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## Women who stutter : experiences of developing self-management and quality of life

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Women Who Stutter: Experiences of Developing Self-Management and Quality of Life

Katherine Milton

A report submitted in Partial Fulfilment of the Requirements for the Award of  
Bachelor of Speech Pathology Honours, Faculty of Computing, Health Science,

Edith Cowan University

Submitted November, 2012

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## Women Who Stutter: Experiences of Developing Self-Management and Quality of Life

### Abstract

**Background and Purpose:** Research suggests that stuttering can impact an individual's quality of life and how they perceive themselves in interactions with others. As a larger proportion of adults who stutter are men, limited research is available regarding the specific experiences of women who stutter (WWS). Existent literature regarding WWS was mainly published in the 1970s -1980s and may no longer represent current issues. This study aimed to explore the current influences on quality of life, perception of stuttering, self-management strategies, and gender issues experienced by WWS.

**Methods and Procedures:** This grounded theory study used a convenience sample of eight WWS recruited through the Speak Easy Association in WA, a support network for people who stutter. Participants came from diverse cultural backgrounds and their ages ranged for 35-80. In-depth, semi-structured interviews (35-40 mins long) were conducted in participant's homes, the first of these acting as a pilot. Interviews were audio/video recorded and transcribed verbatim to form raw data. Thematic analysis was performed using the *NVivo 10* qualitative analysis software program to manage and code data. Intermediate coding and mapping the relationships between categories, themes and subthemes established emerging patterns. The Overall Assessment of the Speakers Experience of Stuttering (OASES) was also utilised to complement interpretation of qualitative data.

**Outcomes and Results:** Through thematic analysis of interview transcripts, a central category of *Sense of Self* (SOS) was identified, surrounded by the emerging key themes of *Relationships*, *Responses of Others*, and *Self-Management*. Various interrelated subthemes were also observed. These categories, themes, and subthemes were fluid throughout co-occurring data collection and analysis phases and did not exist independently of one another, sharing complex relationships. OASES scores generally reflected interview content, affirming the use of this tool in quantifying the impact of stuttering on the lives of people who stutter.

**Conclusions:** This study found that quality of life, perception of stuttering, SOS and identity were impacted by stuttering in these eight WWS. The key points of influence for the eight participants were relationships with family, friends, romantic partners, and the responses from those from their workplace or cultural background towards their stutter. The way the WWS viewed their stutter and SOS also impacted how they managed their speech. The women's strategies for self-management were changeable depending on external life circumstances, SOS and identity. The women highlighted issues related to having children and perception of gender roles in the workplace, indicating potential gender differences in the experience of WWS confirming a need for more extensive research in this area.

Katherine Milton

Deborah Hersh and Charn Nang

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## Women Who Stutter: Experiences of Developing Self Management and Quality of Life

### Introduction

People who stutter (PWS) have speech characterised by sound and syllable repetitions, sound prolongations and complete blocks; these interrupt the flow, rate and rhythm (Lavid, 2003). Statistics indicate that adults who stutter are a minority population. An Australian study by Craig and Tran (2005) found that the prevalence of stuttering across all ages is approximately 1%, with a higher prevalence in children (1.44%); it was lower in adults (0.53%). Furthermore, the ratio of adult males to females who stutter is 4:1, possibly because females appear more resistant to inheriting a stutter, and have better recovery rates, than males (Craig, 2002). This means that there are fewer women available to contribute to studies and explains why women who stutter (WWS) are often under-represented in research. An article in the ASHA Leader, a key American publication for speech-language pathologists, described the population of WWS as a “minority within a minority” (Graham-Bethea & Mayo, 2012, p. 20), a quote that appears highly appropriate for this group. Little is known about the specific experiences of WWS, in Australia and internationally.

A preliminary review of literature surrounding stuttering, with a focus on effects for women, was undertaken. Key issues identified were influences on relationships, career, perceptions of stuttering, and support utilised. A very limited amount of published research was found regarding gender and the experiences of PWS, but this material was mainly published in the 1970s and 1980s and therefore may no longer represent current issues.

### Quality of Life for PWS

Having a stutter may have multi-dimensional effects on an individual. It is recognised in the literature that stuttering can have a significant impact on quality of life

(QOL) through potentially limiting communicative options and increasing anxiety around social interactions (Klein & Hood, 2004; Plexico, Manning & Levitt, 2009a). Feelings, beliefs, self-concept, and socialisation may be impacted as a result of this speech disorder (Aslihan, 2011).

PWS feel a disadvantage in finding a romantic partner, for example, Van Borsel, Brepoels and De Coene (2011) found that young adults saw PWS as being less desirable. Their relationships may be compromised due to fear or avoidant behaviours around interactions (Plexico et al., 2009a). This is an important issue as the ability to form close relationships of this nature can effect an individual's perception of their QOL (Myers, 1999). PWS in romantic relationships were observed to require their spouse to support them through providing target words, remaining patient and accepting, and encouraging PWS during treatment (Beilby, Byrnes, Meagher & Yaruss, 2013).

PWS may face challenges finding work or advancing in the workplace due to stigma associated with stuttering. An older study conducted by Hurst and Cooper (1983) found that employers sometimes believed stereotypes that PWS were tense, nervous or self-conscious, or assumed that PWS were less intelligent than people who did not stutter. This could be a significant disadvantage in trying to attain a competitive position (Gilman, 2012). A survey of PWS conducted by Klein and Hood (2004) showed that of 232 participants, 70% believed stuttering decreased chances of getting hired or advancing within a job and 33% felt stuttering impacted on job performance. On the other hand, 20% of participants turned down a promotion because of their stutter (Klein and Hood, 2004). These findings emphasise that career advancement and opportunities can be adversely affected for PWS, potentially inhibiting goal attainment, self-efficacy and QOL.

## **Perceptions and Reactions towards Stuttering**

Recently published research explored how PWS react, cope and manage with their stutter. Plexico et al. (2009a; 2009b) published two companion papers that used a grounded theory approach to explore positive and negative self-management strategies utilised by participants (seven men and two women). They found some participants coped through avoidance and placed utmost importance on reducing negative reactions of the listener. In contrast, others faced interactive situations with increased openness about their stutter and focused on their own communicative needs (Plexico et al., 2009a).

The avoidant method led to increased social withdrawal and narrowed communication options. It was detrimental to QOL as it increased isolation, and frustration and reduced self-agency and self-acceptance (Plexico et al., 2009a). The participants who assumed control of the situation and were open about their stutters had more positive outcomes, such as reduced helplessness, improved confidence, reduced pressure to be fluent, and a more favourable view of their stutter (Plexico et al., 2009b). These papers provide valuable information regarding management strategies and mechanisms used by PWS. However, fewer women participated and the conclusions did not distinguish between how men and women cope specifically.

Yaruss, Quesal & Murphy (2002) surveyed members of the National Stuttering Association in America (110 men and 72 women). Interestingly, most of the participants in this survey placed the same level of importance on treatment goals that purely addressed their attitude toward their stutter, regardless of changes in fluency, as they did on goals that focused on both fluency and attitude (Yaruss et al., 2002). This indicates the significance of a person's perception of their stutter in self-management.

A single case study by Leahy, O'Dwyer and Ryan (2012) explored narrative-based therapy in relation to helping change one woman's attitudes through focusing on her experience of stuttering. Therapy aimed to externalise the issue and separate the woman from her stutter. It developed positive discourse to help lead her to acceptance. The participant highlighted the importance of support networks, self-agency, self-acceptance and acknowledging the role of stuttering in developing her identity as important in managing her stutter (Leahy et al., 2012). As this was only a single case study, a larger sample is needed in order to look at whether these ideas and experiences are common in WWS.

An American database survey aimed to explore attitudes towards PWS from people who do not stutter (St Louis, 2012). It was conducted in 2010 and 100 people (50 males and 50 females) who did not stutter and had completed the Public Opinion Survey of Human Attributes - Stuttering (POSHA-S) were selected from a database. Findings showed that males and females who do not stutter exhibited slightly differing attitudes towards PWS. St Louis (2012) found that men had more accurate understanding of the etiology of stuttering. Women's attitudes towards PWS were more accepting, and also more positive towards them being placed in roles of responsibility (St Louis, 2012). These differences in the way women without a stutter perceive the disorder warrants further exploration of how WWS perceive their speech.

### **Treatment and Support for Stuttering**

Treatment provided for stuttering in Western countries commonly involves speech pathology treatment in a one-on-one or group setting. PWS may also seek psychological treatment if their stutter is related to anxiety or stress (Guitar & McCauley, 2010). After initial speech pathology intervention, support groups can provide a non-threatening environment to practice self-management strategies. They can serve as a platform for

sharing experiences and reshaping attitudes (Duckham, 2009). The importance of support groups in ongoing stuttering management is highlighted by Yaruss et al.'s study (2002) which found that support groups were the first source of consultation for stutter-related concerns, before a speech pathologist or the internet. This emphasises their importance as a resource in stuttering management.

In Western Australia, specialised support networks for PWS are provided by the Speak Easy Association of WA Inc, a Branch of the Australian Speak Easy Association. The Association rose from the need for ongoing fluency maintenance after intensive speech pathology courses conducted at Sir Charles Gairdner Hospital. The association was founded in 1977 and provides regular support meetings, social gatherings, outreach and advocacy for people PWS. (Duckham, 2009).

