

WHY DO PEOPLE WHO STUTTER ATTEND STUTTERING SUPPORT GROUPS?

By
Nicola Bloye
17069892

A dissertation submitted in fulfillment of the requirements for the degree

Master of Arts (MA) in Speech-Language Pathology

In the

**Department of Speech-Language Pathology and Audiology,
Faculty of Humanities**

At the

University of Pretoria

Supervisor: Dr Shabnam Abdoola

Co-supervisor: Ms Casey Jane Eslick

November 2022

University of Pretoria

Declaration of Originality

UNIVERSITY OF PRETORIA

Full name of student: **Nicola Bloye**

Student number: **17069892**

Topic of work: **Why do people who stutter attend stuttering support groups?**

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this dissertation is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person with a view to handing it in as my own.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.



SIGNATURE OF RESEARCHER

26 October 2022

DATE

Acknowledgements

Firstly, I would like to thank the participants of this study for taking the time to share your stories and perspectives with me. You are all the true experts on stuttering and I learnt so much from each and every one of you.

To the SpeakEasy coordinators, Ms Dina Lillian and Dr Shabnam Abdoola, thank you for encouraging the members of your incredible support groups to participate in my research study.

Dr Shabnam Abdoola and Miss Casey Eslick, thank you both for your many hours of guidance and academic insight. Thank you for believing in me and my research, and for encouraging me each step of the way.

To my incredible Mom, Ann, thank you for your unwavering support and belief in me. Thank you for celebrating every milestone with me, for wiping away my tears and encouraging me to never give up. I dedicate this dissertation to you.

I would like to thank the rest of my wonderful family for their support, encouragement, and love. I could not have done this without you. In particular, I would like to thank my gran, Brenda, for your love and for helping to keep me grounded. To my late granddad, Alan, thank you for watching over me. I hope I have made you proud.

To my wonderful friends, I cannot thank you enough for your words of encouragement and love throughout this process. Thank you for being my biggest fans.

Table of Contents

List of Tables	8
Key terms and definitions	9
Abbreviations	10
Abstract.....	11
Chapter 1. Introduction and orientation.....	13
Chapter 2. Method	16
2.1 <i>Study aim and objectives</i>	16
2.1.1 Aim	16
2.1.2 Objectives	16
2.2 <i>Study design</i>	16
2.3 <i>Ethical considerations</i>	17
2.3.1 Ethical clearance	17
2.3.2 Informed consent and voluntary participation	17
2.3.3 Competence of the researcher	18
2.3.4 Confidentiality	18
2.3.5 Respect for persons, beneficence and avoidance of harm	18
2.3.6 Plagiarism	19
2.4 <i>Study setting</i>	19
2.5 <i>Study participants</i>	20
2.5.1 Procedures for participant selection	20
2.5.2 Sample size	20
2.5.3 Selection criteria	21
2.5.4 Study participants	22
2.6 <i>Data collection procedures</i>	22
2.6.1 Materials and apparatus for data collection	22
2.6.2 Procedures for data collection	22
2.7 <i>Data analysis and management</i>	23

2.8	<i>Reliability and Validity (Trustworthiness)</i>	23
2.8.1	Credibility	24
2.8.2	Transferability	24
2.8.3	Confirmability	24
2.8.4	Authenticity	25
2.8.5	Dependability	25
2.8.6	Validity of semi-structured interview	25
2.9	<i>Pre-test</i>	26
2.9.1	Aim of the pre-test	26
2.9.2	Participants in the pre-test	26
2.9.3	Materials used in the pre-test	27
2.9.4	Results of the pre-test	27
Chapter 3. Article	30
3.1	<i>Abstract</i>	30
3.2	<i>Introduction</i>	31
3.3	<i>Research methods and design</i>	32
3.3.1	Design	32
3.3.2	Setting	32
3.3.3	Population and sampling strategy	33
3.3.4	Data Collection	34
3.3.5	Data analysis	35
3.3.6	Ethical considerations.....	35
3.4	<i>Results</i>	36
3.4.1	Theme 1: Altered perceptions	36
3.4.1.1	Subtheme 1: Increased acceptance of stutter	36
3.4.1.2	Subtheme 2: Improved confidence.....	37
3.4.2	Theme 2: Increased sense of community	37
3.4.3	Theme 3: Support group reciprocity	38
3.4.3.1	Subtheme 1: Learning from others	38
3.4.3.2	Subtheme 2: Encouragement and empowerment.....	39
3.4.4	Theme 4: Support group environment, participants and topics	40
3.4.4.1	Subtheme 1: Environment.....	40

3.4.4.2	Subtheme 2: Value of SLTs as facilitators	40
3.4.4.3	Subtheme 3: Meeting topics	41
3.5	<i>Discussion</i>	41
3.5.1	Altered perceptions	42
3.5.2	Increased sense of community	43
3.5.3	Support group reciprocity	43
3.5.4	Support group environment, participants and topics	44
3.6	<i>Conclusion</i>	46
3.7	<i>Critical Evaluation</i>	46
3.8	<i>Acknowledgements</i>	47
3.9	<i>Competing interests</i>	47
3.10	<i>Author contributions</i>	47
3.11	<i>Funding</i>	48
3.12	<i>Data availability</i>	48
3.13	<i>Disclaimer</i>	48
3.14	<i>References</i>	48
Chapter 4. Results	53
4.1	<i>Theme 1: Altered perceptions</i>	53
4.1.1	Subtheme 1: Increased acceptance of stutter	54
4.1.2	Subtheme 2: Improved confidence	54
4.2	<i>Theme 2: Increased sense of community</i>	55
4.3	<i>Theme 3: Support group reciprocity</i>	55
4.3.1	Subtheme 1: Learning from others	55
4.3.2	Subtheme 2: Encouragement and empowerment	56
4.4	<i>Theme 4: Support group environment, participants and topics</i>	56
4.4.1	Subtheme 1: Environment	56
4.4.2	Subtheme 2: Value of SLTs as facilitators	57
4.4.3	Subtheme 3: Meeting topics	57
Chapter 5. Discussion	59

5.1	<i>Theme 1: Altered perceptions</i>	59
5.1.1	Subtheme 1: Increased acceptance of stutter	59
5.1.2	Subtheme 2: Improved confidence	60
5.2	<i>Theme 2: Increased sense of community</i>	61
5.3	<i>Theme 3: Support group reciprocity</i>	61
5.3.1	Subtheme 1: Learning from others	61
5.3.2	Subtheme 2: Encouragement and empowerment.....	62
5.4	<i>Theme 4: Support group environment, participants and topics</i>	63
5.4.1	Subtheme 1: Environment	63
5.4.2	Subtheme 2: Value of SLTs as facilitators.....	63
5.4.3	Subtheme 3: Meeting topics	64
Chapter 6. Conclusions and critical evaluation		65
6.1	<i>Conclusion and clinical implications</i>	65
6.2	<i>Strengths of the research study</i>	68
6.3	<i>Limitations of the research study</i>	68
6.4	<i>Recommendations for future research</i>	69
References		70
Appendices		77
	<i>Appendix A: Telephonic semi-structured interview schedule</i>	77
	<i>Appendix B: Ethical approval letter from Research Ethics Committee, Faculty of Humanities, University of Pretoria</i>	86
	<i>Appendix C: Information letter and informed consent document</i>	87
	<i>Appendix D: Permission letters from SpeakEasy coordinators</i>	91
	<i>Appendix E: Referral letter for counselling</i>	93
	<i>Appendix F: Referral letter for speech-language therapy services</i>	94
	<i>Appendix G: Referral permission letters from speech-language therapists (Pretoria and Johannesburg)</i>	95

Appendix H: Explanations and rationale for the telephonic semi-structured interview schedule 99

Appendix I: Rating scale 100

Appendix J: Quotes for themes 101

Appendix K: Proof of article submission to the South African Journal of Communication Disorders 106

List of Tables

Table 2.1: Pre-test recommendations and effected changes

Table 3.1: Participant demographics

Table 3.2: Quotes for theme 1: Altered perceptions; subtheme 1: Increased acceptance of stutter

Table 3.3: Quotes for theme 1: Altered perceptions; subtheme 2: Improved confidence

Table 3.4: Quotes for theme 2: Increased sense of community

Table 3.5: Quotes for theme 3: Support group reciprocity; subtheme 1: Learning from others

Table 3.6: Quotes for theme 3: Support group reciprocity; subtheme 2: Encouragement and empowerment

Table 3.7: Quotes for theme 4: Support group environment, participants and topics; subtheme 1: Environment

Table 6.1: Clinical implications for SLTs based on PWS' perspectives regarding their reasons for attending SSGs

Key terms and definitions

Stuttering is characterised by an abnormally high occurrence of interruptions in the forward flow of speech. Stuttering comprises of three components; (1) core behaviours (repetitions, prolongations, and blocks), (2) secondary behaviours (escape and avoidance behaviours), and (3) feelings and attitudes (American Speech-Language-Hearing Association [ASHA], n.d.; Guitar, 2014).

Quality of life can be defined as a person's perception of his/her satisfaction in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns. It is a broad concept and can include the person's independence level, psychological state, physical health, and social and family relationships (Weigel, 2013).

A *stuttering support group's* main purpose is to provide a safe environment in which members can "freely share their feelings and develop a sense of connectedness to others who stutter" (Guitar, 2014, p. 552). Stuttering support groups can also be defined as a place where people who stutter can share experiences in a non-judgemental environment, where the focus is not on fluent speech (Boyle, 2013).

Data saturation is the point in data collection when no additional information is identified, data begins to repeat and further data collection becomes redundant (Kerr et al., 2010).

Information power states that the more information the sample contains that is relevant to the actual study, the fewer participants are required (Malterud et al., 2016).

Abbreviations

ASHA:	American Speech-Language-Hearing Association
DOH:	Department of Health
HPCSA:	Health Professions Council of South Africa
ICF:	International Classification of Functioning, Disability and Health
POPI Act:	Protection of Personal Information Act.
PWS:	person who stutters/people who stutter
QoL:	quality of life
SLT:	speech-language therapist/speech-language therapy
SSG(s):	stuttering support group(s)
WHO:	World Health Organization

Abstract

Background: Stuttering support groups (SSGs) are a known, invaluable resource for people who stutter (PWS). General support groups have been well researched, however, research specifically into SSGs is only emerging. Further insight is needed to guide speech-language therapists' (SLTs) facilitation of SSGs.

Objective: This research is aimed at determining PWS' perspectives regarding why they attend SSGs in Gauteng, South Africa.

Method: Thirteen PWS, between 20-58 years old, who attend SSGs were selected purposively. Their perspectives on SSGs were obtained during semi-structured telephonic interviews and analysed thematically which yielded clinical implications.

Results and Discussion: Four themes; "altered perceptions", "increased sense of community", "support group reciprocity" and "support group environment, participants and topics", were identified. SSGs helped PWS accept their stutter and gain confidence. Clinical implications identified included SLTs encouraging; (1) positive perceptions through education, self-empowerment, sharing success stories, and ways to elicit positive listener reactions, (2) connections between meetings to increase the sense of community, (3) reciprocity in meetings, (4) sharing personal stories to promote learning and self-management, and (5) support, praise and education to empower and encourage PWS. SLTs can encourage equal contributions from willing participants without pressuring others. Disfluency and emotional support should be equally discussed in SSGs.

Conclusion: These perspectives of PWS were used to provide recommendations to SLTs of ways to better meet the needs of PWS who attend SSGs. Recommendations included focusing discussions on fluency and emotions and sharing personal stories. Insights from PWS also helped better inform SLTs of their role within SSGs including guiding conversations and facilitating conversations that foster deeper understanding.

Keywords: disfluency; people who stutter; perspectives; social support; speech-language therapists; stuttering; stuttering support groups; quality of life

Chapter 1. Introduction and orientation

People who stutter (PWS) share a diagnostic label, but that does not mean that they share the same experiences (Weigel, 2013). This is because stuttering is a multifaceted communication disorder with affective, behavioural, and cognitive components (Connery et al., 2019). While the overt behavioral components of stuttering are easily identified, the affective and cognitive (emotions and attitudes) components are significantly more destructive (Medina et al., 2020).

PWS often experience negative affect, fear, shame or embarrassment throughout their lives (Blumgart et al., 2014; Beilby, 2014; Tichenor & Yaruss, 2019). These affective components can be debilitating, with some PWS even describing feeling hopeless or exhausted (Tichenor & Yaruss, 2018). Some PWS may also experience heightened levels of anxiety (Blumgart et al., 2014; Iverach et al., 2018). As a result of these affective components, PWS are likely to avoid and conceal their stuttering, which can limit social participation, result in feelings of isolation, and negatively impact overall well-being (Boyle, 2013). It is also vital to consider the negative impact that communication partners and society can have on a PWS. PWS are frequently portrayed negatively in society, maintaining the stereotype of stuttering as something unusual (Constantino, 2018). Negative listener reactions or judgements can lead to negative self-stigma, or the belief that one does not meet societal norms due to flaws or limits in themselves (Boyle, 2018). In addition to affecting communication and participation, these experiences can impact academic and/or occupational achievement, relationships, and social interactions (Beilby, 2014; Bleek et al., 2012; Boyle, 2015). Taken collectively, these negative impact factors have a detrimental impact on a person's overall quality of life (QoL) (Beilby, 2014; Boyle, 2015).

The International Classification of Functioning, Disability and Health (ICF) encourages SLTs to treat communication disorders holistically (World Health Organization [WHO], 2001) and therefore a large component of a speech-language therapist's (SLT) scope of practice includes addressing PWS' QoL (American Speech-Language-Hearing Association [ASHA], 2016). An SLT, however, cannot directly relate to the emotions that PWS experience daily, unless she/he is a PWS themselves. A setting in which

PWS are, however, likely to be able to directly relate to individuals in a stuttering support group (SSG).

A SSG is a safe environment where people can come together as a community and share their experiences without being judged (Boyle, 2013). Many studies have shown the value of SSGs (Boyle, 2013; Craig et al., 2011; Gerlach et al., 2019; Plexico et al., 2019). Social support, defined as the feeling of being cared for, appreciated, and part of a mutually supportive social network or community (Taylor, 2011), has been found to protect PWS against the detrimental impacts of stuttering (Craig et al., 2011; Gerlach et al., 2019). In a SSG, PWS can openly share their feelings and worries, receive support and affirmation, and be compassionately understood by other PWS who can directly identify with them (Thoits, 2011). Support networks can also help reduce psychological discomfort caused by stuttering, allowing PWS to participate more fully in everyday activities (Blumgart et al., 2014). Finally, social support fosters a sense of belonging, which improves well-being and thus QoL. (Craig et al., 2011). SSGs also provide an excellent opportunity to maintain improvements made in individual speech therapy (Guitar, 2014). The chance to be part of a unique community; a changed mindset in terms of self-identify as a PWS; increased acceptance of themselves and thus a greater willingness to speak openly about their stuttering; and improvements in personal attitudes and feelings such as confidence, self-esteem, and self-image are some additional benefits of SSGs (Blumgart et al., 2014; Boyle, 2013).

