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 clients' 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 involve 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, Blumgart, & Tran, 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; Klompas & Ross, 2004; Plexico, Manning, & DiLollo, 2005; Plexico, Manning, & Levitt, 2009a, b). 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 (Tetnowski, & 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 & Teddlie (2003) identified how a mixed method approach is most beneficial when the researcher wishes to answer questions that would be difficult utilising 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.

## 1.5 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) qualitatively, 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.

# 2.0 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.

#### Insert 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 insult 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 to 2 hours. Interviews consisted of a set of questions adapted from the Boberg & Boberg (1990) research protocol, which was designed to elicit the participants" personal experiences (see Tables 2 & 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 arose. The participants" responses were recorded on a high-quality digital audio recording device that allowed for easy transcription of the interviews.

## Insert Table 2

#### Insert Table 3

The digital recordings were transcribed verbatim and analysed using the QSR Nvivo 9 qualitative analysis software. The process of analysis included open, axial and selective coding to develop a set of themes (Liamputtong & 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. Reiterative 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., 2009). 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 phenomenon 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 the results section. 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 OASES (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 organised 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 4<sup>th</sup> 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, Blumgart, & Tran, 2009) and normative Australian data is available for statistical comparison (Australian Bureau of Statistics, 1997).

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.

3.0 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.

#### Insert 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:

PWS9 The approach I took is that everyone has their weakness and mine is just this.

PPWS9 I"d encourage everyone to work on being more accepting of themselves as a person who stutters and try not to hide in new smoke and mirrors and avoidance.

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

PPWS9 We"re both involved. The individual who stutters and their partner, or whoever"s supporting them, should be involved 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.

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 3.1.7. The subtheme of openness was exemplified by the following quotes:

PPWS1 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:

PWS9 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.

PPWS5 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 speech difficulties as well as general information about dysfluency. The issues discussed also reflected some misconceptions about stuttering as reflected below:

PWS2 I knew I stuttered but I never knew it was something you can cure.

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

PWS8 But I think the cause [of the stutter], it came 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:

PPWS4 He"s gone through nearly all his life with this and he works. He"s done really well with his stuttering.

PPWS5 Then I realised [what] this kind of problem [was like] 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:

PPWS4 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:

PPWS9 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:

PPWS6 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.

PPWS7 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:

PPWS7 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.

PPWS3 There was a kid at school that had a bit of a stutter. And we

PWS3 Teased him?

PPWS3 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:

PPWS6 It is a bit frustrating on my behalf because he won tuse the phone, he won to communicate with people properly. And that is 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.

PPWS9 There are all these things that just keep smacking you in the face in different stages of your life where you reflect back and you think "well this isn"t how it smeant to be".

PPWS9 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:

PPWS7 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".

PPWS6 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.

PPWS9 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 to do with speaking, I made sure I"m not there.
- PWS6 I just try and avoid things when I can. At times I even avoid people. I think that swhy I tend to stick to myself. That smuch 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 am 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:

PPWS6 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.

PPWS5 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?"

PPWS7 No.

PWS7 No, there was nothing.

PPWS7 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 [I 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. It s not fluency, it s just, it s part of fluency.

PPWS7 [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 stuttering] 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 that 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 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], cos 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 programs 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.

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 et al (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.

#### Insert Table 5

## 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 significance differences between the self-reported OASES outcome measures provided by the PWS and the PPWS, OASES SI, t(9) = 1.41, p = .19; OASES SII, t(9) = 1.17, p = .27; OASES SIII, t(9) = -.32, p = .76; or OASES SIV, 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) = -.32, 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-SI, OASES-SII, and OASES-SIII 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-SIV 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.

#### 4.0 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 dysfluent 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.

#### Insert 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 unfailing 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 expectancy of social harm (Messenger, Onslow, Packman & Menzies, 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 strong correlations in the dyad 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 QOL section 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 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 contexts 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.