### **Stuttering and Gender**

In regards to gender issues and stuttering, an unpublished survey from participants who attended a workshop for WWS through the Speak Easy Association provided relevant data from 17 women. They responded to questions regarding QOL, reactions to their stutter, and the support services available in Western Australia. The results, presented at the International Fluency Association 5th International Conference (Nang, Dhu & Geevaratne, 2006), showed that 58% of the women indicated that stuttering had reduced their confidence and/or increased their levels of anxiety whilst speaking. When asked whether or not support groups catered enough for women, 25% felt they did not. Some women in this survey felt their jobs were more negatively affected than those of men who stutter. This indicates that some women felt stuttering had different consequences for men and women (Nang et al., 2006).

At the recent 10<sup>th</sup> World Congress of the International Stuttering Association (ISA) held in the Netherlands, the topic of WWS's experiences was addressed (Blom, Simpson, Herde, & Mertz, 2013). Four WWS spoke about their experiences in their countries and what they believed were important issues. Topics discussed were the impact of stuttering on the female identity, confidence, being a mother who stutters, workplace issues, multiple discrimination (against being a women, having a speech disorder and ethnicity) and the importance of talking to other WWS. The workshop survey, and discussion at the World Congress, is indicative of recent interest in this area. Significant issues have emerged suggesting that further exploration may be useful.

The article by Graham-Bethea & Mayo (2012) highlighted a gap in knowledge regarding WWS and the importance of further research. The authors discussed the fact that most research around WWS was conducted in the 1970s-1980s (Silverman & Zimmer, 1982; Silverman & Zimmer, 1979; Sheehan, 1979). Silverman and Zimmer (1979) indicated that WWS waited longer between the onset of stuttering and initiating treatment (7.4 years) when compared to men (3.6 years). This study found that men were twice as likely to have received counselling for stuttering than women. This finding contrasts with more recent evidence where women were shown to be more likely than men to attend a physician, dentist or hospital, even when pregnancy-related issues are excluded (Rosenstock, 2005). Women may not have sought treatment due to a number of contributing factors such as family responsibilities or, perhaps, they did not place great importance on improving their speech. This latter possibility further emphasised by Silverman and Zimmer (1979) who found that men viewed their speech as more of a handicap than women. Graham-Bethea and Mayo (2012) reason that this is due to differing gender roles in the 1970-80s. Their roles have changed in the household, community and workplace with increased entry into the workforce and attainment positions of leadership

in male dominated fields. Therefore, the issues impacting WWS today may also have changed and require further investigation.

### **Research Aims**

The experience of WWS in today's society remains relatively under-researched and may have changed since older studies. This means that today's services could fall short of current needs. With new insight into this area, health professionals working with WWS can approach treatment with new understanding and sensitivity towards specific issues encountered by this minority group. This study sets out to address the current gap in knowledge around women's experiences of stuttering. The specific study aims are to:

1. Explore the impact that stuttering has on quality of life for women who stutter.
2. Investigate women's perceptions of their stutter when communicating with others.
3. Examine the strategies that women have used to manage their stutters and whether they feel these have been effective.
4. Bring to light any issues in experiences related to stuttering and gender.

### **Research Approach**

#### **Methodology**

A qualitative approach was used for this study as the aims were based around exploring lived experiences and perceptions (Hammersley, 2013). This approach is focused on collecting information on a phenomenon from those affected. Qualitative research deals with rich textual and narrative data that is not easily quantified (Lapan, Quartaroli & Reimer, 2012). A grounded theory methodology was adopted as this study was exploring a new area. No pre-existing theories were formed before collecting data and

findings were instead drawn from themes that emerged during the co-occurring data collection and analysis phases (Birks & Mills, 2011). The methodology was in line with the aims of this study; to generate new knowledge around the aims listed above.

## **Participants**

Eight female participants were recruited through the Speak Easy Association in Western Australia. Convenience sampling, rather than theoretical sampling, was used with participants recruited through pre-existing contacts of the research supervisor due to the time constraints of the research. However, a theoretical interviewing approach was taken to maintain consistency with a grounded theory methodology. Although some of the participants spoke more than one language, each had sufficient skills in English to participate in the interview and data collection process and sign consent documentation. A large range of ages, backgrounds, and ethnicities was achieved. The sample contained women from countries, such as, Singapore, India, England, France, Sri Lanka and Ireland. Using such varied cases may have achieved increased diversity within the data (Lapan, Quartaroli & Reimer, 2012). The participants' ages ranged from 35-80 years of age, with a mean age of 50. Each of the participants had received intervention from a speech pathologist and had a confirmed stuttering diagnosis. Participants were sent out an information sheet (Appendix A) prior to data collection and required to register their willingness to participate and be audio/ video-recorded through signing a consent form (Appendix B).

The participants' interview speech samples were rated using a perceptual severity rating scale shown to be reliable and in correlation with percentage syllables stuttered measures (O'Brian, Packman & Onslow, 2004). Samples were rated by the supervisor and researcher and an average was calculated. A rating of 1 indicated no stuttering and 9 indicated extremely severe stuttering (see Table 1).



Table 1.

*Demographic Characteristics, Previous Treatment and Perceptual Severity Rating of Participants*

Participant	Age	Marriage Status	Occupation	Ethnicity	Previous Treatment Duration	Speak Easy Membership (years)	Mean Sev Rating
Georgina	80	Widowed	Retired	Australian	2 week intensive	46	3.5
Wendy	43	Relationship	Small Business	Indian	2 week intensive	16	5
Lisa	60	De facto	Community Education	Sri Lankan/Australian	2 week intensive	33	4.5
Suzie	35	Married	Admin./Accounts	Nepalese	7 months	1	5.5
Kathy	42	De facto	Human Resources	English	2 week intensive	5	5
Sarah	42	Married	Health Professional	Irish	6 months	16	4.5
Emma	50	Single	Health Professional	Singaporean	Not specified	11	4
Hannah	36	Married	Admin	French	1 year	1	4.5

Note: names changed for confidentiality reasons

**Data Collection Procedures**

Interviews were conducted in the participant's homes within a quiet room. During this time the researcher collected completed case history forms (posted out prior). These gathered basic information and brief stuttering/treatment histories (summarised in Table 1). A topic guide (Appendix C), detailing interview prompts, plus the completed case history forms were used to conduct semi-structured, in-depth interviews of approximately 30-45 minutes in length. This method was extensively documented as valuable in grounded theory research, lending the project internal rigour (Birks & Mills, 2011). The reduced structure allowed for natural flow of conversation and interviewees were free to focus on issues most prominent for them (Birks & Mills, 2011; Hammersley, 2013). These naturally arising issues are vital in giving new insight to this less-researched subject area (Corbin & Strauss, 2008).

The first interview was used to pilot the data collection procedure. The participant was asked whether questions were appropriate and for feedback regarding the researcher's interview style in order to validate the processes. The research supervisor was present at each interview for the purposes of clearer familiarisation with the data and to ensure personal safety. In addition, the supervisor helped facilitate some discussion through asking additional questions or bringing up issues based on shared history with participants.

Interviews were audio-recorded using an Olympus VN-5500PC digital voice recorder with a Yoga EM-012 tie clip microphone. Two participants consented to be videotaped using a Samsung FlashCAM in order to help interpret subtle cues and body language during the interview. For the remainder of the participants, audio data was adequate for the purpose of subsequent transcription and thematic analysis as it was mainly the interview content that was analysed for this study.

In addition to qualitative data, participants were asked to complete the Overall Assessment of the Speaker's Experience of Stuttering (OASES) (Yaruss & Quesal, 2010). This is a quick quantitative tool that generates a score for the impact of stuttering on different areas of life for a PWS. The purpose of conducting the OASES was to quantify the impact of stuttering on the lives of participants and complement interpretation of qualitative data. The OASES explores overall knowledge and feelings regarding stuttering (e.g. "how knowledgeable are you about what treatment options are available?"), reactions towards stuttering (e.g. "how often do you leave a situation because you think you might stutter?"), communication in daily living (e.g. "how difficult is it for you to communicate when introducing yourself?") and quality of life (e.g. "How much does stuttering interfere with your confidence in yourself?") (Yaruss & Quesal, 2010). The OASES was conducted after interviews to reduce influence on main interview findings, although the participants

were given the option to add to their interview recording if more information came to mind upon its completion.

### **Data Analysis Procedures**

Throughout this study, data collection and analysis ran alongside one another. It is the nature of grounded theory that data analysis is cyclically performed as new data is collected (Hammersley, 2013). The purpose of recording interviews was to improve accuracy of verbatim transcription, allowing repeated opportunities to listen to the conversations. This ensured that a participant's views were represented with reduced interviewer recall bias adding rigour to this procedure (Kelly, 2010). The process of verbatim transcription acted as a first stage of 'microanalysis' and allowed the researcher to start becoming familiar with the data, a process highlighted by Payne (2007).

Interview transcripts were then uploaded to the *NVivo 10* qualitative analysis software program (2012) to manage data during the process of thematic analysis. As interview transcripts were gathered and read through line-by-line they were openly coded and initial themes were generated. Data from subsequent transcripts was then layered on top with extra themes generated as new information arose. During this process, theoretical interviewing was used as questions were changed slightly to respond to evolving understanding of issues, helping fill gaps in knowledge and strengthen existing themes and subthemes.

After transcripts were examined at this level, intermediate coding was used to direct data analysis around significant themes (Charmaz, 2006). The codes were connected and sorted in different ways. Relationships between different codes and themes were discussed and dual-coding took place with the research supervisor (present at each interview). To establish inter-rater reliability, two 10% sections of interview transcript

containing particularly rich data were coded in collaboration. Similar emerging themes were identified, however further complexities in relationships between themes and subthemes were brought to the researcher's attention. For example, the theme *Relationships* was originally held within the theme of *Feeling Accepted*, however was later elevated to the position of a theme because of its prominence throughout interviews.