SSGs provide the opportunity for PWS to receive support and improved QoL (Blumgart et al., 2014; Boyle, 2013). Within the context of South Africa, there are support groups available, in some areas, for PWS to attend. An example of a SSG is SpeakEasy, which was founded 15 years ago by a group of PWS, their parents, and SLTs in order to prioritise stuttering in South Africa by improving education, encouraging self-help groups, and enhancing the training and skills of SLTs (Speakeasy, n.d.). Speakeasy runs SSGs in Pretoria and Johannesburg.

Despite the existence of SSGs in South Africa, there is limited research on the value of these SSGs, as well as the reasons why PWS attend them. There only appears to be one study available that directly discusses South African PWS and SSGs

(Vedprakash, 1999). This gap in research must be addressed as a previous study conducted by Klompas and Ross (2004) found that South African PWS also experience a reduced QoL as a result of their stutter. Vedprakash (1999) explored the role and function of the KwaZulu Natal SpeakEasy SSG (no longer running) and concluded that the group had an overall positive effect on all group members' lives. Although Vedprakash (1999) provides valuable insight into the KwaZulu Natal SpeakEasy SSG, no publications could be found on the value of SSGs in the Gauteng province, warranting further research. In addition, the researcher could not locate any formalised guidelines available for SLTs to follow in order to successfully facilitate and manage SSGs.

More recent and in-depth research is therefore warranted to form a better understanding of why PWS attend SSGs. To promote this understanding, it is the perspectives and experiences of PWS that need to be heard. It is possible for patients' rehabilitation experiences, as well as their motivation and functional outcomes, to be improved by including persons with disabilities in goal planning and decision-making. (Evans 2012; Brown et al., 2021).

PWS' perspectives can help SLTs who facilitate SSGs adapt and change the activities, topics of conversation, and goals targeted during SSG meetings to better suit the needs of the PWS who attend. This research also has the potential to assist SLTs in encouraging PWS to attend and actively participate in SSG meetings. The degree of motivation is what inspires a person to progress forward and achieve their goals (Sønsterud et al., 2020; Ratner & Tetnowski, 2014), so it is important that SLTs understand this. Perspectives from PWS who attend SSGs can provide a valuable contribution to the field of stuttering treatment in South Africa. Therefore, to contribute to the existing research regarding stuttering support groups, the researcher aims to describe PWS' perspectives regarding why they attend SSGs, in order to provide evidence-based recommendations for SLTs who facilitate these SSGs to ensure best possible practice.

Chapter 2. Method

2.1 Study aim and objectives

2.1.1 *Aim*

The aim of this study is to understand and describe PWS' perspectives regarding why they attend SSGs.

2.1.2 *Objectives*

The following objectives were formulated in order to achieve the main aim:

- To examine the self-reported impact SSGs can have on PWS' perception of their stutter, their emotional well-being, and their ability to cope with their stutter.
- To determine the components of SSGs that PWS perceive as beneficial.
- To identify further aspects which health professionals can adjust to meet the needs of SSG members.

The data will be used to provide SLTs who facilitate SSGs with evidence-based recommendations.

2.2 Study design

A qualitative research design was used for this study as its focus was to develop an in-depth understanding of various aspects, such as the reasons why PWS attend SSGs and their experiences within SSGs (Brink et al., 2018). This study was considered to be both phenomenological and descriptive, as its purpose was to understand and describe PWS' perspectives regarding why they attend SSGs (Leedy & Ormrod 2021; Sandelowski, 2010). Data was collected using survey research, specifically a telephonic semi-structured interview (Appendix A). A semi-structured interview is typically guided by a flexible interview schedule and can be supplemented by follow-up questions that provide the researcher with opportunities to clarify, explain, probe, and comment (DeJonckheere & Vaughn, 2019). Using a semi-structured interview allowed the researcher to explore PWS' real-life experiences of SSGs and collect narrative data under less structured conditions (Irwin et al., 2014). Members of the Johannesburg and Pretoria SpeakEasy SSG were selected through purposive sampling (Leedy & Ormrod, 2021). The data collected through the semi-structured

interview was analysed using thematic analysis. Some descriptive statistics were used to analyse five questions in the telephonic semi-structured interview (Appendix A), in order to support the qualitative data generated from the other questions.

2.3 Ethical considerations

Ethical considerations are vital to find the balance between the participants' rights and the demands of the research questions, so as to avoid unethical research (Polit & Beck, 2017). To ensure ethical research was conducted, the following principles, considerations, and procedures were put into place and are described in further detail below.

2.3.1 *Ethical clearance*

Prior to conducting data collection, ethical clearance for this research study was granted by the University of Pretoria's Faculty of Humanities' Research Ethics Committee (HUM025/0521) (Appendix B).

2.3.2 *Informed consent and voluntary participation*

Informed consent is the responsibility of the researcher (Leedy & Ormrod, 2021) and highlights the ethical principles of voluntary participation, as well as the principles required for protecting the participants from harm (Babbie & Mouton, 2001). The recruited study participants were informed of the nature of the research and it was clearly explained that participation in the study was voluntary (Leedy & Ormrod, 2021).

To protect SpeakEasy participants from unsolicited communications and adhere to the Protection of Personal Information (POPI) act regulations, stakeholders (SpeakEasy group coordinators) were approached first for permission to approach SpeakEasy members with an information letter and informed consent document (Appendix C). Stakeholders were also invited to sign a permission letter (Appendix D) as confirmation of their consent to distribute the relevant documents to their group members and invite them to participate. Once ethical clearance was granted by the Faculty of Humanities' Research Ethics Committee (Appendix B), stakeholders distributed the information letter and informed consent document (Appendix C) which clearly stated the nature of the research and highlighted that participation was voluntary (Department of Health [DOH], 2015). The members who were interested in participating were invited to sign

the informed consent section of the information letter and informed consent document (Appendix C) and email it back to the researcher. The potential participants were not expected to make an immediate decision regarding whether to participate in the study (DOH, 2015). Once the researcher received signed informed consent documents from the interested participants, a suitable time and date for the interview was arranged with the participant directly.

2.3.3 Competence of the researcher

The researcher conducting this study is a qualified SLT and is therefore trained in the field of stuttering. The researcher is registered with the Health Professions Council of South Africa (HPCSA) with a registration number of ST 0019666.

2.3.4 Confidentiality

Participants were not required or encouraged to provide any identifying information during the telephonic semi-structured interview. Instead, each participant was assigned a numerical code that was used to represent their information during data analysis (e.g., P1, P2). This prevented the collected information from being linked to a specific participant (Brink et al., 2018). Although this study has been made publicly available to other researchers, no identifying information has been included in the article or dissertation, thus ensuring that the participants' information is still kept confidential.

Furthermore, the participants' informed consents (Appendix C) as well as the recordings and transcriptions from the telephonic semi-structured interviews have been securely stored and archived on the Department of Speech-Language Pathology and Audiology's data repository for 15 years as stipulated by regulations compiled by the University of Pretoria. Only the researcher and the research supervisors have access to the participants' data.

2.3.5 Respect for persons, beneficence and avoidance of harm

To ensure that the human rights of the participants were protected throughout the research process, the two fundamental principles of respect for persons and beneficence were applied (Brink et al., 2018). In order to uphold the principle of respect for persons, potential participants were provided with sufficient information in the

information and informed consent document (Appendix C) that allowed them to make an informed choice regarding whether to voluntarily participate in the study (DOH, 2015). The participants were also given the option to withdraw from the study at any time and informed that their participation in SpeakEasy would not be impacted by doing so. By ensuring this, the principle of respect for persons was followed and each participant was able to evoke their right to self-determination (Brink et al., 2018).

The principle of beneficence states that the researcher must ensure the participants' well-being (Brink et al., 2018). There were no risks associated with participating in this research. To further ensure participants' emotional well-being, as discussing their stuttering could trigger an emotional reaction, all participants were given the option of receiving a referral letter containing recommendations of counsellors (Appendix E). The recommended counsellors in Appendix E offer free services to any member of the public and the research participants were invited to contact them in their own capacity. The researcher also offered all the participants the option of receiving a referral letter containing recommendations for SLTs (Appendix F), should the participant wish to seek further intervention for their stutter. The SLTs listed in the referral letter all granted their permission for the researcher to share their contact details and for the research participants to contact them in their own capacity (Appendix G). The participants were also informed that they could ask the researcher for clarification at any point during the telephonic semi-structured interview in order to further ensure the principle of beneficence was adhered to (Brink et al., 2018).

2.3.6 Plagiarism

To avoid research misconduct, the researcher adhered to the principles of scientific and academic professionalism proposed by the Health Professions Council of South Africa (HPCSA; 2008). To ensure that the research community is protected, where the researcher has made use of previous research studies, the author(s) have been given full credit where it is due (HPCSA, 2008; Leedy & Ormrod, 2021). All resources used in this study have been referenced appropriately within the text and reference list using the American Psychological Association (7th ed.) referencing style.

2.4 Study setting

The data for this study was collected from participants who regularly attend SpeakEasy meetings in Gauteng, specifically Johannesburg and Pretoria, as SpeakEasy is an established SSG for PWS. Speakeasy has been running for approximately 15 years (Speakeasy, n.d.). This support group focuses on improving education, encouraging self-help groups, and enhancing the training and skills of SLTs and therefore, provided an ideal setting for data collection. At the Pretoria SpeakEasy meetings, final year SLT students also facilitate, under the supervision of a qualified SLT, and are referred to as “SLT students” in this dissertation.

2.5 Study participants

2.5.1 *Procedures for participant selection*

The participants for this study were selected through purposive sampling. Purposive sampling selects the participants because of their knowledge and experience relating to the topic (Brink et al., 2018). In this study’s case, because the participants were PWS who regularly attend SSGs, their knowledge of the topic was based on first-hand experience. Purposive sampling aids in maximising the range of specific information obtained from and about the context (Brink et al., 2018).

2.5.2 *Sample size*

Purposive sampling studies usually determine sample sizes using data saturation, which is the “gold standard” among qualitative researchers (Guest et al., 2006; Hennink et al., 2017). Data saturation occurs when no additional points are identified, data begins to repeat and further data collection becomes redundant (Kerr et al., 2010). The ideal number of participants for this study was estimated to be at least 12, in accordance with the recommendation made by Guest et al. (2006) for an adequate sample size in qualitative studies that use interviews and purposive sampling of participants.

Despite saturation being held to such a high standard, there are limited studies regarding appropriate analysis methods or the parameters that affect saturation, and a lack of consensus on what it means to reach saturation in purposive samples (Hennink et al., 2017). Therefore, the final number of participants in this study was chosen once sufficient information power had been achieved (Malterud et al., 2016). “Information power indicates that the more information the sample holds, relevant for

the actual study, the lower amount of participants is needed” (Malterud et al., 2016, p. 1753). At thirteen participants, information power was determined to have been reached as the information provided in the data was dense and relevant enough to adequately answer the aim of the study. Data saturation was also considered and occurred after four interviews.

2.5.3 Selection criteria

The participants for this study were selected according to specific inclusion and exclusion criteria which are described below:

- *Person who stutters:* Participants were required to be a PWS. SpeakEasy is a support group not only for PWS but also for their families, SLTs, and anyone else interested in stuttering. Members who were not PWS and who attend meetings as a support system or interventionist were excluded.
- *Age:* This study included PWS aged 18 to 65 years old. PWS under the age of 18 or over the age of 65 were excluded from the study to keep the results focused on the adult population and not children, adolescents or the elderly.
- *Meeting attendance:* Participants had to have attended at least three SpeakEasy support group meetings to be included in the study as three meetings should have been adequate for the participant to be familiar with the SSG. The three meetings did not have to be consecutive.
- *Language abilities:* The SpeakEasy stuttering support groups studied were both conducted in English. The semi-structured telephone interview (Appendix A) was also conducted in English. Therefore, to participate in the semi-structured telephone interview, participants were required to be able to converse in English.
- *Device accessibility:* Due to the COVID-19 pandemic, participants were contacted electronically via WhatsApp and email, and the semi-structured interview was conducted over the phone. Participants were therefore required to have an email address and a mobile phone.
- *Additional communication difficulties:* PWS who had a self-reported history of other communication difficulties were excluded from the study. These

communication difficulties could include hearing difficulties, neurogenic communication disorders or degenerative conditions.

2.5.4 Study participants

A total of 13 participants, ranging from 20 to 58 years of age, participated in this study. Seven participants were from the Johannesburg SpeakEasy SSG, while six were from the Pretoria group. A detailed description of the study participants is provided in chapter 4.

2.6 Data collection procedures

2.6.1 Materials and apparatus for data collection

The telephonic semi-structured interview (Appendix A) contained questions that were directive in nature as this is considered the most effective method to discover what individuals believe, think or know (Brink et al., 2018). The telephonic semi-structured interview (Appendix A) contained 34 questions in total, comprising of both open- and closed-ended questions. Some of the questions (38%) used in the interview schedule were adapted from a study by Medina et al. (2020). Three questions were taken directly from Medina et al's. (2020) study. The telephonic semi-structured interview schedule was divided into four sections, which are described in further detail in Appendix H.

2.6.2 Procedures for data collection

Data collection procedures describe how the researcher approaches answering the research question (Maree, 2016). It allows the researcher to formulate an audit trail, which includes a clear and specific explanation of how data was collected (Brink et al., 2018).

During the time that the researcher was collecting data for this study, the COVID-19 pandemic had resulted in the Pretoria SpeakEasy meetings being held online and the Johannesburg SpeakEasy meetings being temporarily suspended. Taking this into account, the researcher used a telephonic semi-structured interview (Appendix A) as the method of data collection. Conducting the semi-structured interview telephonically allowed the researcher to gather information from the participants without coming into direct contact with them, thus adhering to COVID-19 protocols.

Once the interested members of the Johannesburg and Pretoria SpeakEasy groups had given written consent (Appendix C), they were contacted by the researcher to arrange a time and date for the telephonic semi-structured interview. They were also assigned a participant code (e.g. P1). The telephonic semi-structured interviews were recorded as the participants had already given prior consent to the researcher to record the interview (Appendix C).