# 4.5 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.

### 5.0 References

- Angermeyer, M. C., Kilian, R., Wilms, H., & Wittmund, B. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry*, 52, 278-285.
- Association, A. S.-L.-H. (2007). Scope of Practice in Speech-Language Pathology [Scope of Practice]. Rockville, MD: Author.
- Australian Bureau of Statistics (2006). Australia"s population estimates, September Quarter 2001 June Quarter 2006. http://www.abs.gov.au, December 2006.
- Bloodstein, O., & Bernstein Ratner, N. (2008). *A handbook of stuttering*. (6th ed.). New York: Thomson Delmar Learning.
- Boberg, J. M., & Boberg, E. (1990). The other side of the block: The stutterer's spouse. *Journal of Fluency Disorders*, 15, 61-75.
- Boberg, E., & Kully, D. (1985). *Comprehensive Stuttering Program*. San Diego: College-Hill Press.
- Cooper, E. B., & Rustin, L. (1985). Clinicians" attitudes towards stuttering in the United States and Great Britain: a cross-cultural study. *Journal of Fluency Disorders*, 10, 1-17.
- Cooper, E. B., & Cooper, C. S. (1996). Clinician attitudes towards stuttering: Two decades of change. *Journal of Fluency Disorders*, *21*, 119-135.
- Corcoran, J. A., & Stewart, M. (1998). Stories of Stuttering: A qualitative analysis of interview narratives. *Journal of Fluency Disorders*, 23, 247-264.
- Crabtree, B. F., & Miller, W. L. (1991). A qualitative approach to primary care research: the long interview. *Journal of Family Medicine*, 23, 145-151.
- Craig, A. (2010). The association between quality of life and stuttering. *Journal of Fluency Disorders*, 35, 159-160.

- Craig, A., Blumgart, E., & Tran, Y. (2009). The impact of stuttering on the quality of life of adults who stutter. *Journal of Fluency Disorders*, *34*, 61-71.
- Craig, A., Hancock, K., Tran, Y., Craig, M., & Peters, K. (2002). Epidemiology of stuttering in the community across the entire lifespan. *Journal of Speech and Hearing Research*, 45, 1097-1105.
- Craig, A., & Tran, Y. (2006). Fear of speaking: chronic anxiety and stammering. *Advances in Psychiatric Treatment*, 12, 63-68.
- Cresswell, J.W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage.
- Crowe, T. A., & Cooper, E. B. (1977). Parental attitudes toward and knowledge of stuttering. *Journal of Fluency Disorders*, 10, 342-357.
- Crowe, T. A., & Walton, J. H. (1981). Teacher attitudes towards stuttering. *Journal of Fluency Disorders*, 6, 163-174.
- Daniels, D. E. (2007). Recounting the school experiences of adults who stutter: a qualitative analysis. Bowling Green State University.
- Daniels, D. E., Hagstrom, F., & Gabel, R. (2006). A qualitative study of how African

  American men who stutter attribute meaning to identity and life choices. *Journal of Fluency Disorders*, 31, 200-215.
- Doody, I., Kalinowski, J., Armson, J., & Stuart, A. (1993). Stereotypes of stutterers and non stutterers in three rural communities in Newfoundland. *Journal of Fluency Disorders*, *18*, 363-373.
- Dorsey, M., & Guenther, R. K. (2000). Attitudes of professors and students towards college students who stutter. *Journal of Fluency Disorders*, 25, 77-83.
- Fowlie, G. M., & Cooper, E. B. (1978). Traits attributed to stuttering and nonstuttering children by their mothers. *Journal of Fluency Disorders*, *3*, 233-246.

- Giorgi, A., & Giorgi, B. (2008). Phenomenology. In J. Smith (Ed), *Qualitative psychology* (pp. 26 52). London: Sage Publications.
- Guntupalli, V. K., Kalinowski, J., Nanjundeswaran, C., Saltuklaroglu, T., & Erik Everhart, D. (2006). Psychophysiological responses of adults who do not stutter while listening to stuttering. *International Journal of Psychphysiology*, 62, 1-8.
- Hayhow, R., Cray, A., & Enderby, P. (2002). Stammering and therapy: of people who stammer. *Journal of Fluency Disorders*, 27, 1-17.
- Hughes, S., Gabel, R., Irani, F., & Schlagheck, A. (2010). University students' perceptions of the life effects of stuttering. *Journal of Communication Disorders*, 43, 45-60.
- Hurst, M. A., & Cooper, E. B. (1978). Vocational rehabilitation counselors' attitudes towards stuttering. *Journal of Fluency Disorders*, 8, 13-27.
- Kalinowski, J., Armson, J., Stuart, A., & Lerman, J. (1993). Speech clinicians' and the general public's perception of self and stutterers. *Journal of Speech Language Pathology and Audiology, 17*, 79-85.
- Kalinowski, J., Lerman, J., & Watt, J. (1987). A preliminary examination of the perceptions of self and others in stutterers and nonstutterers. *Journal of Fluency Disorders*, 12, 317-331.
- Kathard, H. (2001). Sharing Stories: Life history narratives in stuttering research.