Arising themes and relationships demonstrated were mapped in consultation with a second research supervisor. Themes were very fluid and changed numerous times during the process of mapping relationships and when producing the final results. It was noted that new information around the themes was emerging from the final interviews. Therefore, saturation cannot be claimed for this project. This is not surprising considering the small sample size, however, there was a breadth to the stories, reflecting the diversity of the group.

The OASES impact scores for each section (discussed in *Data Collection Procedures*) in addition to the overall impact score for each participant were calculated. The impact scores pertaining to the different areas of the OASES were subjectively compared to interview content to ascertain whether they reflected similar levels and areas of impact.

### **Procedures for Rigour**

Neutrality has been demonstrated through the researcher acknowledging their interpretive role in conducting this research from the outset and when presenting results. To demonstrate consistency and reliability according to Tuckett (2005), a brief log was maintained to document processes undergone throughout the project, such as recruitment decisions, interview experiences, analysis experiences, and any changes to plans that occurred within the study. After each data collection meeting, field notes were written

regarding the researcher's overall impression of the participants (e.g. how questions were answered, stutter behaviour patterns, displays of emotion, personality traits, most prominent issues raised).

During the analysis process, inter-rater reliability was established through the researcher and supervisor performing dual-coding. Increased confirmability was ensured with the use of annotations in the *NVivo10* software program (QSR International, 2012) to highlight important quotes and to justify decisions (Charmaz, 2006). An interim synopsis of the study findings to participants was sent to the participants to provide a chance to make comments as to whether opinions and points of view had been accurately represented and validated. This method of member checking was used to provide research interpretations with credibility (Ryan-Nicholls & Will, 2009).

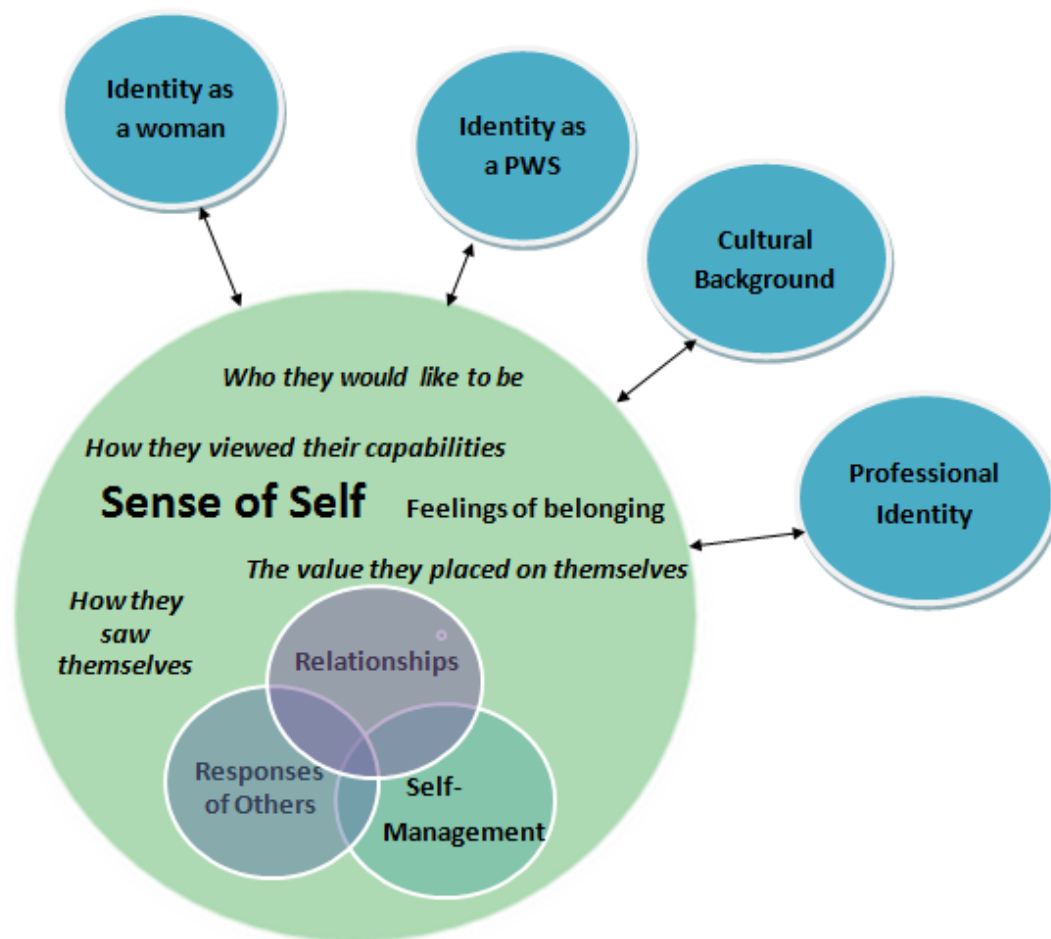
## **Results**

### **Qualitative Data**

To describe the qualitative findings, first person point of view is adopted in this section to acknowledge the interpretative role I have had in analysing, and presenting these findings. I am a female speech pathology student, born in England, however raised in Australia since the age of five after my parent's emigration. I collaborated with two female supervisors in conducting this research. I collected a large quantity of raw data through the eight interview transcripts. The women spoke openly about their experiences and provided rich information on various and complex issues. As part of the member-checking process, summaries of the results below were sent to each participant (Appendix D), they were invited to comment or suggest changes regarding findings if they felt so inclined. Five women responded indicating that they were happy with the overall result.

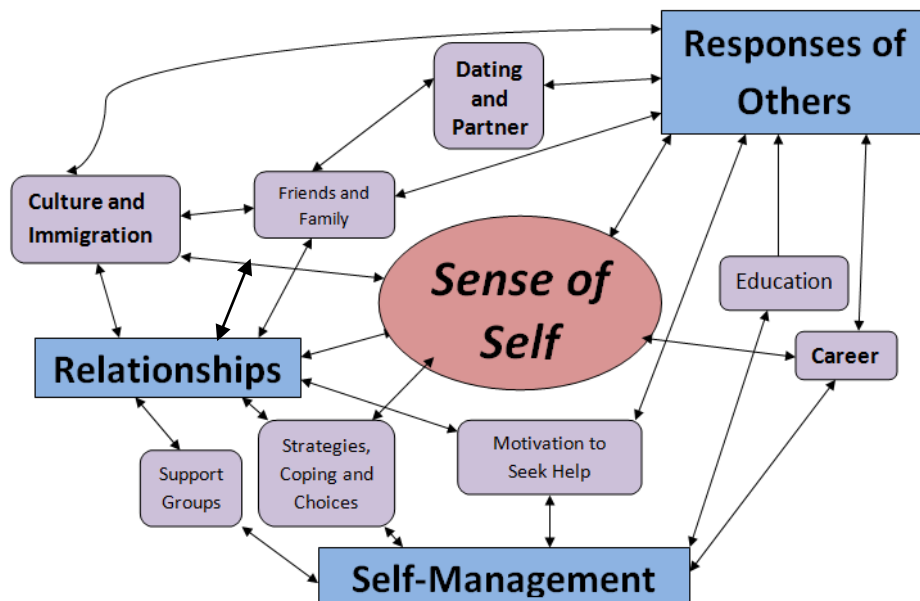
I focused on the main themes that emerged from the data. While these are by no means exhaustive, they provide an initial analysis that can be built upon in future research. I identified three major themes emerging from the data, *Relationships*, *Responses of Others* and *Self-Management*. These had various, interrelated subthemes. Themes and subthemes did not exist independently of one another and shared complex relationships. Through establishing core themes and mapping their relationships, these themes were observed to be encompassed within a core category, *Sense of Self* (SOS). This abstract concept was defined as slow-shifting patterns of internal beliefs the women held regarding themselves (e.g. gender/social roles, value to others, potential capabilities). Loosely based on the psychological notion of self-concept (Bergner and Holmes, 2000), the women's SOS influenced, and was influenced by, their relationships, the way they viewed responses of others towards their stutter, and how they supported themselves. On a larger scale, the women's beliefs and concepts of themselves were related to how they saw themselves as individuals and as members of social groups (e.g. identity as a woman, identity as a PWS). Figure 1 below depicts the complex relationship between the key themes of the data, SOS, and overall identity.

*Figure 1.* An interpretation of the interplay between central themes of Relationships, Self-Management and Responses of Others and the WWS's sense of self and Identity observed through thematic analysis.



To present this section concisely, I discuss subthemes underneath the headings of relevant themes, however, these subthemes may also be related to themes or subthemes discussed elsewhere in this section. It was difficult to separate themes and subthemes within this section due to the close and complex relationships involved (see Figure 2 below for graphic representation of main relationships observed).

Figure 2. A representation of the key relationships noted between the emerging themes and subthemes of this study.



**Theme: Relationships.** The topic of relationships was a prominent subject of discussion. The women often described difficulties they faced when talking in social situations, relating to family members, and establishing romantic relationships and the consequences of this on their SOS. The women in this study spoke about support (or perceived lack thereof) that they felt they received from friends, family and partners, linking this theme closely to *Self-Management*.