2.7 Data analysis and management

Thematic analysis was used to analyse the data generated in the telephonic semi-structured interview. Thematic analysis involves coding and categorising data which in turn gives rise to themes (Medina et al., 2020). Thematic analysis enabled the researcher to distinguish patterns and interpret participants' feelings toward attending SSGs. Data analysis followed a six-phase thematic analysis framework proposed by Braun & Clarke (2006). Firstly, the researcher transcribed the recorded interviews. Each transcript was then re-read to increase familiarity with the data, and initial codes were generated using ATLAS.ti software (Braun & Clarke, 2006). The initial codes captured the explicit meaning of the participants' perspectives and were therefore considered to be semantic (Maguire & Delahunt, 2017). The codes were then reviewed to generate latent codes that delved further into the perspectives of the participants (Maguire & Delahunt, 2017). The study took a bottom-up approach to data analysis, using the codes as a starting point for developing meaningful themes (Terry et al., 2017). The themes were reviewed twice by the research supervisors and the themes were then defined and named (Braun & Clarke, 2006). Some descriptive statistics were used to summarise answers to direct (e.g., yes/no) questions.

2.8 Reliability and Validity (Trustworthiness)

In qualitative research, the term 'trustworthiness' is used in favour of 'reliability' and 'validity' (Leedy & Ormrod, 2021). Trustworthiness is used as a way to examine data quality in qualitative research. Guba and Lincoln (1985) proposed four criteria for ensuring trustworthiness in qualitative research. These include credibility, dependability, confirmability, and transferability. Lincoln and Guba (1994) later included authenticity as the fifth criteria for ensuring trustworthiness. More recent

research still uses these five criteria as a way of ensuring trustworthiness in qualitative research (Brink et al., 2018, Leedy & Ormrod, 2021; Polit & Beck, 2017).

2.8.1 Credibility

According to Brink et al. (2018), credibility refers to confidence in the truth and accuracy of the data and the interpretation of the data. To ensure credibility of the research study's data, the researcher prolonged the engagement in the field until information power was reached (Brink et al., 2018). This allowed the researcher to form a comprehensive understanding of why PWS attend SSGs.

Peer debriefing was also used to establish credibility (Brink et al., 2018). In peer debriefing, the researcher consults with, and debates, the steps of the research process with individuals who are regarded as experts in either the method or the topic being studied (Brink et al., 2018). In the case of this study, the researcher met regularly with research supervisors who are experts in the field of both research and stuttering. These regular meetings allowed for consensus building and data cross-checking (Creswell, 2013).

2.8.2 Transferability

Transferability refers to the extent to which findings are useful to persons in other settings (Polit & Beck, 2017) and the ability to apply the findings in other contexts (Brink et al., 2018). In this study, transferability referred to the provision of information for clinical decision-making and further investigation into other SSGs. Purposive sampling was also used to improve transferability as purposive sampling allowed participants who were knowledgeable about stuttering and SSGs to be selected for the research (Brink et al., 2018). This increased the researcher's data range (Brink et al., 2018). The researcher also ensured that the study's findings were described in sufficient detail for readers to draw conclusions (Leedy & Ormrod, 2021). Staying in the field and continuing with interviews until enough data was collected ensured content-rich and meaningful data, enhancing transferability (Brink et al., 2018).

2.8.3 Confirmability

Confirmability ensures that the data accurately and fairly represents the voice of the participants (Brink et al., 2018). During a process referred to as reflexivity, the

researcher did not identify any personal, social, political, and/or philosophical biases. During the semi-structured interviews, the researcher further attempted to minimise bias by allowing participants time to process the questions and respond, especially when experiencing disfluent moments. The participants were also not prompted with the researcher's own ideas when answering the questions. Additionally, the researcher encouraged the participants to answer the questions as honestly as possible. The researcher does acknowledge that some of the participants were familiar with the researcher as the researcher was previously a student assistant at the SSG meetings. This familiarity, however, did not appear to have an effect on the findings of this research study.

2.8.4 Authenticity

Polit and Beck (2017) and Brink et al. (2018) explain authenticity as the extent to which the researcher is able to fairly and truly describe the participants' range of realities, including their experiences and their emotions. The researcher attempted to describe the experiences and emotions of the participants as they occurred with increased sensitivity and accuracy. According to Schou et al. (2011), the selection of suitable study participants for the study sample and providing content-rich and meaningful descriptions can address authenticity. Participants were those who have knowledge of the phenomenon being studied and were selected through purposive sampling, thus ensuring that they were suitable participants. The researcher attempted to provide content-rich and meaningful descriptions throughout the study.

2.8.5 Dependability

Dependability refers to the provision of evidence in such a way that its conclusions would be similar if it were replicated with the same (or similar) participants in the same (or similar) context (Brink et al., 2018; Polit & Beck, 2017). All techniques applied to ensure credibility directly impacted dependability, specifically peer debriefing and the researcher remaining in the research field until information power was achieved (Brink et al., 2018).

2.8.6 Validity of semi-structured interview

Content validity reflects how well an instrument represents all the components of the variable to be measured (Brink et al., 2018). To ensure the content validity of the

telephonic semi-structured interview (Appendix A), the researcher ensured that all components were clearly defined and in a logical sequence to limit confusing or vague statements. The telephonic semi-structured interview was also reviewed by the researcher's supervisors who are experts in the field of SLT, to determine if it contained representative, clear, and appropriate questions (Leedy & Ormrod, 2021). To further ensure the content validity of the telephonic semi-structured interview, the researcher also conducted a pre-test, which is described in further detail in section 2.9. Additionally, the questions included in the telephonic semi-structured interview (Appendix A) were adapted from a questionnaire used in prior research by Medina et al. (2020), a study that was able to effectively answer the research question they proposed. This further ensured content validity. Face validity, on the other hand, is used to determine whether the data collection instrument measures what it is designed to measure (Brink et al., 2018). The layout of the telephonic semi-structured interview, as well as the readability and clarity of the questions included, were also evaluated during the pre-test to ensure face validity.

2.9 Pre-test

The purpose of a pre-test is to investigate research instruments for possible flaws such as ambiguous instructions or wording and inadequate time limits (Brink et al., 2018).

2.9.1 *Aim of the pre-test*

The pre-test was conducted to evaluate the comprehensibility and appropriateness of the semi-structured interview questions. The pre-test also aimed to test the time required for the completion of the semi-structured interview.

2.9.2 *Participants in the pre-test*

Two qualified SLTs, who are both registered with the HPCSA, participated in the pre-test. The two SLTs are trained to assess, treat, and counsel PWS. One SLT had previously facilitated SSG meetings and was therefore familiar with the group and its members. Both SLTs also view SSGs as a vital part of stuttering intervention.

2.9.3 *Materials used in the pre-test*

The researcher administered the semi-structured interview questions telephonically in the same manner as that planned for the research participants. The SLTs were asked to answer the questions as if they were a person who stutters. They were then asked to critically review the comprehensibility and appropriateness of the questions and provide their feedback and recommendations.

2.9.4 *Results of the pre-test*

The order in which the semi-structured interview questions were administered was deemed to be appropriate and logical. The rating scale (Appendix I), used for questions 10-13, was reviewed and was considered to be both easy to use and to understand. All the changes made, as per the SLTs recommendations, are reflected in Table 2.1.

Table 2.1: Pre-test recommendations and effected changes

Original question	Recommendations, rationale for change and updated question:
<p>Question 8:</p> <p>In terms of your speech, how severe do you consider your stuttering? Please choose one of the following options.</p> <ul style="list-style-type: none"> a. Mild b. Moderate c. Severe d. Other (ask to elaborate) 	<p>Recommendation and rationale:</p> <p>It was recommended that an additional expansion question be added to question 8 to elicit more information from the participants.</p> <p>Updated question:</p> <p>Question 8:</p> <p>In terms of your speech, how severe do you consider your stuttering? Please choose one of the following options.</p> <ul style="list-style-type: none"> a. Mild b. Moderate c. Severe d. Other (ask to elaborate) <p>Can you give me an explanation of why you chose that severity rating?</p>
<p>Question 9:</p> <p>How does your stutter affect your participation and functioning in</p>	<p>Recommendation and rationale:</p> <p>The wording of this question was deemed to be too complicated. Therefore, it was recommended that</p>

<p>everyday life and activities?</p>	<p>the wording of this question be simplified to increase the intelligibility of the question.</p> <p>Updated question:</p> <p>Question 9:</p> <p>How does your stutter affect you in your everyday life?</p>
<p>Question 10:</p> <p>On a scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following stuttering behaviours in terms of how often you experience them when speaking to others in a typical day.</p> <ol style="list-style-type: none"> Repetitions of sounds in words (“Do you have a p-p-p-pencil?”) Repetitions of syllables in words (“Do you have a pen- pen- pen- pencil?”) Repetitions of single syllable words (“I-I-I need a pencil.”) Whole word repetitions (“Do you you you you have a pencil?”) Prolongations of sounds (“I nnnnnneed a pencil”) Blocks (inappropriate stoppage of air or voice) (“I...need a...pencil”) 	<p>Recommendation and rationale:</p> <p>It was recommended that for question 10, the researcher should rather ask the participant if they would like an example of the specific stuttering behaviour instead of providing the example immediately so as not to offend any research participants. It was also recommended that the word “inappropriate” in question 10f, be changed to “uncontrollable”, as the word “inappropriate” may elicit feelings of embarrassment and/or shame from the research participants.</p> <p>Updated question:</p> <p>Question 10:</p> <p>On a scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following stuttering behaviours in terms of how often you experience them when speaking to others in a typical day. I can provide you with an example if requested.</p> <ol style="list-style-type: none"> Repetitions of sounds in words (Example if needed - “Do you have a p-p-p-pencil?”) Repetitions of syllables in words (Example if needed - “Do you have a pen- pen- pen- pencil?”) Repetitions of single syllable words (Example if needed - “I-I-I need a pencil.”) Whole word repetitions (Example if needed - “Do you you you you have a pencil?”) Prolongations of sounds (Example if needed - “I nnnnnneed a pencil”) Blocks (uncontrollable stoppage of air or voice) (Example if needed - “I...need a...pencil”)

<p>Question 30:</p> <p>What were your expectations when you first started attending this support group?</p>	<p>Recommendation and rationale:</p> <p>The wording of question 30 was suggested to be too general. As a result, concern was expressed that this may result in the participants providing answers that differ from the answers the question intended to elicit. The question was then altered to be more specific to increase the likelihood of participants providing detailed answers.</p> <p>Updated question:</p> <p>Question 30:</p> <p>What did you think SpeakEasy was going to be like or be about before you attended your first meeting?</p>
<p>Question 31:</p> <p>What are your expectations for this support group now?</p>	<p>Recommendation and rationale:</p> <p>Similarly to question 30, the wording of question 31 was also deemed to be too general. As a result, this generalisability may result in the participants providing answers that differ from the answers the question intended to elicit. The question was then altered to be more specific to increase the chances of generating more distinctive themes.</p> <p>Updated question:</p> <p>Question 31:</p> <p>What do you want and need from your support group?</p>

Chapter 3. Article

Authors: Miss Nicola Bloye, Dr Shabnam Abdoola, Miss Casey Eslick
Journal: South African Journal of Communication Disorders
Date submitted: 30 November 2022

3.1 Abstract

Background: Stuttering support groups (SSGs) are a known, invaluable resource for people who stutter (PWS). General support groups have been well researched, however, research specifically into SSGs is only emerging. Further insight is needed to guide speech-language therapists' (SLTs) facilitation of SSGs.

Objective: This research is aimed at determining PWS' perspectives regarding why they attend SSGs in Gauteng, South Africa.

Method: Thirteen PWS, between 20-58 years old, who attend SSGs were selected purposively. Their perspectives on SSGs were obtained during semi-structured telephonic interviews and analysed thematically which yielded clinical implications.

Results and Discussion: Four themes; "altered perceptions", "increased sense of community", "support group reciprocity" and "support group environment, participants and topics", were identified. SSGs helped PWS accept their stutter and gain confidence. Clinical implications identified included SLTs encouraging; (1) positive perceptions through education, self-empowerment, sharing success stories, and ways to elicit positive listener reactions, (2) connections between meetings to increase the sense of community, (3) reciprocity in meetings, (4) sharing personal stories to promote learning and self-management, and (5) support, praise and education to empower and encourage PWS. SLTs can encourage equal contributions from willing participants without pressuring others. Disfluency and emotional support should be equally discussed in SSGs.

Conclusion: These perspectives of PWS were used to provide recommendations to SLTs of ways to better meet the needs of PWS who attend SSGs. Recommendations

included focusing discussions on fluency and emotions and sharing personal stories. Insights from PWS also helped better inform SLTs of their role within SSGs including guiding conversations and facilitating conversations that foster deeper understanding.

Keywords: disfluency; people who stutter; perspectives; social support; speech-language therapists; stuttering; stuttering support groups; quality of life

3.2 Introduction

Stuttering is commonly associated with overt disfluent speech, however, the negative emotional and psychological effects have a far greater impact on the lives of people who stutter (PWS). Many PWS experience challenges that extend beyond their ability to communicate, such as high levels of psychological distress, negative affect, fear, shame or embarrassment (Tran et al., 2011; Blumgart et al., 2014; Beilby, 2014; Tichenor & Yaruss, 2019). Social anxiety is also common in PWS and may cause avoidance of speaking situations, potentially leading to feelings of social isolation (Iverach & Rapee, 2014). These difficulties may persist throughout their lives, from educational settings, where negative effects on educational achievement can be seen, to the workplace, where PWS may choose occupations that require less communication (Isaacs, 2021; O'Brian et al., 2011; Guitar, 2014; McAllister et al., 2012). As such, these challenges may result in PWS not reaching their full vocational, occupational, and educational potential. The personal and environmental barriers experienced by PWS have been found to limit their participation in everyday activities, and a lower quality of life (QoL) has been reported in a number of domains (Figliomeni, 2015; Craig et al., 2009; Mohammadi et al., 2013; Nang et al., 2018).

Previous research has demonstrated that the QoL of PWS can be improved by attending stuttering support groups (SSGs) (Blumgart et al., 2014; Boyle, 2013). SSGs are usually facilitated by speech-language therapists (SLTs) and offer a safe environment where PWS can come together as a community and share their feelings and experiences without being judged (Boyle, 2013). Many studies have shown the value of SSGs (Craig et al., 2011; Gerlach et al., 2019; Plexico et al., 2019). Through PWS' perspectives, past research determined that social support could protect PWS against the negative effects of stuttering and may enhance participation in activities of daily living (Tran et al., 2011; Gerlach et al., 2019). SSGs also play an important role

in reducing PWS' internalised stigma, accepting their stutter, and improving PWS' psychological well-being (Boyle, 2013). SSGs can provide a setting in which individual stuttering therapy progress can be maintained (Guitar, 2014). It is thus evident that research into the benefits of SSGs is extensive, however, to the researchers' knowledge, there are no formalised guidelines for SLTs on how to effectively facilitate and manage SSGs.