  International Journal of Language and Communication Disorders, 36, 52-57.
- Kershaw, T. S., Mood, D. W., Newth, G., Ronis, D. L., Sanda, M. G., Vaishampayan, U., et al. (2008). Longitudinal analysis of a model to predict quality of life in prostate cancer patients and their spouses. *The Society of Behavioural Medicine*, *36*, 117-128.
- Kim, Y., Kashy, D. A., Wellisch, D. K., Spillers, R. L., Kwei Kaw, C., & Smith, T. G. (2008). Quality of life of couples dealing with cancer: dyadic and individual

- adjustment among breast and prostate cancer survivors and their spousal caregivers.

  The Society of Behavioural Medicine, 35, 230-238.
- Klein, J. F., & Hood, S. B. (2004). The impact of stuttering on employment opportunities and job performance. *Journal of Fluency Disorders*, 29, 255-273.
- Klompas, M., & Ross, E. (2004). Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: personal accounts of South African individuals. *Journal of Fluency Disorders*, 29, 275-305.
- Lass, N. J., Ruscello, D. M., Pannbacker, M., Schmitt, J. F., & Everly-Myers, D. S. (1989).

  Speech-language pathologists' perceptions of child and adult female and male stutterers. *Journal of Fluency Disorders*, *14*, 127-134.
- Lass, N. J., Ruscello, D. M., Pannbacker, M., Schmitt, J. F., Middleton, G. F., & Schwepppenheiser, K. (1995). The perceptions of stutterers by people who stutter. Folia Phoniatrica et Logopaedica, 47, 247-251.
- Lass, N. J., Ruscello, D. M., Pannbacker, M., Schmitt, J. F., Orlando, M. B., Dean, K. A., et al. (1992). Teachers' perceptions of stutterers. *Language Speech and Hearing Services in Schools*, 23, 78-81.
- Linn, G. W., & Caruso, A. J. (1998). Perspectives on the effects of stuttering on the formation and maintenance of intimate relationships. *Journal of Rehabilitation*, 64, 12-15.
- McCallum, J. (1995). The SF-36 in an Australian sample: Validating a new, generic health status measure. *Australian Journal of Public Health*, 19, 160-166.
- McHorney, C. A., & Tarlov, A. R. (1995). Individual-patient modelling in clinical practice: are available health status surveys adequate? *Quality of Life Research*, 4, 293-307.

- Messenger, M., Onslow, M., Packman, A., & Menzies, R. (2004). Social anxiety in stuttering: measuring negative social expectancies. *Journal of Fluency Disorders*, 29, 201-212.
- Moustakas, C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage.
- Myers, D. G. (1999). *Close relationships and quality of life*. In D. Kaheneman, E. Diener & N. Schwarz (Eds.), Well-being: The foundations of hedonic psychology (pp. 374-391). New York: Russel Sage Foundation.
- Patrick, D., & Erickson, P. (1993). *Health status and health policy: Quality of life in health care evaluation and resource allocation*. New York: Oxford University Press.
- Petrunik, M., & Shearing, C. D. (1983). Fragile facades: Stuttering and the strategic manipulation of awareness. *Social Problems*, *31*, 125-138.
- Plexico, L., Manning, W. H., & DiLollo, A. (2005). A phenomenological understanding of successful stuttering management. *Journal of Fluency Disorders*, *30*, 1-22.
- Plexico, L., Manning, W. H., & Levitt H., (2009a). Coping responses by adults who stutter: Part I. Protecting the self and others. *Journal of Fluency Disorders*, *34*, 87-107.
- Plexico, L., Manning, W. H., & Levitt H., (2009b). Coping responses by adults who stutter:

  Part II. Approaching the problem and achieving agency. *Journal of Fluency Disorders*, *34*,108-126.
- Rami, M. K., Kalinowski, J., Stewart, M., & Rastatter, M. P. (2003). Self-perceptions of speech language pathologists-in-training before and after pseudostuttering experiences on the telephone. *Journal of Disability Rehabilitation*, 6, 491-496.
- Sanson-Fisher, R.W., & Perkins, J.J. (1998). Adaptation and validation of the SF-36 Health Survey for use in Australia. *Journal of Clinical Epidemiology*, *51*, 961-967.
- Sheehan, J. G. (1970). Stuttering: research and therapy. New York: Harper and Row.