**Friends - “I’ve got a friend and he says ‘take your time’ and it makes me worse”.**

All of the women spoke about the impact of stuttering on friendships throughout different stages of life. Six women commented that they found it difficult to talk socially within group situations and felt they were not able to say their part. This issue was raised when discussing early social experiences as well as adult interactions with colleagues, close friends and acquaintances. Lisa, 60 year old women working in community education, commented, “I can get up and give a talk but when it comes to just general conversation



with a group of people, that's when you're having the problems...you've gotta get in there and push in".

**Georgina**, an 80 year old Australian lady, did not seek treatment until she was 44 years old after the death of her husband. She became a widow with four children. She recalls the following experience when socialising with the wives of her husband's friends:

"I'd be left to talk to the girls, the girls would all be talking, three or four of us, and my speech would be so bad and I'd be huffing (demonstrates huffs) as I was trying to get my words out....I was trying to talk with no breath and it was so bad, and the men would come in and I'd be happy, because I wouldn't have to talk"

**Family-** *"rather than telling me to "slow down" I would've rather had something a bit more positive"*. Seven of the women spoke about the responses of their family. Some said, as children, they had been teased or pressured by family members. Other participants mentioned feeling that communicative attempts were not acknowledged.

**Wendy**, a 43 year old woman, talked about her experience relating to her family:

"at home I was bullied actually, funny enough, the brothers picked on me... my mum used to lose her patience sometimes... it was very matriarchal at home... she didn't have a lot of time for me, subsequently she would lose her patience, saying "come on, get the word out"... that really frustrated me" (Wendy).

**Lisa** recalled feeling ignored when speaking with her father:

"my family was a very strict...I think I probably felt a little bit alone...one moment I remember....my dad, when he used to do the gardening I'd go out there as a little kid and I'd be babbling away and he never used to be listening and he'd just go "uh...uh...uh" but I couldn't get my words out edgeways... I'll always remember that".

Most of the women discussed their perception that family and friends did not appear to know how to support them effectively, their understanding of the condition and access to services (if available) appeared to be an influencing factor. I noticed this

especially with the older women, those that were not brought up in Western culture or those living rurally. Suzie, 35 year old lady from an Asian country, said: “they didn’t realise that maybe I was struggling, maybe they didn’t care”.

**Sarah**, a 42 year old woman who immigrated to Australia, now lives with her husband and child. Sarah described her mother’s support as follows:

“I lived in rural Ireland, probably there were very few speech therapists within an hour’s journey and with four kids my mother wasn’t gonna... so I kinda lived with it... with my mother she was very compassionate around it, but she didn’t know what to do, didn’t understand... if she’d kinda picked up on it earlier, she probably would have done something, she actually said that, if she’d have realised the impact it would’ve had on me later in life, she would have done something about it when she was younger... and she thought I’d grow out of it”.

On the subject of their own children, the three women who had children spoke, to some degree, about the idea of passing the stutter on to them. Sarah described herself as “concerned” when I asked how she felt after noticing her child also had a stutter. Others talked about the perceived negative reactions of others. Wendy, a woman who does not have children, said “not having children, which is a good thing, I probably would have stuttered dropping them off to school I would have made a fool of myself”. Sarah talked about her experience in the school environment; “if I feel there’s a mother there or a father there...that they’d be judging me, I would avoid them”.

**Dating –“I think the hardest time is....when you’re trying to find a partner”.** The participants commonly spoke about their experiences with dating and how stuttering impacted on this aspect of their lives. A contributing factor appeared to be lack of confidence: “it was more related to my confidence level too... I felt that guys weren’t interested in me” (Sarah). Kathy, a 42 year old who lived with her fiancé, talked about her perception that men made comparisons between “someone like that (meaning someone

who does not stutter) or me”. She suggested “it just makes you that less confident in yourself”.

The women who spoke about their experiences of dating expressed that they were often quiet and withdrawn on dates. They mentioned they would let the other person do most of the talking and “just throw a word in here and there” (Georgina). Some recalled using body language; “what I would do back then, I would just sit and smile... the first year we started dating he would do most of the talking and I was just following” said Hannah, a 36 year old woman who emigrated from Europe.

Here **Lisa** talks about the difficulty she had disclosing her stutter when first dating her partner, she contrasts this to her perception of the male experience:

“The dating thing is really yeah...horrible you’re always covering up...I did tell him because it was worrying me... it’s a not perfect thing, you know you don’t feel perfect...from my point of view as a female it was bad but I think for a male it’d be worse because males do more talking don’t they? Like if they go over the movies they get the tickets, so how would you feel, you’re getting a ticket at the movies or if you’re going and getting a coffee for someone you usually do the ordering”.

**Partners- “the man I married talked to everybody which was fine because I didn’t have to...”**. Some commonalities were noticed in the described characteristics of the partners of the women in relationships (see Table 2 below).

Table 2.

*Characteristics and the Ways in which they are Supported by Romantic Partners Described by the WWS.*

#### **Commonly Described Characteristics of Partners**

- “confident” (Georgina, Wendy and Sarah)
- “outgoing” (Lisa)
- “relaxed” (Hannah)
- “protective nature” (Wendy)

- “he was always very fluent” (Wendy)
- “he’s smart” (Sarah and Hannah)
- “very well able to speak” (Sarah)
- “he speaks more than me” (Lisa)
- “dominant” (Wendy)
- “friendly” (Georgina)

#### **Commonly Described ways the Women are Supported by Partners**

- “if I can’t make that phone call he makes it for me....he does things that I avoid” (Kathy)
- “he hasn’t been judgemental” (Hannah)
- “speaking on my behalf” (Wendy)
- “he orders for me now so I don’t even have to worry about that” (Kathy)
- “my husband did all the talking for me” (Georgina)
- “he’s always been very supportive when I’ve done like therapy and all that” (Suzie)
- “he doesn’t make anything of it” (Sarah)
- “he organises everything” (Kathy)

In the above table the word ‘support’ is used loosely. Despite good intentions, when partners took on communicative duties, these women were ultimately disempowered. The older women, Lisa and Georgina, attributed this male dominance to the gender roles of their generations; “I don’t know whether it’s any different now, perhaps the women do more but in my day, the males were very dominant” (Lisa). Kathy, aged 42, also mentioned, “I think for us females... we’re a bit more protected I guess... for a boy he feels like he has to provide for the family”. I noticed that the women acknowledged this decreased self-agency.

The women's reflections on their dependence on partners and the consequences of this:

"yeah so I became really reliant on him... became really quiet, in a way he wasn't really doing the right thing by speaking at the time for me I actually became very dependent on him to do all of the talking socially as well" - **Wendy**

"my husband did all the talking for me... I mean it was good in one way but in another you depend too much on another person, so I don't think that support is the answer"  
- **Georgina**

"with someone like him it can make you a bit lazy....if he's happy to do it I'll just let him do it but, but I can begin relying on him too much, that it's good sometimes when he's not there coz I have to do it, coz I do lose that technique, coz it is a practice thing... practice your smooth speech" - **Kathy**

**Theme: Responses of Others.** This theme is closely linked to the theme of *Relationships*. Its focus lies on the influence of other's reactions on feelings of connectedness. All of the women spoke about encountering negative response towards their stutter more pervasively than positive reactions. I noticed that reactions of others within cultural, school and workplace settings influenced the degree to which these women identified as belonging. The main context in which these women had faced negative reactions to their speech was at work. Culture, differing family values, and issues related to immigration also played a role in their perception of 'fitting in'.

The women reflected on the influence of other's responses on their SOS; "so growing up it affected my self esteem, for a long time I believed I was a really stupid bad person and deserved to be treated this way because I stuttered" (Hannah). Emma, a career-oriented lady aged 50, commented, "it definitely made study a lot more difficult, it made work a lot more difficult, it made socialising a lot more difficult, and together with that because your self-esteem goes lower as well, it impacts your assertiveness".

**Education-** *“there were times when I knew the answers to questions in class or at university level and I would be afraid to answer because of my speech”*. All of the women talked about the responses of others over school and university years, again, in a mostly negative way. One exception was Kathy, who mentioned that she was not picked on as others took her “under their wing” because they “felt sorry” for her. The women spoke of issues like labelling from teachers or students, being bullied, or coming up against challenges from teachers/lecturers.

The issue of being labelled in these early years was raised by four women, and some of the comments were:

“it was set in concrete I think when I was going to school and I was told it was a slight stutter” - **Lisa**

“what happened was it was a girl at school who said to me you have a stutter and that was my first memory, I was about nine... just the shame of it because she said it in front of a group” - **Sarah**

**Wendy** spoke of her teacher’s reaction to protect her in class and how she felt:

“I had my first block at school...they asked me to read a paragraph...I couldn’t come out with the word “chocolate” and then my teacher was like embarrassed for me and she was like “ok ok sit down, that’s alright” and I couldn’t complete the reading and that was really embarrassing for me in front of everybody”.

**Emma** commented about a response she got at university:

“they actually wanted me to leave [the course] thinking it would be too much for me thinking it would be too much talking involved and not cope with the load”.

**Career**—“*I think in my confidence level when I worked...it limited me, I have that belief system that it limited me*”. The seven women who were employed expressed difficulties securing work and/or performing some tasks required for their jobs as a result of their stutter; “going to work was almost a nightmare for me, I used to think “oh my god, how is it gonna go today? Am I gonna have a speech problem?” (Wendy). They discussed challenging reactions of prospective employers, supervisors, colleagues, or service users.