Although SLTs usually take on the role of facilitating SSGs, it is the community of PWS' voices that need to be heard to contribute their perspectives and experiences. PWS' perspectives can provide a valuable contribution to the field of stuttering treatment because including people with disabilities in decision-making and goal-setting can improve patients' rehabilitation experiences, motivation, and functional outcomes (Evans, 2012; Brown et al., 2021). The degree of motivation can inspire and influence a PWS' desire to seek intervention or to be productive during therapy (Sønsterud et al., 2020; Ratner & Tetnowski, 2014; Weigel, 2013). It is therefore essential to understand the perspectives of PWS so as to best help them further their personal goals beyond traditional stuttering therapy settings.

PWS' perspectives can provide evidence-based clinical implications which may assist SLTs in tailoring SSG activities, topics of discussion, and goals to better meet the needs of PWS who attend. This research also has the potential to help SLTs to motivate PWS to attend and actively participate in SSG meetings.

3.3 Research methods and design

3.3.1 *Design*

The research design was descriptive and phenomenological as the study aimed to understand and describe PWS' perspectives regarding why they attend SSGs (Leedy & Ormrod, 2021; Sandelowski, 2010).

3.3.2 *Setting*

A South African SSG, served as the research setting. This SSG has two groups that run in Gauteng. Both groups are facilitated by SLTs. At one of the SSG groups, final year SLT students also facilitate, under the supervision of a qualified SLT, and are referred to as "SLT students" in this article.

3.3.3 Population and sampling strategy

Purposive sampling was used to select PWS who had first-hand experience attending SSGs. The SLTs who coordinate the SSGs were sent a letter requesting permission to recruit members of their respective SSGs to participate. On the researcher's behalf, the coordinators distributed an information letter and informed consent document to members of their groups. Group members were invited to read the document and ask the researcher questions. Interested members were invited to sign the informed consent document and email it back to the researcher.

The following inclusion and exclusion criteria were applied: (a) be a PWS, (b) be between the ages of 18 and 65, (c) have attended at least three SSG meetings, (d) be able to read and converse in English, (e) have access to an email address and a mobile phone, and (f) have no other self-reported or formally diagnosed communication difficulties. Thirteen people from 20 to 58 years old (mean = 35 years old), three females and ten males, were selected to participate. Table 3.1 presents detailed demographic information about the participants.

The final sample size was determined when information power was reached, as recommended by Malterud et al. (2016). "Information power indicates that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed" (Malterud et al., 2016, p. 1753). The information power was considered to have been reached at thirteen participants since the information contained in the data was dense and relevant enough to adequately answer the study's aim. Data saturation, the point when no additional information is identified, data repeats, and further data collection becomes redundant (Kerr et al., 2010), was also considered and occurred after four interviews.

Table 3.1: Participant demographics

Participant	Age (years)	Age category (years)	Gender	Race	Age of disfluency onset category (years)	Self-rating of own stuttering severity	Speech therapy history
P1	50	46-55	Male	Indian person	2-6	Mild	Yes
P2	20	18-25	Male	White person	7-13	Moderate	Yes
P3	25	18-25	Male	White person	2-6	Mild to moderate	Yes
P4	27	26-35	Male	Black person	7-13	Moderate	Yes
P5	33	26-35	Male	White person	7-13	Mild	Yes
P6	52	46-55	Female	Coloured person	7-13	Moderate to severe	Yes
P7	34	26-35	Male	Black person	2-6	Moderate	Yes
P8	44	36-45	Female	Coloured person	2-6	Mild	Yes
P9	58	56-65	Male	White person	2-6	Moderate to severe	Yes
P10	26	26-35	Male	Black person	7-13	Mild	Yes
P11	27	26-35	Male	Black person	2-6	Moderate	Yes
P12	30	26-35	Female	Black person	2-6	Moderate	Yes
P13	25	26-35	Male	Black person	2-6	Moderate	Yes

3.3.4 Data Collection

After participants provided informed consent, data was collected via telephonic semi-structured interviews. Interviews lasted approximately one hour. The interview schedule included 34 questions, consisting of both open-ended and closed-ended questions. Closed-ended questions were used to obtain biographic and demographic information. Open-ended questions were used to invite the participants to share

information. The questions were divided into four sections: (1) biographic and demographic information, (2) fluency history and behaviours, (3) speech-language therapy treatment, and (4) support groups. The interview schedule was adapted from Medina et al. (2020) with additional questions added to gain further insight into PWS perspectives regarding SSGs.

A pre-test was conducted to rule out ambiguous questions and ensure the content and face validity of the interview schedule (Brink et al., 2018; Leedy & Ormrod, 2021). After two qualified SLTs reviewed the interview schedule, some questions were altered to ensure better understanding and elicit more specific responses from participants. Questions were determined to be representative, clear, and appropriate.

3.3.5 Data analysis

Data analysis followed Braun & Clarke's (2006) six-phase thematic analysis framework. Firstly, recorded interviews were transcribed by the researcher. Thereafter, each transcript was re-read for increased data familiarity, and initial codes were generated using ATLAS.ti software (Braun & Clarke, 2006). The initial codes were semantic in nature as they captured the explicit meaning of participants' perspectives (Maguire & Delahunt, 2017). The codes were then reviewed to generate latent codes that probed deeper into participants' perspectives (Maguire & Delahunt, 2017). A bottom-up approach to data analysis was used, where codes were the starting point to develop meaningful themes (Terry et al., 2017). Themes were reviewed twice by the co-authors and all three authors then defined and named the themes (Braun & Clarke, 2006). Some descriptive statistics were used to summarise answers to direct (e.g., yes/no) questions.

3.3.6 Ethical considerations

The Faculty of Humanities' Research Ethics Committee at the University of Pretoria provided ethical clearance (reference: 17069892 (HUM025/0521)). All participants provided written informed consent and their privacy was maintained by using an alphanumeric code in place of names. Participants' informed consents, recordings, and transcriptions of their interviews have been securely stored and archived on the University of Pretoria's data repository.

3.4 Results

During data analysis, four major themes emerged; "altered perceptions", "increased sense of community", "support group reciprocity" and "support group environment, participants, and topics".

3.4.1 Theme 1: Altered perceptions

When asked if attending a SSG had a positive influence on their perception of their stutter, twelve participants (n=12; 92.3%) reported it did alter their perception positively. One participant (n=1; 7.7%), however, reported no influence. The participant [P5] who experienced no change in their perception of their stutter through attending SSG meetings explained that this was due to negative listener reactions and attitudes – “The world out there, still thinks very very bad of us... so I still have a bit of a negative view of not being able to speak fluently.”

3.4.1.1 Subtheme 1: Increased acceptance of stutter

Many participants reported SSG meetings helped them to accept their stutter [P1, P3, P4, P6, P8, P9, P10, P11] (n=8; 61.5%). Participants reported that accepting themselves as a PWS played a role in them developing a more positive perception of their stutter [P1, P9, P11] (n=3; 23.1%), influenced their emotional wellbeing [P4, P8, P10, P11] (n=4; 30.8%) and/or helped them to better cope with their stutter [P3, P10] (n=2; 15.3%). The participants' quotes can be seen in Table 3.2.

Table 3.2: Quotes for theme 1: Altered perceptions; subtheme 1: Increased acceptance of stutter

“...stuttering... is not the biggest thing in our lives... it's one part of who we are. It's something that shouldn't get the complete focus of our energies.” [P1]
“...it [SSG] provides you with a place to work on that acceptance of your speech...” [P3]
“...it [SSG] helped me a lot... to be able to accept...myself...” [P4]
“...it's [SSG] also helped me see that it's not the end of the world.” [P6]
“I was able to, together with the one-on-one therapy, I was able to accept and embrace the fact that I stutter.” [P8]
“I realized that my situation is not the end of the world. It could have been a lot worse.” [P9]
“...it's [SSG] taught me to accept the way I am.” [P10]
“...it [SSG] has helped me to really accept that I have a speech problem... and even normalise [stuttering]...” [P11]

3.4.1.2 Subtheme 2: Improved confidence

Attending SSG meetings helped improve the confidence of some participants [P4, P7, P8, P10, P12] (n=5; 38.5%). Participants reported that their improved confidence allowed them to challenge themselves to complete new tasks and improve their communication. Four participants [P4, P7, P10, P12] (n=4; 30.8%) linked improved confidence to a more positive perception of their stutter. The participants' quotes are shown in Table 3.3.

Table 3.3: Quotes for theme 1: Altered perceptions; subtheme 2: Improved confidence

"...boosts my self-esteem, to be confident." [P4]
"...it [SSG] made me more confident speaking to... some people. I'm usually battling with speaking with certain people with their position or status in life... but it [SSG] did somehow make me more open..." [P7]
"In my family, going to the shops, I would get someone else to speak for me because I wouldn't want to speak. At work, I would get a colleague to ask the boss for something...now I'm the person that does all speaking to everybody else." [P8]
"I think again with the confidence, to step out and do things that I wouldn't normally do." [P8]
"...it [SSG] gives me more self-control and self-confidence." [P10]
"And [SSG] also boosts my confidence and I'm free" [P12]

3.4.2 Theme 2: Increased sense of community

Participants [P1, P2, P3, P4, P8, P9, P13] (n=7; 53.9%) reported that attending a SSG helped them realise they are not alone in their stuttering journey. These reduced feelings of isolation resulted in PWS [P1, P2, P3, P4, P8] (n=5; 38.5%) having a more positive perception of their stutter, improved emotional well-being [P4, P13] (n=2; 15.4%) and for one participant [P1] (n=1; 7.7%), played a role in coping with their stutter. One participant [P8] (n=1; 7.7%) reported that becoming aware they are not alone improved their speech fluency. Participants' quotes can be viewed in Table 3.4.

Table 3.4: Quotes for theme 2: Increased sense of community

“... [the] support group really helps [me]...to not feel alone...” [P1]
“... [the SSG] kind of opened my eyes, that people like me are in the same situation like me...” [P2]
“...they [SSGs] just help you to not feel as isolated...to not feel as if it's just you and every day you're going up against your speech and having a tough time on your own...” [P3]
“I think it helped me a lot...I'm not alone.” [P4]
“That's why my fluency increased, because I saw it as it is what it is... I'm not the only one in the world who stutters.” [P8]
... it [SSG] helped me... to see that you're not the only one...” P9]
“...you know that we're not alone and there are people out there willing to give you support...” [P13]

3.4.3 Theme 3: Support group reciprocity

Three participants (n=3; 23.1%) emphasised the reciprocal nature of SSGs. According to the participants [P1, P2, P5], an SSG is a valuable setting for both sharing and receiving “insight” [P2], upliftment [P1], “help” [P1, P5], “support” [P1], and “advice” [P5].

3.4.3.1 Subtheme 1: Learning from others

Participants [P1, P2, P4, P5, P9, P12, P13] (n=7; 53.8%) value the opportunity to learn techniques and coping strategies from other PWS as well as get external opinions during SSG meetings. It was mentioned that learning from other PWS was both an effective way to help one cope with their stuttering [P2, P4, P6, P13] (n=4; 30.8%) and an aspect of SSG meetings that participants enjoy [P2, P4, P5, P12] (n=4; 30.8%). Quotes from the participants can be seen in Table 3.5.

Table 3.5: Quotes for theme 3: Support group reciprocity; subtheme 1: Learning from others

“I found that...oftentimes the best way to learn [is] from others opinions because you can draw from that.” [P1]
“... just gaining that insight, and also giving my insights to them. That conversation is what I like the most.” [P2]
“I...want to learn more and discuss more things.” [P4]
“I just want to attend these things [SSG meetings] just to learn from others, what they did to overcome their problems... It is... good for people who suffer from the same problems to just learn from each other” [P5]

“So I definitely think it helped me... to learn a bit from them [other PWS] as well.” [P9]
“I’m learning, you know, each time we have those meetings, there’s always a takeaway point” [P12]
“I... get to learn on how other ways of improving my stuttering” [P13]

3.4.3.2 Subtheme 2: Encouragement and empowerment

Five participants [P1, P3, P5, P6, P10] (n=5; 38.5%) reported that they felt encouraged during and after attending the SSG meetings for a variety of reasons. Participants reported being encouraged and motivated by listening to others’ stories [P1, P10] (n=2; 15.4%) and watching others persevere through difficult disfluent moments [P5] (n=1; 7.7%). P6 explained that praise from other PWS also made them feel more empowered. Lastly, P3 explained that attending a SSG had made them feel more positive and optimistic about their speech. The participants’ quotes are shown in Table 3.6.

Table 3.6: Quotes for theme 3: Support group reciprocity; subtheme 2: Encouragement and empowerment

“...when I come out of a [SSG] meeting, I always feel inspired... because I’ve just come from a platform where people have been honest, really, I mean people have stripped themselves, to bare, to expose themselves as much as they did to, to explain the core feelings which they actually experiencing...” [P1]
“It’s encouraging. You feel as if there’s like people who are trying to help. You’re not fighting the battle on your own...” [P3]
“It [SSG] definitely does help you to feel a bit more positive and optimistic about your speech.” [P3]
“...it [SSG] does give me a bit of hope because, for example, at the very first [SSG meeting], there was a person who struggled to speak way more than what I ever did, and he did overcome it, um, so it was quite inspiring for me to see...” [P5]
“...after you speak, then somebody would like say something or, “well done”, or “that was good”, so it’s very encouraging...” [P6]
“...when you walk away from there, you feel a little bit empowered and it’s going to be okay, the team encourages you...” [P6]
“The things that they [other PWS] were saying, it motivates me...” [P10]

3.4.4 Theme 4: Support group environment, participants and topics

3.4.4.1 Subtheme 1: Environment

Participants [P1, P2, P3, P4, P6, P7, P8, P10, P12] (n=9; 69.2%) expressed how the SSG meetings created an environment where they felt heard, safe, relaxed, free and/or experienced a sense of belonging. Some of the participants' (n=5; 38.5%) quotes can be seen in Table 3.7. Some participants [P4, P5, P13] (n=3; 23.1%) voiced their desire for monthly SSG meetings to occur more frequently, with a wider range of dates and times for greater flexibility.