- St Louis, K. O. (2001). *Living with stuttering: story basics, resources, and hope.*Morhantown: Populore.
- St Louis, K. O., & Lass, N. J. (1981). A survey of communicative disorders students' attitudes towards stuttering. *Journal of Fluency Disorders*, 6, 49-79.
- St. Louis, K. O., Reichel, I., Yaruss, J. S., & Lubker, B. B. (2009). Construct and concurrent validity of a prototype questionnaire to survey public attitudes toward stuttering. *Journal of Fluency Disorders*, 34, 11-28.
- Starks, H., & Brown Trinidad, S. (2007). Choose your method: a comparison of phenomenology, discourse analysis and grounded theory. *Qualitative Health Research*, 17, 1372-1380.
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research. London: Sage.
- Tashakkori, A., & Teddlie, C. (2003). *Handbook of mixed methods in social & behavioural research*. California: Sage Publications.
- Tetnowski, J. A., & Damico, J. S. (1999). A demonstration of the advantages of qualitative methodologies in stuttering research. *Journal of Fluency Disorders*, 26, 17-42.
- Turnbaugh, K. R., Guitar, B. E., & Hoffman, P. R. (1979). Speech clinicians' attribution of personality traits as a function of stuttering severity. *Journal of Speech and Hearing Research*, 22, 37-45.
- Van Borsel, J., Brepoels, M., & De Coene, J. (2011) Stuttering, attractiveness and romantic relationships: The perception of adolescents and young adults. *Journal of Fluency Disorders*, *36*, 41-50.
- Vargo, F. A., & Stewin, L. L. (1984). Spousal adaptation to disability: ramifications and implications for counselling. *International Journal for the Advancement of Counselling*, 7, 253-260.

- Ware, J. E., & Gandek, B. (1998). Overview of the SF-36 health survey and the international quality of life assessment (IQOLA) project. *Journal of Clinical Epidemiology*, *51*, 903-912.
- Ware, J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). SF-36 Health survey manual and interpretation guide. Boston: The Health Institute.
- White, P. A., & Collins, S. R. C. (1984). Stereotype formation by inference: a possible explanation for the "stutterer" stereotype. *Journal of Speech and Hearing Research*, 27, 567-570.
- Woods, C. L., & Williams, D. E. (1976). Traits attributed to males and normally fluent males. *Journal of Speech and Hearing Research*, 19, 267-278.
- Yairi, E., & Williams, D. E. (1970). Speech clinician's stereotypes of elementary school boys who stutter. *Journal of Communication Disorders*, *3*, 161-170.
- Yaruss, J. S. (1997). Clinical measurement of stuttering behaviours. *Contemporary Issues in Communication Science and Disorders*, 24, 33-44.
- Yaruss, J. S. (2010). Assessing quality of life in stuttering treatment outcomes research. *Journal of Fluency Disorders*, 35, 190-202.
- Yaruss, J. S., & Quesal, R. W. (2004). Stuttering and the International Classification of Functioning, disability and Health (ICF): An update. *Journal of Communication Disorders*, *37*, 35-52.
- Yaruss, J. S., & Quesal, R. W. (2006). Overall Assessment of the Speaker"s Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment.

  \*Journal of Fluency Disorders, 31, 90-115.\*
- Yaruss, J. S., & Quesal, R. W. (2008). *OASES: Overall Assessment of the Speaker's Experience of Stuttering*. Bloomington, MN: Pearson Assessments.

- Yaruss, J.S., & Quesal, R.W. (2010). *OASES: Overall Assessment of the Speaker's Experience of Stuttering*. Bloomington, MN: Pearson Assessments.
- Yeakle, M. K., & Cooper, E. B. (1986). Teacher perceptions of stuttering. *Journal of Fluency Disorders*, 11, 345-359.
- Zhang, J., Saltuklaroglu, T., Hough, M., & Kalinowski, J. (2009). Jobs, sex, love and lifestyle: When nonstutterers assume the roles of stutterers. *Folia Phoniatrica et Logopaedica*, *61*, 18-23.