**Hannah** talks about her experience of attending job interviews when she arrived in Australia:

“When I first moved here my stutter was strong and it was my biggest problem...when you go for interviews you can’t stutter otherwise you don’t get the job, so that was a big sort of stress for me...you don’t really find work because you stutter in an interview people look at you funny like “oh, what’s wrong with her?”...like for example at interviews people start looking at you “ah..” (surprised/confused face) this way and “ah, okay....bye” (makes shooing motion with hand)...and then the interview will end very shortly...they show me the door quite fast”

**Emma** recalled this negative reaction whilst working within a hospital:

“I remember this phone call when I worked for [hospital] and I was stuttering, I was phoning an agency of some sort and they thought I was unwell, so you know you get that sort of thing”.

On the other hand, she reflected that her immediate colleagues were a main source of support in managing her stutter:

**Researcher:** “Who has supported you on your journey with your stuttering?”

**Emma:** “Ah my colleagues... in my journey I would say that... [colleagues] were fantastic, they were the ones that really stood up for me”.

In some cases, the women attributed the responses of others within the workplace to gender issues; “being a project team it was pretty much male-oriented and I was the only girl there, I think guys are more patient with guys, I suppose a bit of boys club” (Wendy).

**Sarah** describes feeling intimidated when presenting at meetings whilst working within a male-dominated occupation:

“there was only really myself and another lady amongst a group of men...in a meeting of ten or fifteen, so I found that intimidating... I could feel that some were a bit embarrassed and kinda felt for me... but just some of the types of men who were like managers and that...”

***Culture and Immigration – “when I talk with my people from my country...***

***maybe I don’t want to talk to them by the way they think about me”.*** Seven of the eight participants were born overseas and the subject of culture was recurrent. The women spoke about how people from their cultures responded to them.

**Suzie** is a Nepalese lady aged 35 now living with her husband. She recalled experiences of being a WWS within her culture and the impact on her and her family:

“back home... it is kind of stereotyped if somebody has a bit of a disability and everything, so it means that “okay your family has this”...my aunty had problem facing that okay because she was a marriageable age at that time...so it’s like have a major effect on her”.

The seven women from overseas talked of emigrating to Australia and the challenges and benefits this created. Coming from a different culture could create further barriers to communication; “culture was different as well... I’ve been here for four years, I still pick up the small differences in culture, a lot of the differences are nonverbal communication or even in the way we say things” (Hannah). Interesting views were also expressed in comparing Australians’ responses to stuttering and disability with people in their country of origin: “people can be very mean... in Perth, it’s not like that, they don’t discourage when they have disability and things, they encourage, they don’t mind” (Suzie).



**Hannah** told of how her stutter was received in Australia after immigration:

“it impacted a lot when I moved here because the first year I was stuttering a lot...I think Aussies are more laid back, they will just look at me like “uh” (shows surprised face) then walk away, but I didn’t have the talk down and the spiteful reactions, I didn’t have much of that”.

Four of the migrant women mentioned that their stutter was sometimes masked behind their accents or that Australians perceived their stutter to be a cultural way of speech/related to English as a second language. The women saw this as a benefit in reducing negative responses, “sometimes they thought it was something to do with my accent, I thought “oh thank god” (laughs)” (Hannah). This suggested a preference to be identified by their culture, rather than their speech disorder.

**Wendy** and **Sarah** spoke of how their culture helped to hide their stutters:

“It’s sort of picked up as a cultural thing with me, everybody said “oh it must be a cultural thing where you stop and start, stop and start at talking”” - **Sarah**

“Australians would think it’s cultural, the way that I speak, because I thought that about Wendy when she’d pause I thought, “oh this is a cultural thing”” - **Wendy**

**Theme: Self Management.** Self management in this context refers to internal coping processes and external support enlisted from professionals or significant others (also discussed under *Relationships*). This definition was chosen because the act of going out and seeking professional support was often one which occurred as part of a decision to take control of the stutter. This was a prominent theme throughout the data and was related closely to the other themes as the women’s relationships and the responses of others towards their stutters was often an impetus for seeking support. The majority talked of personal changes such as increased confidence and resilience throughout their lives depending on external events and shifts in SOS. They discussed choices they made to

support themselves as WWS. Most also discussed the importance of clinical treatment (i.e. support groups/ speech therapy/psychology) for directed management.

*Strategies and Coping Processes – “deep inside me I think I have a certain amount of assertiveness”*. Often the women discussed the notion of initially feeling helpless about how to manage their stutter; “I had no understanding of stuttering, or insufficient understanding” (Emma). This was particularly apparent for those raised in different cultures and the older women who grew up in Australia. Some of the women had different expectations of how much they should rely on others for support. The women also mentioned different internal qualities, feelings or beliefs helped or hindered them in managing their stutter.

**Georgina** discusses the helplessness she felt around her stutter during the 60s and 70s in Australia:

“I was on my own with my stuttering, completely on my own...you’ve got no idea what it’s like when you stutter and you’ve got no treatment available at the time”.

Different ideas expressed on what support to expect from others:

“you can’t expect other people to take on your problem... you have to do it yourself” – **Georgina**

“this is your journey, you have to travel yourself, no one can travel with you, that’s how I felt it’s more lonely” - **Suzie**

Most of the women spoke of inherent personality traits, such as assertiveness, positivity and confidence in ability, to form a base of internal resilience to assist in managing their stutter. Ongoing changes to the women’s SOS and their perceptions towards stuttering throughout life were expressed.

Comments regarding attitude changes:

Overall Confidence:

“being positive about yourself as opposed to being all shy” – **Wendy**

Confidence in Speech Ability:

“getting a bit more confidence even though I’m still not overly confident I feel more confident about my ability to speak... I know I can be fluent” – **Lisa**

Reduced Anxiety Regarding the Responses of Others:

“believing in yourself and your ability...don’t think that people will judge you by your stutter, people will judge you by your ability and also what you do and as a person, so what I’ve found so far is I’m a bit strong person” - **Suzie**

Seven of the women mentioned trying to hide their stutter or keep it a secret within certain environments (see *Dating* above) because of worries about how they would be perceived or responded to. The women were selective with whom they chose to disclose to regarding their stutter: “I’m pretty ok with it, I mean it would depend, if I feel the person’s going to judge me or... I wouldn’t let them know anything that’s vulnerable... it would depend on the person” (Sarah). Emma, on the other hand, used her stutter as an example of overcoming difficulty in her job as a healthcare professional; “I use it to teach” she commented.

**Lisa** talks about the interesting notion of self-disclosure only with those who also have a perceived shortcoming:

“people that find it hard to get jobs.... some are sort of disabled, some of them have had nervous breakdowns.....they’re returning to work, I told **them**, but I haven’t told the real people (laughs)”.

***Choices – “imagine me choosing something where you don’t have to talk much”.***

The women commented about how their stutter impacted some of the choices they made in their lives, mainly in their career paths and those they formed supportive relationships with (see *Partners* section above). These decisions were made consciously or unconsciously.

Lisa said, “I can have a good life, I have a great partner, I’ve got great friends, I’ve got a

good job”, signifying the external elements in her life that she had built to help support herself. The women commonly chose careers in which they would not have a large speaking role; “I chose to go to the place less demanding in terms of speaking” (Suzie). On the other hand, Georgina selected a job she thought would challenge her speech, commenting, “I somehow wanted to get jobs on switchboards and on the phone... I thought it would improve my speech”.

***Motivation to Seek Help - “I thought if I can find some... way of speaking that it might help me and it did, it was a turning point in my life”.*** Most of the women accessed treatment at various times over their lives for differing reasons. Two predominant motivations I observed were long-term romantic relationships coming to an end, and the desire to minimise negative reactions towards stuttering at work, or for a mixture of these reasons: “my husband died and I was in the office... and stuttering terrible, absolutely terrible” (Georgina). It was interesting to note that these sources of motivation often came from external events.

**End of relationships:**

“I’d split up from my husband right? So and I felt like “I’m gonna be getting out with people” and stuff like that and I was very conscious” - ***Lisa***

“I think when he mentioned the divorce word and, when I hit forty and got more confident and I actually went and saw a psychologist” – ***Wendy***

**Employment:**

“I would say just related to my confidence level you know...in my job dealing with some people and not being able...not feeling as though I was taken seriously” – ***Sarah***

“there’s certain consultants...who are a bit more challenging and he asks a question and you know the answer, you can’t get it out and your offsideer doesn’t know the answer and she’s the one that can talk better, so I decided maybe it’s time to try speech therapy again” - ***Emma***

***Support Groups and Treatment- “having somebody who knows how to tackle it and who can give you more support”.*** The women all highlighted the need for specific clinical support in managing their stutter. Seven of the woman mentioned the benefits gained from speech therapy for directly speech-related treatment, such as learning smooth speech or different breathing techniques. Although Emma had been frustrated at the lack of information and rationale provided in speech therapy, she still spoke of the need for clinical support; “you actually have to understand the neuroanatomy, the physiology of stuttering”. Support groups for stuttering appeared to play an increased role in managing the psychosocial impacts of stuttering for the women. The majority acknowledged a need to maintain their level of fluency on an ongoing basis and discussed the positive and negative experiences of attending these groups (see Table 3 below).

Table 3.