Table 3.7: Quotes for theme 4: Support group environment, participants and topics; subtheme 1: Environment

"I've got this off my chest and at least someone's heard me. I've been heard." [P1]
"...they're [other PWS] not going to judge, or things like that. It's a place to speak openly about things like that." [P2]
"The atmosphere of the meeting...really plays a big role, it's not a serious conversation, it's...an open heart-to-heart conversation..." [P2]
"... [the SSG]...has been an important safe space where you can express your emotions and... [discuss] the emotional aspects of disfluent moments...that really helps a lot" [P2]
" [The SSG] to me is a support environment..." [P3]
"I feel more relaxed..." [P4]
"What I enjoy about [the SSG]... is... we don't judge." [P4]
"Nobody laughs at you ... it's a safe place." [P6]
"It's an open environment." [P7]
"It [SSG] was the one platform [where] you can speak, and no one gives a rat's ass." [P8]
"... feel [as though] we are home." [P10]
"I always feel as if I'm different and so when I'm at [the SSG], I'm at home and... I feel like I belong." [P12].
"Sometimes the time is not convenient as such." [P4]
"...maybe like two options [of dates for SSG meetings] per month that people can choose one of the two, that would be good." [P5]
"I wish that maybe... we could have more sessions..." [P13]

3.4.4.2 Subtheme 2: Value of SLTs as facilitators

Two participants [P3, P6] (n=2; 15.4%) expressed that they enjoyed having SLTs and SLT students as SSG facilitators. One of these participants, P3 (n=1; 7.7%), mentioned that having SLTs at the meetings allowed those who stutter and those who

treat stuttering to collaborate – “it’s so valuable as well to have...that collaboration between like the people who experience it every day and then the people who are actually educated on it.” P3 also felt encouraged that SLTs were trying to help and advocate for PWS – “It’s encouraging. You feel as if there’s like people who are trying to help.” The other participant, P6 (n=1; 7.7%), stated that they believed SLTs should participate to “guide the conversation,” “coordinate it [an SSG meeting] with professionalism”, and that SSG attendees are “aligning to the agenda”. P6 also expressed that the unique theoretical and clinical knowledge SLTs bring to SSG meetings further reinforced their value. P6 explains, “they’ve [SLTs] got the knowledge that’s different to us living with it [stuttering]. So I understand myself, but they would understand everybody.” P2 (n=1; 7.7%) mentioned that “there were times when [they were] the only participant in the group that was a stutterer and it felt like all of the attention was on [them], and almost like an interrogation”. P2 therefore suggested that SLTs should also answer questions and share their insights to prevent PWS feeling as though they are being interrogated.

3.4.4.3 *Subtheme 3: Meeting topics*

Participants [P2, P3, P6, P7, P8] (n=5; 38.5%) suggested SSG meetings should focus on speech and disfluency. These participants suggested that topics should involve “...things going on in the world of disfluency and like speaking about new...research ideas, or new techniques” [P3] and be “centred around stuttering” [P6]. P7 suggested that activities be “...more stuttering related”. P8 reported that “unpacking all the emotions attached to stuttering” during SSG meetings was beneficial. P3 expressed that they found it positive when SSG meetings were “educational but... supportive at the same time.” P2 said “...[the SSG] has been an important safe space where you can express your emotions and... the emotional aspects of disfluent moments and sharing that, talking about it, that really helps a lot...”

3.5 **Discussion**

PWS who attend SSGs shared their thoughts and opinions on why they attend SSGs. Their perspectives highlighted important clinical implications for SLTs who facilitate SSGs. These clinical implications were used to inform recommendations for SLTs, such as guidance on the role of SLTs in meetings, the purpose and structure of SSGs, and suggested topics of discussion and activities.

3.5.1 Altered perceptions

As one participant reported, and in congruence with prior research, negative listener reactions could negatively impact PWS' perception of their stutter (Bajaj et al., 2017; Yaruss & Quesal, 2004). It is therefore important that SLTs facilitate interactions that include relatives and listeners who are not PWS. During SSGs, SLTs can provide PWS with means to encourage positive interactions, such as sharing individual experiences, or using self-advertising or self-disclosure statements, which are shown to yield more positive listener reactions (Kittilstved, 2014; McGill et al., 2018).

The findings identified that SSGs helped PWS to accept their stuttering, which contrasts with De Nardo, et al. (2016) who found no link between support groups and self-acceptance. One participant reported that stuttering is part of who they are and should not define their individual identity, raising the idea of stuttering and identity. Similarly, Blumgart et al. (2014) and Boyle (2013) found that attending SSG meetings can result in a changed self-identity as a PWS, and improved self-acceptance. As self-acceptance of a PWS is linked to an improved QoL (Swartz et al., 2014), SLTs should address acceptance during SSG meetings. According to Sheehan (2018), education promotes self-acceptance. SLTs can ensure that PWS receive a holistic, comprehensive, and accurate understanding of their stuttering, possibly through presentations, guest speakers, and question-and-answer sessions. SLTs can also encourage self-empowerment by using "I" statements when referring to stuttering, and validate members' stories, vulnerable moments and honesty, to foster an accepting environment, and ensure that no member's efforts to share are dismissed (Sheehan, 2018).

PWS reported increased participation in previously avoided tasks as a result of increased confidence, a finding that is supported by Blumgart et al. (2014). Gore & Luckman Margulis (2022) proposed activities that can improve confidence in a therapy setting. These activities can be adapted for SSGs and can include sharing stories about successful communication interactions as well as discussing ways to foster cognitive resilience and combat negative reactions. SLTs should emphasise that SSGs encourage second chances.

3.5.2 Increased sense of community

A supportive social network fosters greater psychological resilience (Boyle, 2015) which can protect PWS from the negative psychosocial effects of stuttering including social isolation (Craig et al., 2011; Gerlach et al., 2019; Iverach & Rapee, 2014). One PWS stated they had previously formed a buddy system with another PWS in their SSG where they would communicate with each other and practice fluency techniques between SSG meetings. SLTs can facilitate a supportive network by creating a secure platform where members who wish to connect outside the SSG setting can share their contact details. These connections, that extend beyond a pre-arranged group meeting, may further increase the sense of community and reduce feelings of isolation. The expressed desire for increased frequency of SSG meetings, indicates PWS' interest in more frequent connection and can increase the sense of community within the SSG. SLTs could also use a hybrid approach for SSG meetings, where both in-person and online meetings are available. A hybrid approach removes a location barrier, may improve attendance and can increase the number of SSG attendees. Although research has shown that rehabilitation services can be made further accessible through an online platform (Molini-Avejonas et al., 2015), it is still important to consider that many people in South Africa do not have access to the means needed for online services. Further research could therefore look into how SLTs can make SSGs more accessible for PWS throughout South Africa.

3.5.3 Support group reciprocity

“Learning from others” and “encouragement and empowerment” were the two subthemes under theme three. Under each of these subthemes, participants alluded to the theme of reciprocity of a SSG.

Participants value learning coping techniques from other PWS because it gives them insight from people who can relate to them and their experiences. Past research has shown that listening to a PWS share their own story can reduce the stigma associated with stuttering (Boyle, 2016). Facilitating SLTs could give PWS the opportunity to share their stories and encourage active listening to help reduce the negative stigma associated with stuttering. SLTs could also invite guest speakers who stutter or who are professionals in the management of stuttering. Group meetings can be an ideal

setting for people with disabilities to learn about self-management, which can be facilitated by members sharing their knowledge and skills with others (World Health Organization [WHO], 2010).

Thoits' (2011) discussion found that SSGs allow PWS to share their feelings and worries, receive support and affirmation, and be compassionately understood. Similarly, the participants in this study wanted to support and be supported by others and to uplift and be uplifted. Participants also felt encouraged by watching others with more severe stutters, persevere through difficult stuttering moments. Future research should investigate the impact of PWS' perception of their stutter when they meet PWS with less severe stuttering than their own. PWS and SLTs need to be informed about how this experience may impact a person's reaction in order to address this within SSGs. Receiving support and praise from other PWS was both encouraging and empowering for the participants in this study, a finding that is also supported by previous research (Tichenor & Yaruss, 2019).

As the combination of education and empowerment is shown to effect positive change, empowerment is an important component of stuttering therapy (Gore & Luckman Margulis, 2022). Empowerment has also been found to be achieved through gaining knowledge and information (Barak et al., 2008). SLTs who facilitate SSGs can help PWS learn about their stuttering from other PWS and professionals. SLTs can encourage group members to share stories about self-disclosing their stuttering, and personal tips (Gore & Luckman Margulis, 2022). An SSG can also provide a safe environment in which PWS can apply and troubleshoot self-disclosure techniques taught in individual speech therapy. SLTs could encourage members to discuss any stigma they have encountered in their lives and share strategies they used to challenge or overcome this stigma (Gore & Luckman Margulis, 2022). SLTs can also encourage friends and family members to attend meetings occasionally, and centre the agenda around information about stuttering and ways in which they, as family members and friends, can best help PWS.

3.5.4 Support group environment, participants and topics

According to Craig et al. (2011), social support promotes a sense of belonging. Similarly, the PWS in this study valued how the SSG's supportive environment made

them feel heard, safe, and relaxed, and/or gave them a sense of belonging. Therefore, to help all members feel heard, SLTs could monitor each member's contribution in the SSG meeting, and direct questions or points of discussion to those who have not contributed as much. PWS did, however, value knowing that they are not expected to speak during the SSG setting, should they not wish to. Therefore, SLTs should reassure members that they are not required to contribute verbally in order to attend SSG meetings. Maintaining confidentiality is also important in the field of SSGs as it has been linked to increased self-disclosure within a group setting (Doshi et al., 2019). The SLT can request that members do not share personal information, details and/or stories about their fellow group members with others outside of the SSG. The WHO, however, highlights that different cultures may view confidentiality in various ways and therefore suggests that the rules of confidentiality be decided by the group (WHO, 2010).

Participants expressed the opinion that SSG meetings should focus on speech and disfluency, in addition to addressing the emotional aspects of stuttering. As the SLT is the one that creates the agenda for the meeting, the SLT must ensure both of these topics are covered. To assist with this, SLTs could ask members at the end of each SSG meeting what topics they would like covered in the next meeting. The researcher was unable to locate any studies that have been conducted to date, with the purpose of determining what topics PWS would like to discuss within SSG meetings. This is therefore a topic that should to be researched further in order to ensure that the topics discussed are of interest, importance, and relevance to the SSG members to best meet their needs.

The WHO proposed that people with similar disabilities, as well as rehabilitation professionals should share information, ideas, and experiences to encourage mutual understanding and collaboration (WHO, 2010). This is supported by this study as PWS value and enjoy having SLTs facilitate support groups. PWS in previous research expressed appreciation for the facilitators of their SSG meetings. They specifically valued how facilitators ensure equal speaking opportunities for members, allowed members freedom to go off-topic, generated topics for meetings and planned the meetings (Medina et al., 2020). PWS in this study support and further expand on findings by Medina et al., (2020) regarding their perspectives of the SLT's role within

the SSG. PWS suggest that SLTs collaborate as much as possible with PWS during SSG meetings, advocate for PWS, facilitate conversations in which SLTs can develop a deeper understanding of PWS and their experiences, and share their clinical and theoretical knowledge. Although the PWS in this study viewed SLTs as a positive presence in their respective support groups, past research has shown that SLTs' presence can be perceived negatively if they are only there for observational purposes Trichon (2007). Therefore, SLTs must strike a balance between active and passive participation.

3.6 Conclusion

This study used the perspectives and voices of PWS, along with previous research, to guide evidence-based recommendations for SLTs who facilitate SSGs. PWS expressed that they value having a welcoming, safe, and relaxed environment. SLTs need to strike a balance between being passive and active participants, so that they do not over-contribute but are also not perceived as observers. Topics for SSGs could include fluency as well as the emotional aspects of stuttering. SLTs can use SSGs to help PWS have a more positive attitude toward themselves and their stuttering, as well as provide the tools and resources they need to have more positive experiences when speaking with people who do not stutter. Interestingly, PWS suggested that forming relationships outside of the SSG should also be encouraged. SLTs can also encourage SSG members to share their stories when they are ready, and facilitate the discussion so that all members benefit from each meeting. As suggested by PWS, facilitating SLTs should also consider increasing the frequency of meetings. SLTs can empower members by educating them about their stuttering and facilitating conversations in which PWS can learn from other PWS and professionals.

With these clinical implications derived from PWS' personal perspectives and opinions, facilitating SLTs may now be able to better tailor activities, topics of discussion, and goals, to the PWS who attend. This may encourage PWS to pursue personal goals outside of traditional stuttering therapy settings.

3.7 Critical Evaluation

A strength of this study is that it appears to be the first of its kind to develop evidence-based recommendations for SLTs who facilitate SSGs by listening to voices of PWS

who attend. The diversity of the participants allowed a wide range of perspectives to be obtained. Additionally, the current findings support previous research which enhances the study's reliability. Lastly, all ethical considerations, including confidentiality, respect for persons, beneficence, and avoidance of harm, were all observed throughout the study.

The researchers do acknowledge some weaknesses in the study. It may be difficult to generalise the findings of this study to a wider population of SLTs and SSGs due to the small sample size. Future studies should include a larger sample size of PWS who attend SSGs. Different SSGs should also be used as not all groups are conducted and facilitated in the same way. Additionally, no participants self-described their stuttering severity as "severe". In order to ensure that SSGs are meeting the needs of PWS with all levels of stuttering severity, future research should seek perspectives from more PWS who consider themselves to have a severe stuttering severity. Lastly, the participants who attended one of the SSGs were familiar with researcher who collected the data for this study as the researcher was previously a student assistant at the SSG meetings. Although this familiarity did not appear to have an effect on the findings of this research study, future studies should use PWS who are unfamiliar with the researcher.

3.8 Acknowledgements

The authors would like to thank the participants for their honesty, for sharing their stories, and for their time given participating in this research.

3.9 Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

3.10 Author contributions

N.B., as the primary researcher, conducted the data collection and analysis as well as compilation of the article. S.A. and C.E., as the research supervisors, conceptualised the study, provided guidance on data collection and analysis as well as contributed to the writing of the article.

3.11 Funding

The authors received no financial support for the study, authorship, and/or publication of this article.

3.12 Data availability

The data that supports the findings of this study are not openly available due to reasons of sensitivity and confidentiality.

3.13 Disclaimer

The views expressed in this article are those of the authors and are not an official position of the institution or journal.

3.14 References

- Bajaj, G., Anil, M., Varghese, A., Bhat, J., Sheth, P., & Hoode, A. (2017). Me, My Stuttering, and Them! Effect of Self-Disclosure of Stuttering on Listener Perception. *Rehabilitation Process and Outcome*, 6, 1–10.
- Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, 24(5), 1867–1883. <https://doi.org/10.1016/j.chb.2008.02.004>
- Beilby, J. (2014). Psychosocial impact of living with a stuttering disorder: knowing is not enough. *Seminars in Speech and Language*, 35(2), 132–143. <https://doi.org/10.1055/s-0034-1371756>
- Blumgart, E., Tran, Y., & Craig, A. (2014). Social support and its association with negative affect in adults who stutter. *Journal of Fluency Disorders*, 40, 83-92. <https://doi.org/10.1016/j.jfludis.2014.02.002>
- Boyle, M. (2013). Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience. *Journal of Fluency Disorders*, 38(4), 368-381. <https://doi.org/10.1016/j.jfludis.2013.09.001>
- Boyle, M. P. (2015). Relationships between psychosocial factors and quality of life for adults who stutter. *American Journal of Speech-Language Pathology*, 24(1), 1–12. https://doi.org/10.1044/2014_AJSLP-14-0089

- Boyle, M. P., Dioguardi, L., & Pate, J. E. (2016). A comparison of three strategies for reducing the public stigma associated with stuttering. *Journal of Fluency Disorders*, 50, 44–58. <https://doi.org/10.1016/j.jfludis.2016.09.004>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brown, J., Ackley, K., & Knollman-Porter, K. (2021). Collaborative goal setting: a clinical approach for adults with mild traumatic brain injury. *American Journal of Speech-Language Pathology*, 30(6), 2394–2413. https://doi.org/10.1044/2021_AJSLP-21-00078
- Craig, A., Blumgart, E., & Tran, Y. (2009). The impact of stuttering on the quality of life in adults who stutter. *Journal of Fluency Disorders* 34(2), 61–71. <https://doi.org/10.1016/j.jfludis.2009.05.002>
- Craig, A., Blumgart, E., & Tran, Y. (2011). Resilience and stuttering: Factors that protect people from the adversity of chronic stuttering. *Journal of Speech, Language, and Hearing Research*, 54(6), 1485-1496. [https://doi.org/10.1044/1092-4388\(2011/10-0304\)](https://doi.org/10.1044/1092-4388(2011/10-0304))
- De Nardo, T., Gabel, R. M., Tetnowski, J. A., & Swartz, E. R. (2016). Self-acceptance of stuttering: a preliminary study. *Journal of Communication Disorders*, 60, 27–38. <https://doi.org/10.1016/j.jcomdis.2016.02.003>
- Doshi, P. V., Robak, R. W., Grffin, P. W., & Ward, A. W. (2019). Confidentiality in Counselor Experiential Training Groups: An Exploratory Study. *Journal of Counseling Research and Practice*, 5(1), 3. <https://egrove.olemiss.edu/jcrp/vol5/iss1/3>
- Evans, J. J. (2012). Goal setting during rehabilitation early and late after acquired brain injury. *Current Opinion in Neurology*, 25(6), 651–5. <https://doi.org/10.1097/WCO.0b013e3283598f75>
- Figliomeni, E. (2015). Quality of life of people who stutter. [Masters thesis, The University of Toledo].
- Gerlach, H., Hollister, J., Caggiano, L., & Zebrowski, P. (2019). The utility of stuttering support organization conventions for young people who stutter. *Journal of Fluency Disorders*, 62, 105724. <https://doi.org/10.1016/j.jfludis.2019.105724>
- Gore, K., & Luckman Margulis, C. (2022). 3Es: an all-inclusive stuttering therapy tool. *Perspectives of the ASHA Special Interest Groups*, 7(3), 716–727. https://doi.org/10.1044/2022_PERSP-20-00300

- Guitar, B. (2014). *Stuttering: An Integrated Approach to Its Nature and Treatment* (4th ed.). Wolters Kluwer.
- Isaacs, D. (2021). Satan is holding your tongue back: stuttering as moral failure. *African Journal of Disability* 10. <https://doi.org/10.4102/ajod.v10i0.773>
- Iverach, L., & Rapee, R., 2014, 'Social anxiety disorder and stuttering: Current status and future directions', *Journal of Fluency Disorders* 40, 69–82. <https://doi.org/10.1016/j.jfludis.2013.08.003>
- Kittilstved, T. (2014). Education and changing the perceptions of stuttering. *Proceedings of the National Conference on Undergraduate Research (NCUR)*, Lexington. <https://doi.org/0.13140/2.1.2961.3763>
- Leedy, P. D., Ormrod, J. E., & Johnson, L. R. (2021). *Practical research: Planning and design* (12th ed). Pearson.
- Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The All Ireland Journal of Teaching and Learning in Higher Education*, 9(3), 3351-33514. <http://ojs.aishe.org/index.php/aishe-j/article/view/335>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- McAllister, J., Collier, J., & Shepstone, L. (2012). The impact of adolescent stuttering on educational and employment outcomes: evidence from a birth cohort study. *Journal of Fluency Disorders* 37(2), 106–121. <https://doi.org/10.1016/j.jfludis.2012.01.002>
- McGill, M., Siegel, J., Nguyen, D., & Rodriguez, S. (2018). Self-report of self-disclosure statements for stuttering. *Journal of Fluency Disorders*, 58, 22–34. <https://doi.org/10.1016/j.jfludis.2018.09.004>
- Medina, A., Almeida, N., Amarante, K., Martinez, N., & Prezzemolo, M. (2020). Adults who stutter and their motivation for attending stuttering support groups: A pilot study. *Perspectives of The ASHA Special Interest Groups*, 5(1), 142-154. https://doi.org/10.1044/2019_persp-19-00049
- Mohammadi, H., Rezaei, M., Moradi, S., Barani, M., Badri, S., & Heydari, A. (2013). Comparison of quality of life in people who stutter and normal individuals. *Journal of Kermanshah University of Medical Sciences* 16(6). <https://brieflands.com/articles/jkums-77340.html>

- Molini-Avejonas, D., Rondon-Melo, S., de La Higuera Amato, C., & Samelli, A. (2015). A systematic review of the use of telehealth in speech, language and hearing sciences. *Journal of telemedicine and telecare*, 21(7), 367-376.
- Nang, C., Hersh, D., Milton, K., & Lau, S. (2018). The impact of stuttering on development of self-identity, relationships, and quality of life in women who stutter. *American Journal of Speech-Language Pathology* 27(3s), 1244–1258. https://doi.org/10.1044/2018_AJSLP-ODC11-17-0201
- O'Brian, S., Jones, M., Packman, A., Menzies, R., & Onslow, M. (2011). Stuttering severity and educational attainment. *Journal of Fluency Disorders* 36(2), 86–92. <https://doi.org/10.1016/j.jfludis.2011.02.006>
- Plexico, L. W., Erath, S., Shores, H., & Burrus, E. (2019). Self-acceptance, resilience, coping and satisfaction of life in people who stutter. *Journal of Fluency Disorders*, 59, 52–63. <https://doi.org/10.1016/j.jfludis.2018.10.004>
- Ratner, N., & Tetnowski, J. (2014). *Current issues in stuttering research and practice*. Psychology Press.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84. <https://doi.org/10.1002/nur.20362>
- Sheehan, C. (2018). *Acceptance in stuttering therapy: A clinician perspective* [Master's thesis, Appalachian State University].
- Sønsterud, H., Feragen, K., Kirmess, M., Halvorsen, M., & Ward, D. (2020). What do people search for in stuttering therapy: Personal goal-setting as a gold standard? *Journal of Communication Disorders*, 85, 105944. <https://doi.org/10.1016/j.jcomdis.2019.105944>
- Swartz, E., Irani, F., & Gabel, R. (2014). Coping with stuttering. *Perspectives on Fluency and Fluency Disorders*, 24(2), 58–68. <https://doi.org/10.1044/ffd24.2.58>
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig & W. Stainton Rogers (Eds), *The SAGE handbook of qualitative research in psychology*. SAGE Publications Ltd. <https://dx.doi.org/10.4135/9781526405555.n2>
- Thoits, P. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior*, 52(2), 145-161. <https://doi.org/10.1177/0022146510395592>

- Tichenor, S. E., & Yaruss, J. S. (2019). Group experiences and individual differences in stuttering. *Journal of Speech, Language, and Hearing Research*, 62(12), 4335–4350. https://doi.org/10.1044/2019_JSLHR-19-00138
- Tran, Y., Blumgart, E., & Craig, A. (2011), Subjective distress associated with chronic stuttering. *Journal of Fluency Disorders* 36(1), 17–26. <https://doi.org/10.1016/j.jfludis.2010.12.003>
- Trichon, M. (2007). Getting the maximum benefits from support groups: Perspectives of members and group leaders. *Perspectives on Fluency and Fluency Disorders*, 17(1), 10–13. <https://doi.org/10.1044/ffd17.1.10>
- Weigel, M. (2013). *Adolescents who stutter: Perception of effective therapy techniques* [Master's thesis, Duquesne University]. <https://dsc.duq.edu/etd/1348>
- World Health Organization (WHO). (2010). Community-based rehabilitation: CBR guidelines. Empowerment component. WHO Press. World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/44405/9789241548052_empower_eng.pdf?sequence=5
- Yaruss, J., & Quesal, R. (2004). Stuttering and the internal classification of functioning, disability, and health (ICF): an update. *Journal of Communication Disorders* 37, 35–52.

Chapter 4. Results

A total of 13 participants (n=13; 100%), ranging from 20 to 58 years of age, participated in this study. Seven participants (n=7; 53.8%) were from the Johannesburg SpeakEasy SSG, while six (n=6; 46.2%) were from the Pretoria group. Three participants (n=3; 21.3%) identified as female and the remaining participants identified as male (n=10; 76.9%). Seven participants (n=7; 53.8%) were in the 26-35 year age bracket and two participants (n=2; 15.4%) were in the 18-25 and 46-55 year age brackets respectively. One participant (n=1; 7.7%) was in the 36-45 year age category, and the 56-65 age category also had a single participant (n=1; 7.7%). Categorised by race, six participants (n=6; 46.2%) identified themselves as black people, four (n=4; 30.8%) as white people, two (n=2; 15.4%) as coloured, and one participant (n=1; 7.7%) identified as an Indian person. Although the term “coloured person” is now formally recognised as “mixed race”, the term “coloured” was the participants’ preferred racial identifier. When looking at the age of onset of stuttering, eight participants (n=8; 61.5%) experienced onset between the ages of 2-6, while five (n=5; 38.5%) were between 7 and 13 years of age when they began stuttering. Participants had varying perceptions of the severity of their own stuttering, with six participants (n=6; 46.2%) self-describing as moderate and four (n=4; 30.8%) perceiving their stuttering as mild. Three participants (n=3; 21.3%) selected the option of “other”. Under the “other” category, two participants (n=2; 15.4%) described their stuttering as moderate to severe and a single participant (n=1; 7.7%) perceived their stuttering to be mild to moderate. All participants (n=13; 100%) had a history of speech therapy. Two participants (n=2; 15.4%) requested to receive referral letters to counsellors and SLTs.

During the process of analysing the data, four major themes emerged. These were "altered perceptions," "reduced feelings of isolation", "support group reciprocity", "support group environment, participants and topics". All the quotes identified for each theme are listed in Appendix J.

4.1 Theme 1: Altered perceptions

One question (question 25, Appendix A) included in the semi-structured interview asked participants if attending SSG meetings had influenced their perception of their stutter. When asked if attending a SSG had a positive influence on their perception of their stutter, twelve participants (n=12; 92.3%) reported it did alter their perception positively. One participant (n=1; 7.7%), however, reported no influence. The participant [P5] who experienced no change in their perception of their stutter through attending SSG meetings explained that this was due to negative listener reactions and attitudes – “The world out there, still thinks very very bad of us... so I still have a bit of a negative view of not being able to speak fluently.” Two underlying subthemes, “increased acceptance of stutter” and “improved confidence”, were identified.

4.1.1 Subtheme 1: Increased acceptance of stutter

According to the findings of the first subtheme, some participants (n=8; 61.5%) [P1, P3, P4, P6, P8, P9, P10, P11] were better able to accept their stutter as a result of attending SSG meetings. As P8 explained, through participation in SSG meetings, they were able to “accept and embrace the fact that [they] stutter”. According to P3, “it [SpeakEasy] provides you with a place to work on that acceptance of your speech...”. Participants reported that accepting themselves as a PWS helped them develop a more positive perception of their stutter [P1, P9, P11] (n=3; 23.1%), influenced their emotional well-being [P4, P8, P10, P11] (n=4; 30.8%), and/or improved their ability to cope with their stutter [P3, P10] (n=2; 15.3%).

4.1.2 Subtheme 2: Improved confidence

Some participants [P4, P7, P8, P10, P12] (n=5; 38.5%) stated that they had experienced an increase in their confidence level as a direct result of their participation in the SSG meetings. This improved level of confidence resulted in an increased level of participation in some speaking situations. P8 reflected that they were now able “to step out and do things that I wouldn't normally do. Be the first person to speak, that was never me.” P7 said that as a result of their increased confidence, they now feel more comfortable communicating with people who have a higher position or status than they do – “It [SpeakEasy] made me more confident speaking... I'm usually battling with speaking with certain people, with their position or status in life... but it [SpeakEasy] somehow made me more open...” In addition, four participants [P4, P7,

P10, P12] (n=4; 30.8%) related their increased confidence to a more positive perspective of their stuttering.

4.2 Theme 2: Increased sense of community

Participants [P1, P2, P3, P4, P8, P9, P13] (n=7; 53.9%) reported that the setting of the support group helped reinforce the fact that there are also other PWS, as well as helped them realise that their journey with stuttering is not something they need to face alone. “I think that SpeakEasy and support groups in general... help you to not feel as isolated...to not feel as if it's just you, and every day you're going up against your speech and having a tough time on your own...” [P3]. One participant [P8] (n=1; 7.7%) even reported that coming to the realisation that they are not alone improved the fluency of their speech – “That’s why my fluency increased, because I saw it as ‘it is what it is’, you know?... It was the realisation that I’m not the only one in the world that stutters.” [P8]. No longer feeling isolated in their stuttering journey resulted in PWS having a more positive perception of their stutter [P1, P2, P3, P4, P8] (n=5; 38.5%), improved emotional well-being [P4, P13] (n=2; 15.4%) and/or played a role in coping with their stutter [P1] (n=1; 7.7%).

4.3 Theme 3: Support group reciprocity

Three participants [P1, P2, P5], (n=3; 23.1%) emphasised the reciprocal nature of SSGs. According to the participants, an SSG is a valuable setting for both sharing and receiving “insight” [P2], upliftment [P1], “help” [P1, P5], “support” [P1], and “advice” [P5].

4.3.1 *Subtheme 1: Learning from others*

Seven participants [P1, P2, P4, P5, P9, P12, P13] (n=7; 53.8%) reported that during SSG meetings, they value the opportunity to learn techniques and coping strategies from other PWS. They also value being able to problem solve. Learning from other PWS was highlighted as an effective technique to help one cope with their stuttering [P2, P4, P6, P13] (n=4; 30.8%), as well as a component of SSG meetings that participants enjoy [P2, P4, P5, P12] (n=4; 30.8%). P2 explained that “hearing about other people with disfluencies and how disfluencies affect their lives, and what they do to overcome these disfluent moments...just gaining that insight, and also giving my insights to them - that conversation is what I like the most.”