*Comments of the Women in this Study Regarding Experiences of Support Groups Run by the Speak Easy Association*

Positive Experiences	Negative Experiences
<ul style="list-style-type: none"> <li>• “you see people worse and you think “god”, “I could be worse”, I think in that way you appreciate what you’ve got”</li> <li>• “having that variety, the change of scenery, having different ideas what techniques...suggestions and everything so it was very good”</li> <li>• “the speech thing wasn’t a burden for us ...we didn’t care if we had a block nobody was there to poke fun at you or judge your intelligence”</li> <li>• “social interaction I gained out of Speak Easy, coming to a new country as a migrant, not having friends”</li> <li>• “I’ve been so inspired by members”</li> <li>• “It was the first time I met other people who stutter and I face the same struggles and the same rejection and social isolation as a</li> </ul>	<ul style="list-style-type: none"> <li>• “It was mostly men, so there was only really Wendy and myself, we actually were a lot younger than most of the men too”</li> <li>• “I found that some had worse stutters than me, so it’s like I wasn’t really being challenged”</li> <li>• “I found that some definitely had a patron of victimhood...I kind of got tired of that because it wasn’t really a positive experience”</li> <li>• “I think now that I’ve got older, and I have to catch buses and trains and things when I go”</li> <li>• “people come and go”</li> <li>• “when I got...competent at it, it switched, the sense that you become a support person instead”</li> </ul>

<p>result....to find understanding, it was healing”</p> <ul style="list-style-type: none"> <li>• “Speak Easy for me...is a place that you can be yourself, you don’t have to put on the Speak Easy fluency act if you don’t want to, you can be yourself, obviously you mix with other people and it’s a good place to practice your smooth speech”</li> <li>• “while I was supporting others, it was supporting me”</li> </ul>	
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## Quantitative Data

OASES scores were generally unsurprising and reflected interview material. One exception was Kathy, whose impact scores were higher than what would have been expected from the insight she provided. She appeared dismissive of issues in relation to her stutter and well-being. This could indicate lack of insight as a potential coping mechanism that Kathy has adopted, or that she may have felt uncomfortable discussing QOL issues within her interview. Although this was a small sample, this information affirms the use of the OASES as a tool in examining the impact of stuttering on different aspects of a PWS’s life. None of the women in this sample’s scores lay within the ‘severe’ category; therefore these results may not express the insight of a severely impacted woman. Table 4 below provides a summary of impact scores and severity of affect indicated by the OASES.

Table 2.

*OASES Scores Calculated for the Areas of Impact and Overall Score of the Participants*

Participant	General Information Score	Reactions to Stuttering Score	Communication in Daily Situations Score	Quality of Life Score	Overall Score
Georgina	1.7 mild/mod	1.36 mild	1.32 mild	1.32 mild	1.41 mild
Wendy	2.45 mod	2.9 mod	2.46 mod	2.04 mild/mod	2.48 mod
Lisa	2.32 mod	2.77 mod	1.96 mild/mod	2.32 mod	2.36 mod
Suzie	2.25 mod	1.83 mild/mod	1.96 mild/mod	1.64 mild/mod	1.9 mild/mod
Kathy	2.8 mod	3.05 mod/sev	2.76 mod	2.28 mod	2.73 mod
Sarah	1.9 mild/mod	2.36 mod	2.8 mod	1.32 mild	2.12

Emma	1.72 mild/mod	1.5 mild/mod	1.35 mild	1.04 mild	mild/mod 1.33 mild
Hannah	2.5 mod	3.4 mod/sev	2.6 mod	3.64 mod sev	3.08 mod/sev

## Discussion

The premise of this study was to explore issues regarding QOL, perception of stuttering, gender, and self-management for WWS. The findings provide deeper knowledge of the areas of impact and highlight the complex variety of interrelated ways in which stuttering coloured these women's lives.

### Quality of Life and Perceptions of Self and Others towards Stuttering

The effect of stuttering on the women's lives was so pervasive that it was impossible to separate their stutter from other elements of their experience. Stuttering was so embedded within their lives that it appeared to become part of their identities. The central category emerging from thematic analysis was related to SOS, the women's convictions regarding who they are (see Figure 1). SOS impacted upon their relationships, perceptions of other's responses to their stutter, ability to manage their speech and, in turn, their QOL. This reaffirms Aslihan's statement that stuttering can affect one's self-concept, feelings and beliefs (2011). It adds to knowledge regarding the multiple affects of stuttering on the lives of PWS.

QOL was affected as stuttering impacted feelings of connectedness with family, friends, significant others, colleagues or broader cultural communities. The women commonly felt a lack of understanding or support from these groups. The woman spoke of an eroded sense of confidence and increased anxiety during some social interactions, such as talking within a group or going on dates. As detailed in Plexico et al., one reason for this apprehension was concern relating to how others would respond to their stutter (2009a).

Combined with outcomes from the women's workshop survey (Nang et al., 2006), reporting 58% of the participants noted reduced confidence and increased anxiety during interactions, it can be suggested that these factors significantly influence how WWS relate to others.

The women spoke about the role of romantic partnerships in shaping their SOS. They also discussed the impact that these had on their QOL. The women often spoke of being unconfident when looking for a partner and drew comparisons between themselves and women who did not stutter. This finding adds weight to Van Borsel et al.'s work that found comparisons between PWS and people who did not stutter were unfavourable (2011). The emphasis that the women placed on relationships supported Myers' statement that the formation of these close relationships has strong bearing on an individual's perception of QOL (1999). Unfavourable comparisons and lack of assurance with romantic relationships may impact the women's beliefs regarding their value as potential partners. This exemplifies how stuttering might impact SOS for WWS.

The seven women in the study from different cultural backgrounds discussed this prominent influence on their lives. The women commonly felt isolated from cultural groups due to cultural views and understandings of stuttering. Furthermore, stuttering added to existing challenges of immigration. It affected experiences of finding work, meeting new friends and adjusting to cultural communication differences. In some instances, this appeared to contribute negatively to SOS and distort cultural identity.

Interestingly, for some of the migrant women, the experience of emigration to Australia appeared beneficial for QOL. They reported more positive listener-responses and an increased understanding within work and social contexts. The women also used cultural differences to mask their stutter (e.g. accent). The women preferred to be identified as



“different” for their culture, rather than for their stutter, indicating that the women are, again, attempting to reduce negative listener responses in a manner consistent with avoidant coping mechanisms outlined in Plexico et al.’s study (2009a). Although limited current knowledge exists regarding the influence of culture for WWS, this study unearthed possible positive and negative outcomes. Issues of stuttering, discrimination and ethnicity were discussed at a recent ISA World Congress, signifying growing awareness of this issue (Blom et al., 2013).

The majority of the women expressed hindrances to their careers related to real, or perceived, limitations on their speech abilities. The women commonly mentioned gravitating towards jobs less demanding on their speech. They talked of adverse responses during interviews or meetings and felt particularly daunted by some work tasks (e.g. answering the phone at reception). This is closely in line with Klein and Hood’s survey finding 33% of participants felt that stuttering affected how they did their job (2004). Most of the women appeared to share the views of the participants in Klein and Hood’s research about decreased chances of attaining and advancing within a job (2004). This is indicative of the dramatic impact stuttering can have on the careers of WWS. Stuttering appeared to influence notions of capability and identity as a professional, self-worth, value to community and job satisfaction, further impacting QOL.

### **Self-Management Strategies**

Perhaps one of the more meaningful findings regarding self-management was its interplay with influential life events, SOS, and identity. Processes of self-management were observed to be fluid and the women supported themselves in different ways over the course of their lives. A reciprocal relationship was noted between SOS and self-management. SOS, as with many aspects of a person’s life, was not static. Bergner and

Holmes' work described a person's concept of self as slow-shifting, however, dynamic throughout a lifetime (2000). The women often discussed how their SOS led them down paths of management, or, how management had brought about changes in SOS (e.g. increased confidence and belief in ability). Changes in perception of their stutter, and SOS, were often attributed to internal traits such as assertiveness, positivity and confidence. This affirms the implementation of stutter management that is focused on developing positive self-acceptance, such as the narrative-based therapy described in Leahy et al.'s case study (2012). The importance of management that considers the changing needs, circumstances and lifestyle demands of WWS can also be suggested.

A delicate relationship between internal coping mechanisms and reliance on external sources of support for stuttering management was observed. It was commonly observed that the ways in which the women inwardly dealt with their stutter were closely impacted by external life factors. The women were often spurred to seek treatment based on external circumstances, such as the end of a relationship. Treatment was also sought for work-related reasons. This is a point of difference from older research that suggested women were less likely to seek treatment than males as they viewed their stutter as less of a disadvantage (Silverman & Zimmer, 1979). The interview findings regarding the reasons this group of women sought treatment confirmed Graham-Bethea and Mayo's suggestions that changes in women's roles in the workplace since the publication of older research has influenced WWS's needs for stuttering management (2012), thus confirming the need for more up-to-date research regarding the experiences of WWS.

It was noted that the women supported themselves through managing external aspects of their lives, creating situations in which they felt comfortable. Their choice of career path or even personality traits shown in romantic partners were sometimes influenced by their stutter. The women's long-term partners showed common characteristics, described as

confident, well-spoken and outgoing. Some women tended to allow their partner to take over in interactions, reflecting a tendency to choose partners that helped compensate for stuttering. The women acknowledged that this ultimately increased their dependence on external support, indicating negative internalised beliefs regarding abilities as a speaker. Additionally, this may be an avoidant coping mechanism, as described in Plexico et al., to lower anxiety around speaking in social situations (2009a). Partners also supported the women in those ways mentioned by Beilby et al. (2013), through acceptance, patience and being non-judgmental again, emphasising the importance of others' responses towards the women's stuttering. These findings shed light on the emphasis the women placed on enlisting external support and important role that partners played in support of WWS.

On the most part, the women reflected positively about attending Speak Easy stutter support groups. The women mentioned benefits like finding understanding, receiving suggestions and social interaction, supporting Yaruss et al.'s findings regarding the importance of support groups as a source of exchange for PWS (2002). A noteworthy downside of stuttering support groups mentioned by the women was that they were often the minority, potentially creating a barrier to management. Leahy et al. identified support networks as a positive influence on attitudes to stuttering, as WWS may be unable to share their specific female experiences with others, this could indicate adverse implications for self-management (2012).