4.3.2 Subtheme 2: Encouragement and empowerment

Five participants [P1, P3, P5, P6, P10] (n=5; 38.5%) reported that they felt encouraged and motivated during and after attending the SSG meetings for a variety of reasons including listening to others' stories [P1, P10] (n=2; 15.4%) and watching others persevere through difficult disfluent moments [P5] (n=1; 7.75). P6 (n=1; 7.7%) explained that praise from other PWS also made them feel more empowered and said "when you walk away from there [SpeakEasy], you feel a little bit empowered and it's going to be okay, the team encourages you." Lastly, P3 (n=1; 7.7%) explained that attending a SSG had made them feel more "positive and optimistic" about their speech.

4.4 Theme 4: Support group environment, participants and topics

In the semi-structured interview schedule (Appendix A), participants were asked a variety of questions relating to aspects of SSGs. The following three subthemes were identified: "environment", "value of SLTs as facilitators" and "meeting topics".

4.4.1 Subtheme 1: Environment

Participants [P1, P2, P3, P4, P6, P7, P8, P10, P12] (n=9; 69.2%) expressed that SSG meetings provided a supportive setting in which they were able to feel heard, safe and relaxed, and experience a sense of belonging. P1 (n=1; 7.7%) stated that they were able to freely express themselves and that they did so with the perception of being heard. P2 (n=1; 7.7%) expressed that "the atmosphere of the meeting...really plays a big role, it's not a serious conversation, it's...an open heart to heart conversation..." Two participants [P2, P6] (n=2; 15.4%) described the SSG setting as a "safe" environment in which they can express their emotions and not feel fearful of being laughed at. P12 (n=1; 7.7%) summed up the environment of a SSG by saying "I always feel as if I'm different and so when I'm at SpeakEasy, I'm at home and... I feel like I belong." The positive environment and atmosphere created during the SSG meetings is something that some participants viewed as being a highlight of their experience.

Participants [P4, P5, P13] (n=3; 23.1%) also voiced their desire for SSG meetings to take place more frequently and offer a greater degree of flexibility, for example, P5 suggested having "two options [for SSG meetings] per month [so] that people can

choose one of the two”. An additional option would be to vary the times of the meetings as “sometimes the time is not convenient” [P4].

4.4.2 Subtheme 2: Value of SLTs as facilitators

Two participants [P3, P6] (n=2; 15.4%) expressed that they enjoyed having SLTs as SSG facilitators. One of these participants, P3 (n=1; 7.7%), mentioned that the presence of SLTs at the meetings fostered the possibility of “collaboration” between those who stutter and those who treat stuttering. This participant also felt encouraged that SLTs were trying to help and advocate for PWS – “It’s encouraging. You feel as if there’s like people who are trying to help.” The other participant, P6 (n=1; 7.7%), stated that they believed SLTs should participate to “guide the conversation,” “coordinate it [SSG meetings] with professionalism”, and that SSG attendees are “aligning to the agenda”. The unique theoretical and clinical knowledge that SLTs offer to SSG meetings, as stated by P6, further reinforces the value of these professionals. P6 explains, “they’ve [SLTs] got the knowledge that’s different to us living with it [stuttering]. So, I understand myself, but they would understand everybody.”

One participant [P2] (n=1; 7.7%) did mention that when there are only a few PWS present at a meeting, the SLTs should also answer questions and share their insights so that the PWS do not feel as though they are being interrogated. This was a suggestion made by P2 who shared a story of when they were the only PWS in the SSG meeting and expressed that “it felt like all of the attention was on me and almost like an interrogation.”

4.4.3 Subtheme 3: Meeting topics

The view provided by some of the participants [P2, P3, P6, P7, P8] (n=5; 38.5%) was that SSG meetings ought to centre around speech and disfluency. They provided examples such as “...things going on in the world of disfluency and like speaking about new... research ideas, or new techniques ” [P3] and “centred around stuttering” [P6]. P7 suggested that activities be “...more stuttering related”. P8 reported that “unpacking all the emotions attached to stuttering” during SSG meetings was beneficial. P3 expressed that they found it positive when SSG meetings were “educational but... supportive at the same time.” P2 said “...[the SSG] has been an

important safe space where you can express your emotions and... the emotional aspects of disfluent moments and sharing that, talking about it, that really helps a lot...”

The themes and subthemes discussed in this chapter were generated from the perspectives of the PWS who attend SSGs. PWS provided valuable information ranging from how SSGs impact them emotionally to important functional suggestions for the facilitation of SSGs. These points were utilised to develop evidence-based recommendations for SLTs who facilitate SSGs, which are discussed in further detail in chapter 5.

Chapter 5. Discussion

The common themes discovered were used to develop possible recommendations for SLTs who facilitate SSGs in order to achieve the research study's aim.

5.1 Theme 1: Altered perceptions

As previously stated by one participant, and in congruence with previous research, negative listener reactions can negatively impact PWS' perception of their stutter (Bajaj et al. 2017; Yaruss & Quesal 2004). Research has also shown how a PWS' QoL and their view of themselves can be significantly altered when other people have unfavourable impressions of them (Kittilstved, 2014). As a result, it could be suggested that SLTs not only focus on helping PWS have a more positive outlook on themselves and their stutter, but also on providing them with the tools and resources they need to have more pleasant experiences while speaking to others who do not stutter. This could be accomplished through sharing individual experiences and/or techniques amongst themselves or through the use of strategies such as self-advertising or self-disclosure statements, both of which have been demonstrated to yield more positive listener reactions (Kittilstved, 2014; McGill et al., 2018).

5.1.1 *Subtheme 1: Increased acceptance of stutter*

Participants described that attending SSG meetings had provided a setting in which acceptance of their stutter could be fostered. With an increased sense of self-acceptance, some participants came to an independent realisation that having a stutter is "not the end of the world" [P6] and that stuttering should not define a PWS' entire individual identity. This study's findings contradict research conducted by De Nardo et al. (2016) who concluded that there is no correlation between participating in support groups and increasing one's level of self-acceptance. This study's findings, however, do support research by Blumgart et al. (2014) and Boyle (2013), who discovered that attending SSG meetings can result in a changed mindset in terms of self-identity as a PWS and improved self-acceptance. According to Swartz et al. (2014), self-acceptance as a PWS is associated with an improved quality of life (QoL). Acceptance of stuttering has also been shown to reduce the desire to conceal stuttering as well as the pressure to always be fluent (De Nardo et al., 2016).

Addressing and encouraging self-acceptance should therefore be an important component addressed by SLTs in SSG meetings.

Stuttering education was identified as a critical factor in promoting self-acceptance (Sheehan, 2018). SLTs should therefore ensure that members who attend SSGs are provided with the necessary education in order to develop a holistic, comprehensive, and accurate understanding of their stuttering. Presentations, guest speakers, and even question-and-answer sessions could be used to accomplish this. SLTs can also encourage self-acceptance through promoting self-empowerment by encouraging the use of "I" statements when referring to stuttering, validating members' stories, vulnerable moments and honesty, fostering an accepting environment, and ensuring that no member's efforts to share are dismissed (Sheehan 2018).

5.1.2 Subtheme 2: Improved confidence

Participants expressed that as a result of feeling more confident and less fearful about their stutter, they were able to step out of their comfort zones and challenge themselves to participate in previously avoided tasks. This supports previous research by Blumgart et al. (2014) who found that support networks aid in reducing the psychological discomfort caused by stuttering, and thus allow PWS to participate more in everyday activities.

According to Gore & Luckman Margulis (2022), when a PWS expresses that they are proud of a communication attempt, can show cognitive resilience in the face of negative reactions, and can demonstrate a desire to try a communication attempt again, they are considered to have confidence in their identity as a communicator as well as a PWS. These are activities SLTs can encourage within the SSG setting in order to facilitate improved confidence. SLTs, for example, can encourage members to share ways in which they can own and develop cognitive resilience in order to combat negative reactions. Furthermore, SLTs should always emphasise that SSGs are a setting where second chances and attempts are always guaranteed and encouraged.

5.2 Theme 2: Increased sense of community

Under this theme, participants valued how attending SSG meetings had made them aware that there are other PWS and SLTs, who are there to provide them with support and reduce the feeling of isolation. Previous research has found that being part of a mutually supportive social network protects PWS from stuttering's negative effects (Craig et al., 2011; Gerlach et al., 2019). Increased social support is also a predictor of QoL and greater psychological resilience (Boyle, 2015; Craig et al., 2011). In order to further reduce the feelings of isolation that PWS may experience, SLTs could encourage group members to connect between meetings to foster connections that extend beyond a pre-arranged group meeting. SLTs could possibly create a secure platform where members who wish to connect outside SSGs can share their contact details. Members who have connected outside of the SSG setting can then offer support to one another on a regular basis and can practise their communication skills together, without the fear of being judged or scrutinised.

The expressed desire for an increased frequency of SSG meetings indicates PWS' interest in more frequent connection and can further increase the sense of community within the SSG. SLTs should also further increase the accessibility of SSG meetings. Research has shown that rehabilitation services can be made further accessible through an online platform (Molini-Avejonas et al. 2015). Therefore, SLTs could utilise a hybrid approach (online and in-person SSGs) as this may remove a location barrier and may increase the number of SSG attendees.

5.3 Theme 3: Support group reciprocity

5.3.1 *Subtheme 1: Learning from others*

Participants value the opportunity to learn techniques and coping strategies from other PWS because it gives them the chance to gain insight from people who can directly relate to them and their previous experiences. Medina et al. (2020) discovered that PWS enjoy and place a high value on gaining knowledge from other PWS who attend SSG meetings. Sharing personal stories, knowledge and skills has the potential to reduce the stigma associated with stuttering and encourage self-management (Boyle, 2016; WHO, 2010). SLTs therefore should encourage conversations in which PWS can share their stories. To encourage learning through sharing and listening, SLTs

could also invite guest speakers who stutter or are professionals in the management of stuttering.

5.3.2 Subtheme 2: Encouragement and empowerment

Thoits' (2011) discussed how support group settings provide individuals with opportunities to openly share their feelings and worries, receive support and affirmation, and be compassionately understood (Thoits, 2011). The participants of this study expressed similar desires stating that they wanted to both support others and be supported themselves, as well as uplift and be uplifted. Receiving support and praise from other PWS was described as both encouraging as well as empowering. This is supported by previous research that found that attending SSG meetings can lead to participants feeling more empowered (Tichenor & Yaruss, 2019). Participants also felt encouraged by watching others with more severe stutters, persevere through difficult stuttering moments.

Empowerment is an important and key component of stuttering therapy (Gore & Luckman Margulis, 2022). In an SSG setting, facilitating SLTs should encourage progress reflection by encouraging members to share something that they are proud of themselves for, whether it be something in their personal lives or related to their speech (Gore and Luckman Margulis, 2022). Self-disclosure can also promote empowerment in speech therapy (Gore and Luckman Margulis, 2022). In the SSG setting, SLTs could encourage group members to share stories about disclosing their stuttering, as well as personal tips and tricks that other members could apply if they choose to self-disclose their stuttering. An SSG can also provide a safe environment in which PWS can apply and troubleshoot self-disclosure techniques taught in individual speech therapy.

Empowerment has also been found to be achieved through gaining knowledge and information (Barak et al., 2008). As a result, SLTs who facilitate SSGs should ensure that PWS are informed and educated about their stuttering, as well as facilitate conversations in which PWS can learn from other PWS and other professionals. The combination of education and empowerment has been found to elicit change (Gore & Luckman Margulis, 2022). Identifying celebrities who stutter, inviting a friend to attend a session, watching motivational videos about stuttering, discussing the stigma of

stuttering, and educating family and friends about stuttering are some activities that SLTs can incorporate within the SSG setting to elicit change (Gore & Luckman Margulis, 2022).

5.4 Theme 4: Support group environment, participants and topics

5.4.1 *Subtheme 1: Environment*

Participants described how SSG meetings provide a supportive environment in which they were able to feel heard, safe, and relaxed, and experience a sense of belonging. Craig et al. (2011) found that social support fosters a sense of belonging, a feeling which P12 shares – “I always feel as if I’m different and so when I’m at SpeakEasy, I’m at home and... I feel like I belong.” A sense of belonging has been found to improve well-being and QoL (Craig et al., 2011).

It is therefore essential for the SLT who facilitates SSGs to create and maintain an environment that allows the members to feel heard, safe, relaxed and as though they belong. To allow all members to feel heard, the SLT can possibly be encouraged by allowing all those who wish to speak to have equal speaking opportunities. A way in which facilitating SLTs can ensure the SSG setting feels safe is by promoting as much confidentiality as possible. The SLT can request that members do not share personal information, details and/or stories about their fellow group members with others outside of the support group setting. Maintaining confidentiality has been linked to increased self-disclosure within a group setting (Doshi et al., 2019). The WHO, however, highlights that different cultures may view confidentiality in various ways and therefore suggests that the rules of confidentiality be decided by the group (WHO, 2010). A feeling of safety within the SSG setting can also be ensured by reassuring members that they do not need to contribute to the SSG meeting in order to attend.

5.4.2 *Subtheme 2: Value of SLTs as facilitators*

Participants valued and enjoyed having SLTs and SLT students in the SSG meetings. The WHO proposed that people with similar disabilities and rehabilitation professionals should share information, ideas, and experiences in order to encourage mutual understanding and collaboration (WHO, 2010). Research by Medina et al. (2020) also found that participants liked having SLTs participate in SSG meetings. They found that

participants viewed SLTs as essential in ensuring speaking opportunities for all members, allowing members freedom to go off-topic, generating topics for meetings, and planning. Specifically for this study, results support and further expand on Medina et al's. (2020) research. PWS suggest that SLTs collaborate as much as possible with PWS during SSG meetings, advocate for PWS, facilitate conversations in which SLTs can develop a deeper understanding of PWS and their experiences, and share their clinical and theoretical knowledge. Members also valued the SLTs' professionalism and viewed the SLT as being essential to the meetings because they help guide the conversation and align with the agenda. Facilitating SLTs should use the above members' perceptions of SLTs' roles in SSG, from both this research study and the study conducted by Medina et al. (2020), to inform their practice for facilitating SSGs.

Although SLTs have mostly been viewed as positive components of SSG meetings, Trichon (2007) found that their presence can be perceived negatively if they are only there for observational purposes. This was something that P2 alluded to when they suggested that in meetings where there are only a few PWS, the SLTs should also participate by answering questions and sharing their insights so that the PWS does not feel interrogated. Facilitating SLTs must thus strike an appropriate balance between being a passive and active participant.