### **Stuttering and Gender**

An understanding into the women's perceptions of gender in relation to stuttering was gained even though little was mentioned specifically in response to questions regarding such issues. This limited specific contribution may suggest that the women have not directly thought about this topic. Issues of gender were diffuse throughout the women's stories. They revealed interesting experiences from a woman's perspective

related to finding a partner, having a family and career. However, further comparative studies between men and women are required to determine whether these experiences are indeed gender specific. The women also mentioned feeling outnumbered by men at stuttering support group meetings. A finding that women feel they are a minority is unsurprising however, when the ratio of males to females who stutter is 4:1 (Craig, 2002). This potentially impacts their ability to share gender-specific experiences and receive understanding from others living the experience.

The women who had children discussed apprehension they felt when interacting with some parents at school due to feeling judged or misunderstood. They also discussed concerns about recovery, and confusion about cause, when their children were also noticed to stutter. The issue of stuttering and motherhood has recently been raised at the ISA World Congress (Blom et al., 2013). Although the issue is yet to be explored, it could potentially have significant effects on feminine identity for WWS. Mothers who stutter may require stutter management with increased support and extra information about the causality of the condition.

The women attributed some negative responses they received towards their stutter in the workplace to perceived gender roles. Some felt that when they were outnumbered or managed by males, they were met with less patience or understanding. This adds depth to Graham-Bethea and Mayo suggestion that the growing numbers of women in higher powered, male-dominated positions the workplace has impacted the experience for WWS (2012). This could suggest that WWS are perceived as outsiders in male-oriented workplaces, for differences in their gender but also for their speech disorder. This could also be evidence of remaining stereotypes with regards to stuttering in the workplace (e.g. less intelligent) (Hurst and Cooper, 1983).

The reactions of others towards women in the workplace, or to mothers who stutter, may also be influenced by differing perceptions and expectations of women in society as opposed to males. This may account for differing experiences of stuttering between the genders. This confirms a need for further research into the changing roles of WWS.

### **Clinical Implications**

The study findings provide health professionals working with WWS an increased awareness of the issues illuminated through these women's stories. Health professionals may not be aware of, or cater for, concerns highlighted because of the larger number of males that stutter (Craig, 2002). The finding that external factors, SOS, and identity influenced self-management strategies emphasised and confirmed the importance of addressing internal beliefs as indicated by Aslihan (2011), Plexico et al. (2009b) and Leahy et al. (2012). The far-spread and changeable impacts of stuttering on these women call for management that is deeply entrenched in other aspects of WWS's lives.

Steps could be taken towards spreading awareness in workplaces regarding stuttering and ways to support WWS. This may help to increase their colleagues' understanding of what a stutter is, and assist them to respond appropriately to WWS. Employers could become increasingly responsible for modifying jobs to better suit the needs of WWS, monitoring discrimination and ensuring equal opportunities for recruitment and promotion.. As the women worried about having children and the judgement of other parents it may be beneficial to provide school communities with increased education with regards to stuttering. This could reduce WWS's concerns about their children's speech as well as the negative assumptions of other parents. Efforts could be made to link WWS with one another to provide a support network for sharing their specific feminine experiences.

### **Strengths and Limitations and Future Directions**

The primary strength of this study was the rich data collected and the inductive nature of the grounded theory methodology. Findings emerged from the women's highly personalised accounts, relating experiences in their own words. The use of the OASES to supplement interview data further supported the interview findings. A variety of methods were applied throughout this project to establish rigour and credibility.

Although emergent themes were generated that provide an exploratory base for future research, small sample size was used in this study and saturation of data was not achieved, reducing the potency of theory generated. Due to limited research in this area, there is a need for further exploration in many areas. While the sample of participants was broad and diverse in terms of culture, age and speech pathology background, all of the women were recruited through the Speak Easy Association and had accessed speech pathology.

Analysing the experience of women who are not involved with self help may also unearth further important issues. A closer look at the benefits WWS receive from stuttering support groups, and whether their traditional role as communicators has bearing on these, may be worthwhile.

As no sample of men who stutter was used, emerging gender issues could not be compared to those of men's experiences. Contrasting gender issues with a sample of men who stutter may be beneficial for drawing more direct comparisons into the issues of relationships, culture and workplace challenges.

Additionally, this study highlighted some interesting culture and immigration issues in relation to the way other cultures perceived WWS and their families. There is room for closer inspection of the experiences of migrants who stutter.

## **Conclusion**

The findings of this study indicated that stuttering was not just a speech disorder, instead it coloured WWS's whole experience of life. Although not definitive, this grounded theory study findings have raised some interesting ideas for consideration and confirmed a need for more extensive research in this area. A need for management that is sensitive to a woman's lifestyle is highlighted. Considering these eight women's accounts of their experiences with stuttering it can be seen that stuttering touched aspects of their lives such as relationships, career, SOS, identity and QOL. Stuttering impacted, not only on their experiences of being women, but also on their experiences of being mothers, career women, immigrants, family members, friends, partners and, potentially, many more. It can be argued that stuttering cannot be viewed divorced from gender, or, for that matter, any other aspect of a person's identity. The implications of this are that stuttering greatly impacts, who the women are, who they would like to be, their processes of self-management and their QOL.

## References

- Aslihan, I. (2011). Stuttering. *Current Approaches in Psychiatry*, 3(4), 704-728.
- Beilby, J.M., Byrnes, M.L., Meagher, M.L., & Yaruss, J.S. (2013). The impact of stuttering on adults who stutter and their partners. *Journal of Fluency Disorders*, 38, 14-29.
- Bergner, R.M., & Holmes, J.R. (2000). Self-concepts and self-concept change: A status dynamic approach. *Psychotherapy: Theory, Research, Practice, Training*, 37(1) 36-44.
- Birks, M., & Mills, J. (2011). *Grounded Theory: A practical guide*. London: SAGE Publications.
- Blom, A., Simpson, C., Herde, A., Mertz, P. (2013, June). *Women who stutter: What matters*. Presented at the 10<sup>th</sup> World Congress for People Who Stutter. De Werelt Congress Center, Lunteren, The Netherlands
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: SAGE Publications.
- Corbin, J. & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd Ed.). CA: SAGE Publications.
- Craig, A. & Tran, Y. (2005). The epidemiology of stuttering: The need for reliable estimates of prevalence and anxiety levels over the lifespan. *Advances in Speech–Language Pathology*, 7 (1), 41–46.



- Craig, A. Hancock, K., Tran, Y., Craig, M., & Peters, K. (2002). Epidemiology of stuttering in the community across the entire life span. *Journal of Speech, Language, and Hearing Research*, 45, 1097-1105.
- Duckham, I. (2009). *Fluency and Freedom*. Perth, WA: Speak Easy Association WA Inc.
- Gilman, J. (2012). Disability or identity? Stuttering, employment discrimination, and the right to speak differently at work. *Brooklyn law review*, 77(3), 1179.
- Graham-Bethea, J., & Mayo, R. (2012). A Minority within a Minority. *The ASHA Leader*, February 1, 20-21.
- Guitar, B., & McCauley, R.J. (2010). Treatment of stuttering: Established and emerging approaches. Baltimore, MD: Lippincott Williams & Wilkins
- Hammersley, M. (2013). *What is Qualitative Research?*. London: Bloomsbury Publishing.
- Hurst, M.I., & Cooper, E.B. (1983). Employer attitudes towards stuttering. *Journal of Fluency Disorders*, 8(13), 109-128.
- Kelly, S.E. (2010). Qualitative interviewing techniques and styles. In *The SAGE handbook qualitative methods in health research* (pp. 307-327). London: SAGE Publications.
- Klein, J.F., & Hood, S.,B. (2004). The impact of stuttering on employment opportunities and job performance. *Journal of Fluency Disorders*, 29(4), 255-273.
- Lavid, N. (2003). *Understanding Stuttering*. Jackson: University Press of Mississippi.
- Leahy, M.M., O'Dwyer, M., & Ryan, F. (2012). Witnessing stories: Definitional ceremonies in narrative therapy with adults who stutter, *Journal of Fluency Disorders*, 37(4), 234-241.

- Lapan, S.D., Quartaroli, M.T., & Reimer, F.J. (2012). *Qualitative Research: An introduction to methods and design*. San Francisco: Wiley.
- Myers, D. G. (1999). *Close relationships and quality of life*. In D. Kahneman, E. Diener, & N. Schwarz (Eds.), *Well-being: The foundations of hedonic psychology* (pp. 374–391). New York: Russell Sage Foundation.
- Nang, C., Dhu, P., & Geevaratne, L. (2006). A survey of the self-help needs of women who stutter. *Fluency Association 5th International Conference*. Dublin, Ireland.
- O'Brian, S., Packman, A., & Onslow, M. (2004). Measurement of stuttering in adults: Comparison of stuttering-rate and severity-rating methods. *Journal of Speech, Language and Hearing Research*, 47, 1081-1087.
- Payne, S. (2007). Grounded theory. In *Analysing qualitative data in psychology* (pp. 65-87). London: SAGE Publications.
- 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(2), 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(2), 108-126.
- NVivo: Qualitative data analysis software, version 10 [Computer software], (2012) QSR International Pty Ltd.
- Rosenstock, I.M. (2005). Why people use health services. *Milbank Quarterly*, 83(4), 1-28.

- Ryan-Nicholls, K. D., & Will, C.I. (2009). Rigour in qualitative research: Mechanisms for control. *Nurse Researcher*, 16(3), 70-85.
- Sheehan, J. (1979). Level of aspiration in female stutterers: Changing times? *Journal of Speech, Language, and Hearing Research*, 44, 479-486.
- Silverman, E-M., & Zimmer, C.H. (1979). Women who stutter: Personality and speech characteristics. *Journal of Speech and Hearing Research*, 22, 553-564.
- Silverman, E-M., & Zimmer, C.H. (1982). Demographic characteristics and treatment experiences of women and men who stutter. *Journal of Fluency Disorders*, 7(2), 273-285.
- St Louis, K.O. (2012). Male versus female attitudes toward stuttering. *Journal of communication disorders*, 45(3), 246.
- Tuckett, A. (2005). Part II. Rigour in qualitative research: complexities and solutions. *Nurse Researcher*, 13(1), 29-42.
- 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.
- Yaruss, J.S., Quesal, R.W., & Murphy, B. (2002). National Stuttering Association members' opinions about stuttering treatment. *Journal of Fluency Disorders*, 27(3), 227-242.
- Yaruss, J.S., & Quesal, R.W. (2010). *OASES: Overall Assessment of the Speaker's Experiences of Stuttering*. Bloomington: Pearson.

## *Appendix A*

### **Information Sheet Sent to Participants Before they Registered Consent.**

#### **INFORMATION SHEET – WOMEN WHO STUTTER Experiences of developing self management and quality of life**

My name is Katie Milton and I am a final year Honours student in Speech Pathology at Edith Cowan University, under the supervision of Dr Deborah Hersh and Dr Charn Nang. I am interested in the experiences of women who stutter. I am conducting a research project aimed at improving understanding of the specific experiences of women who stutter in relation to quality of life and how stuttering is managed. Women who stutter of ages 18 and above are invited to participate in the study.

Should you choose to provide consent to participate in this study, I will meet with you at a time and place of convenience to you for approximately one and a half hours to discuss your experiences. If consent is given you will be audio and/or videotaped – the choice will be up to you. The purpose of this session will be to explore the impact of stuttering on your quality of life, interaction with others and any methods you use to manage this. I am particularly interested in issues related to stuttering and gender. Before recording you will be asked to complete a brief case history form which will collect basic information about you and your stutter. During the recording session I will ask various questions, however the interview is loosely structured, allowing you to discuss issues that you feel are important. After the interview has taken place I will ask you to complete the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES). This is a brief questionnaire that generates a score based on quality of life factors.

The information that you provide will be analysed for recurring themes using specialised software. Your interview data will be stored in secure facilities at Edith Cowan University and will be accessible only to research staff directly involved in the project; information will be de-identified to preserve confidentiality. If you would like, a copy of your interview transcription can be provided in order for you to ensure that your point of view has been interpreted appropriately. When the study is completed you will be sent a summary of the project findings.

Participation in this research is entirely voluntary and you are free to withdraw from the project at any time without the need to provide reason or justification. Should you choose to withdraw consent; records of your participation will be destroyed.

If you have questions about any aspect of this project please contact me on 0409682827. I am also contactable via email: [kmilton0@our.ecu.edu.au](mailto:kmilton0@our.ecu.edu.au). Furthermore, if you would like to talk to someone who is not related to the project concerning ethics issues please contact [ethics officer]. Research Ethics officer at Edith Cowan University, on 6304 2170.

Katie Milton

Edith Cowan University

*Appendix B*

**Documentation to Register Willingness of Participants to Take Part in this Study and  
be Audio/Video-recorded.**

**CONSENT FORM**

**Project Title: Women who stutter: Experiences of developing self  
management and quality of life**

I .....have read the information provided concerning this study,  
and any questions I have asked have been answered to my satisfaction. I agree to  
participate in this project, realising that I may withdraw from the study at any time without  
reason and without prejudice.

I understand that all information provided will be treated as strictly confidential, and will  
not be released by the investigator unless this is required by law. I have been advised as to  
what information is being collected, what the purpose is, and what will be done with the  
information upon completion of the research.

I agree that research data gathered for the study may be published, may be used for future  
related studies, and may be used for teaching and other educational purposes provided that  
neither my name, nor other identifying information, is used.

Please indicate whether you would like to be videorecorded during this project (if you  
indicate that you would not like to be video recorded, solely audio-recording will be used):  
**YES NO**

If you have consented to be videorecorded, please indicate whether you permit the video/  
or sections of the video to be used for teaching or educational purposes: **YES NO**

Signed: .....

Date: .....

## Appendix C

## Topic Guide used for Semi-Structured In-Depth Interviews

<b>Quality of Life:</b>  Tell me a bit about your experience of stuttering?	How was it for you – during your childhood	<ul style="list-style-type: none"> <li>• Has that changed over time? How?</li> <li>• How did that make you feel?</li> <li>• Can you tell me some more about that?</li> <li>• What were the consequences of that?</li> <li>• How could that have been different?/what could you/ they have done differently?</li> <li>• Can you tell me about one of these times?</li> </ul>
	<ul style="list-style-type: none"> <li>- at school</li> <li>- at university</li> <li>- at work</li> </ul>	
	Is there a particular moment or time you can share with us that involved your stutter? (negative/positive)	
	Has there been times where stuttering has influenced decisions you have made?	
	Where does stuttering fit in with your hobbies/ social life? (past/present)	
<b>Interactions:</b>  What has been your experience when communicating with others?	Has the impact of your stutter changed over time? If so how?	
	Can you tell me about situations in which you feel comfortable/ uncomfortable? (past/present)	
	Is there a particular moment or time you can share with us that involved your stutter in an interaction? (negative/positive)	
	What is your perception of how your stutter is seen by others?	
	How do you feel when you stutter during an interaction?	
	What do you do when you stutter during an interaction and has this changed over time? If yes, what do you think has impacted on this?	
	Has the impact of your stutter on communication changed over time? If so how?	

<b>Strategies:</b>  What have you found helpful for managing your stutter?	How do you feel this has improved your stutter/ quality of life?	
	If you have had previous therapy, could you describe what your goals were for your stutter at the time, and what you feel the outcomes were?	
	Can you tell me what led you down this management path?	
	What advice would you give to another person/woman with a stutter?	
	What have you found to be unhelpful?	
<b>Gender:</b> I am interested in women's experiences of stuttering because very little has been written about it. What are your thoughts?		

## *Appendix D*

### **Member Checking: Interim Summary of Results Sent to Participants for Feedback**

Over the eight interviews, three prominent areas of discussion were observed in the interview content. These are summarised below:

#### **Relationships**

- The women often found it difficult speaking within group situations, across different environments and life stages
- Some of the women grew up feeling teased, pressured or unacknowledged by family members
- Most of the women had the perception that, although their friends and family may have wanted to help, they did not know how best to support them
- The women often found the experience of dating challenging and would often be withdrawn on dates and try to hide their stutter
- Those women with partners described them as intelligent, relaxed, outgoing, well spoken and confident
- Partners would sometimes support the women by taking on communication responsibilities, some of the women reflected on becoming dependent on their spouse (also noted to be a generational and cultural issue)

#### **Responses of Others**

- The women were selective with the types of people or environments where they would disclose they had a stutter (e.g. trying to hide it during dates/ job interviews or revealing it to use as a teaching tool)
- The women reflected the way in which others responded to their stutter influenced their self-concept and confidence
- Most of the negative responses from others that were discussed happened in the workplace (e.g. interviews ending quickly, being asked if they are ill)
- The women sometimes felt that negative responses towards their stutter in the workplace were amplified in occupations where they were outnumbered by male colleagues
- The women spoke about the effects of being labelled or treated differently for having a stutter at a school and university (e.g. shaming or worsening the condition)
- It was observed that having a stutter could negatively influence how women (and sometimes their families) were perceived by other people from their cultural group
- Some of the women who emigrated mentioned their stutter could be masked behind their accent or that Australians perceived it to be a cultural way of speech; most saw this as a benefit

#### **Self-Management**



- Treatment for stuttering and processes of management were noted to be ongoing and changeable: the women often received treatment for their stutter numerous times over their lives due to events that were occurring at the time (e.g. emigration, attending university, travel)
- The main life events that prompted the women in this study to seek treatment for their stutter were following the end of a long-term romantic partnership or facing a need to minimise negative responses at work
- The women often mentioned a period of feeling helpless in managing their stutter and some of the reasons for this were a lack of services or understanding of how to manage the condition (particularly mentioned by older generation Australians and those growing up in other countries)
- The women spoke of inherent personality traits that they feel are useful in managing a stutter, such as assertiveness, confidence and positivity
- Attitudes to stuttering and the support required by the women appeared to change throughout different life stages and events
- It was observed that the choices the women made, for example, in relation to the qualities shown in their partners or work/career options, were influenced by what they felt would be supportive for them as women who stutter
- The women highlighted the need for specific, clinical treatment in providing direct support
- Support groups were useful for the following reasons: seeing how others coped/managed their stutter, realising the range of severity, inspiration from others, opportunities to practice, feedback and suggestions from others, a place to feel comfortable and a source of social interaction
- Support groups were unhelpful for the following reasons: mainly men at the groups, not feeling challenged enough, some people there had negative attitudes so that the experience was not a positive one, and the fact that they were difficult for some of the women to travel to

*If you have any questions or further comments please call Katie Milton on 0409 682 827 or email [kmilton0@our.ecu.edu.au](mailto:kmilton0@our.ecu.edu.au)*