5.4.3 Subtheme 3: Meeting topics

Participants expressed the opinion that SSG meetings should focus on speech and disfluency, in addition to addressing the emotional aspects of stuttering. As the SLT is the one that creates the agenda and topics for the meeting, the SLT must ensure both of these topics are covered. SLTs could ask members at the end of each SSG meeting what topics they would like covered in the next meeting.

Through the voices and perspectives of PWS, and consulting relevant literature, valuable recommendations on how to best facilitate SSGs were provided for SLTs. By listening to the voices of PWS, SLTs may be able to better inform clinical practice and possibly improve rehabilitation experiences, motivation, and functional outcomes of SSGs.

Chapter 6. Conclusions and critical evaluation

6.1 Conclusion and clinical implications

This research study aimed to understand and describe PWS' perspectives regarding why they attend SSGs. Listener reactions, according to PWS, prevent them from having a more positive attitude about themselves and their stutter. PWS reported increased acceptance of their stuttering as well as an improved level of confidence. Seven out of the thirteen participants expressed their desire to no longer feel alone in their journey with stuttering, making this finding significant and highlighting it as a primary reason behind why PWS attend SSG meetings. PWS emphasised the importance of reciprocity within the SSG because they value learning from others as well as contributing their insight and knowledge, encouraging and being encouraged, supporting others and being supported. Being encouraged by others was also found by PWS to be empowering by PWS. PWS expressed that they value the welcoming, safe, and relaxed environment created within the SSG meetings. SLTs are viewed as valuable role players in SSG meetings. PWS expressed their views on the SLT's role in SSG meetings, which included being professional, giving clinical and theoretical expertise, and bringing the group together. However, they also stated that SLTs must strike a balance between being passive and active participants in order to avoid being viewed as only observers. Fluency and the emotional implications of stuttering were suggested as topics for SSGs by PWS.

The voices of PWS who attend SSGs, along with previous research, were used to inform evidence-based recommendations for SLTs who facilitate SSGs. These recommendations are presented as clinical implications in Table 6.1.

With these clinical implications obtained from PWS' own voices and perspectives, facilitating SLTs may now be better able to inform their practise and address the needs of the PWS who attend their meetings. They may also be able to better personalise activities, subjects of conversation, and goals for the PWS who attend. This may motivate PWS to pursue personal goals outside of traditional stuttering therapy settings.

Table 6.1: Clinical implications for SLTs based on PWS' perspectives regarding their reasons for attending SSGs

Reason for attending SSG	Clinical implication for SLTs
Altered perceptions	<ul style="list-style-type: none"> • Increase the likelihood that PWS will have more positive experiences when speaking to people who do not stutter through: <ul style="list-style-type: none"> - Encouraging members to share individual experiences and/or techniques - Teaching strategies such as self-advertising or self-disclosure statements
Increased acceptance of stutter	<ul style="list-style-type: none"> • Holistically educate SSG members about stuttering, possibly through presentations, guest speakers, and question-and-answer sessions • Encourage the use of "I" statements to foster self-empowerment • Acknowledge and validate members' contributions • Foster an accepting environment
Increased confidence	<ul style="list-style-type: none"> • Encourage members to be proud of their communication attempts • Encourage members to share ways in which they can own and develop cognitive resilience to combat negative reactions • Encourage second chances and attempts
Increased sense of community	<ul style="list-style-type: none"> • Encourage group members to connect between meetings • Create a secure platform in which members who wish to connect outside the SSG setting can share their contact details and consent to being contacted • Increase the frequency of SSG meetings • Employ a hybrid approach (in-person and online SSG meetings)
Learning from others	<ul style="list-style-type: none"> • Encourage participants to share their own stories to reduce the stigma associated with stuttering and encourage self-management • Invite guest speakers and professionals who work in the field of stuttering
Encouragement and empowerment	<ul style="list-style-type: none"> • Encourage SSG members to reflect on their progress • Encourage members to discuss and share stories and tips for self-disclosure of stuttering and allow the SSG setting to be a setting in which members can troubleshoot self-disclosure techniques • Provide holistic education on stuttering

	<ul style="list-style-type: none"> • Share life stories of celebrities who stutter • Watch motivational videos • Encourage members to discuss any stigma they have encountered in their lives and encourage them to share the strategies they used to challenge or overcome this stigma. • Encourage friends and family members of group members to attend some meetings and provide them with information about stuttering and ways in which they can help PWS
Environment	<ul style="list-style-type: none"> • Ensure that those who wish to speak get equal speaking opportunities • Encourage confidentiality and allow the rules of confidentiality to be decided by group members • Reinforce that there is no pressure to speak and/or contribute during meetings
Value of SLTs as facilitators	<ul style="list-style-type: none"> • Allow equal speaking opportunities for all • Allow freedom to go off-topic • Generate appropriate topics for meetings • Plan meetings • Collaborate with group members • Discuss ways in which one can advocate for PWS • Facilitate conversations in which SLTs can develop a deeper understanding of PWS and their experiences • Be professional • Share clinical and theoretical knowledge • Guide conversations • Align with agenda • Ensure a balance between passive and active participation
Meeting topics	<ul style="list-style-type: none"> • Include topics focused on fluency and speech • Include topics focused on the emotional aspects of stuttering • Ask members which topics they would like to discuss in the next meeting

6.2 Strengths of the research study

- One of the research study's strengths appears to be that it is the first of its kind to collect perspectives from PWS who attend SSGs and use these perspectives, as well as previous research, to generate evidence-based recommendations for SLTs who facilitate SSGs. This research study can therefore serve as a basis for further research in the field of generating evidence-based guidelines for facilitating SSGs.
- Another strength of this research study was the diversity of the participants in terms of gender, age, and race. This enabled a variety of perspectives to be obtained from individuals from various ethnic and cultural groups, backgrounds, and stages of life.
- An additional strength of the research study is that the current findings support previous research. This enhances the research study's reliability and may lead to more rapid progress in the area of developing evidence-based guidelines for SSGs.
- Lastly, all ethical considerations were adhered to during this research study, which can be viewed as a strength. Confidentiality, respect for persons, beneficence, and avoidance of harm were all observed.

6.3 Limitations of the research study

- Due to the small sample size of this research, it may be difficult to generalise the findings to a wider population of SLTs and SSGs. Future studies should include a larger sample size of PWS who attend SSGs. Different SSGs should also be used as not all groups are conducted and facilitated in the same way.
- In this research study, participants had varying perceptions of the severity of their own stuttering, with six participants self-describing as moderate, four perceiving their stuttering as mild, two describing their stuttering as moderate to severe, and a single participant perceiving their stuttering to be mild to moderate. Future research should seek perspectives from more PWS who consider their stuttering severity to be severe in order to ensure that SSGs are meeting the needs of PWS with all levels of stuttering severity.
- The participants who attended the Pretoria SpeakEasy meetings were familiar with the researcher as she was previously a student assistant at the SpeakEasy

meetings. Although this familiarity did not appear to have an effect on the findings of this research study, future studies should use PWS who are not familiar with the researcher.

6.4 Recommendations for future research

- Some participants in this research study reported that meeting other PWS with more severe stuttering severity than them changed their perception of their stutter. Future research should look into the impact of PWS' perception of their stutter when they meet PWS with less severe stuttering than their own. This may cause a negative reaction to their speech, and SLTs need to be informed on how to best address this within SSGs.
- The participants in this research study had all received individual speech therapy intervention in the past. Future research should seek to determine whether PWS who have never received individual speech therapy have the same perspective on why they attend SSGs. This ensures that SLTs meet the needs of all PWS who attend SSGs, regardless of therapy history.
- The researcher was unable to locate any studies that have been conducted to date, with the purpose of determining what topics PWS would like to discuss within SSG meetings. This is therefore a topic that should be researched further in order to ensure that the topics discussed are of interest, importance, and relevance to the SSG members to best meet their needs.
- Although research has shown that rehabilitation services can be made further accessible through an online platform (Molini-Avejonas et al. 2015), it is still important to consider that many people in South Africa do not have access to the means needed for online services. Further research could therefore look into how SLTs can make SSGs more accessible for PWS throughout South Africa.

References

- American Psychological Association. (2010). Publication manual of the American Psychological Association (6th ed.). American Psychological Association.
- American Speech-Language-Hearing Association (ASHA). (n.d.). *Fluency Disorders (Practice Portal)*. Retrieved from www.asha.org/practice-portal/clinical-topics/fluency-disorders/.
- American Speech-Language-Hearing Association. (2016). Scope of Practice in Speech-Language Pathology [Scope of Practice]. Available from www.asha.org/policy
- Babbie, E and Mouton, J. 2001. The Practice of Social Research. Oxford University Press.
- Bajaj, G., Anil, M., Varghese, A., Bhat, J., Sheth, P., & Hoode, A. (2017). Me, My Stuttering, and Them! Effect of Self-Disclosure of Stuttering on Listener Perception. *Rehabilitation Process and Outcome*, 6, 1–10.
- Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, 24(5), 1867–1883. <https://doi.org/10.1016/j.chb.2008.02.004>
- Beilby, J. (2014). Psychosocial impact of living with a stuttering disorder: knowing is not enough. *Seminars in Speech and Language*, 35(2), 132–143. <https://doi.org/10.1055/s-0034-1371756>
- Bleek, B., Reuter, M., Yaruss, J., Cook, S., Faber, J., & Montag, C. (2012). Relationships between personality characteristics of people who stutter and the impact of stuttering on everyday life. *Journal of Fluency Disorders*, 37(4), 325-333. <https://doi.org/10.1016/j.jfludis.2012.07.003>
- Blumgart, E., Tran, Y., & Craig, A. (2014). Social support and its association with negative affect in adults who stutter. *Journal of Fluency Disorders*, 40, 83-92. <https://doi.org/10.1016/j.jfludis.2014.02.002>
- Boyle, M. (2013). Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience. *Journal of Fluency Disorders*, 38(4), 368-381. <https://doi.org/10.1016/j.jfludis.2013.09.001>
- Boyle, M. P. (2015). Relationships between psychosocial factors and quality of life for adults who stutter. *American Journal of Speech-Language Pathology*, 24(1), 1–12. https://doi.org/10.1044/2014_AJSLP-14-0089

- Boyle, M. P. (2018). Enacted stigma and felt stigma experienced by adults who stutter. *Journal of Communication Disorders*, 73, 50–61. <https://doi.org/10.1016/j.jcomdis.2018.03.004>
- Boyle, M. P., Dioguardi, L., & Pate, J. E. (2016). A comparison of three strategies for reducing the public stigma associated with stuttering. *Journal of Fluency Disorders*, 50, 44–58. <https://doi.org/10.1016/j.jfludis.2016.09.004>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brink, H., Van der Walt, C., & Van Rensburg, G. H. (2018). Fundamentals of research methodology for healthcare professionals (4th ed.). Juta.
- Brown, J., Ackley, K., & Knollman-Porter, K. (2021). Collaborative goal setting: a clinical approach for adults with mild traumatic brain injury. *American Journal of Speech-Language Pathology*, 30(6), 2394–2413. https://doi.org/10.1044/2021_AJSLP-21-00078
- Christensen, R. H. B. (2015). Analysis of ordinal data with cumulative link models—estimation with the R-package ordinal. *R-package version*, 28.
- Connelly, L. M. (2016). Trustworthiness in Qualitative Research. *Medsurg Nursing*, 25(6), 435-436. <https://www.proquest.com/scholarly-journals/trustworthiness-qualitative-research/docview/1849700459/se-2?accountid=14717>
- Connery, A., McCurtin, A., & Robinson, K. (2019). The lived experience of stuttering: a synthesis of qualitative studies with implications for rehabilitation. *Disability and Rehabilitation*, 42(16), 2232–2242. <https://doi.org/10.1080/09638288.2018.1555623>
- Constantino, C. D. (2018). What can stutterers learn from the neurodiversity movement? *Seminars in Speech and Language*, 39(4), 382–395. <https://doi.org/10.1055/s-0038-1667166>
- Craig, A., Blumgart, E., & Tran, Y. (2011). Resilience and stuttering: Factors that protect people from the adversity of chronic stuttering. *Journal of Speech, Language, and Hearing Research*, 54(6), 1485-1496. [https://doi.org/10.1044/1092-4388\(2011/10-0304\)](https://doi.org/10.1044/1092-4388(2011/10-0304))
- Creswell, J. W. (2013). *Qualitative inquiry & research design: choosing among five approaches* (3rd ed.). SAGE Publications.

- De Nardo, T., Gabel, R. M., Tetnowski, J. A., & Swartz, E. R. (2016). Self-acceptance of stuttering: a preliminary study. *Journal of Communication Disorders*, 60, 27–38. <https://doi.org/10.1016/j.jcomdis.2016.02.003>
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, 7(2), e000057. <https://doi.org/10.1136/fmch-2018-000057>
- Department of Health. (2015). *Ethics in health research: principles, processes and structures (2nd ed.)*. Department of Health Republic of South Africa.
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed mode surveys: The tailored design method (4th ed.)*. John Wiley & Sons Inc.
- Doshi, P. V., Robak, R. W., Grffin, P. W., & Ward, A. W. (2019). Confidentiality in Counselor Experiential Training Groups: An Exploratory Study. *Journal of Counseling Research and Practice*, 5(1), 3. <https://egrove.olemiss.edu/jcrp/vol5/iss1/3>
- Evans, J. J. (2012). Goal setting during rehabilitation early and late after acquired brain injury. *Current Opinion in Neurology*, 25(6), 651–5. <https://doi.org/10.1097/WCO.0b013e3283598f75>
- Gerlach, H., Hollister, J., Caggiano, L., & Zebrowski, P. (2019). The utility of stuttering support organization conventions for young people who stutter. *Journal of Fluency Disorders*, 62, 105724. <https://doi.org/10.1016/j.jfludis.2019.105724>
- Gore, K., & Luckman Margulis, C. (2022). 3Es: an all-inclusive stuttering therapy tool. *Perspectives of the Asha Special Interest Groups*, 7(3), 716–727. https://doi.org/10.1044/2022_PERSP-20-00300
- Guba, E., & Lincoln, Y. (1985). *Naturalistic Enquiry*. SAGE Publications.
- Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, 2(163-194), 105.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1).
- Guitar, B. (2014). *Stuttering: An Integrated Approach to Its Nature and Treatment (4th ed.)*. Wolters Kluwer.
- Health Professionals Council of South Africa. (2008). General ethical guidelines for health researchers.

- Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: how many interviews are enough? *Qualitative Health Research*, 27(4), 591–608. <https://doi.org/10.1177/1049732316665344>
- Hughes, J. L., Camden, A. A., & Yangchen, T. (2016). Rethinking and updating demographic questions: Guidance to improve descriptions of research samples. *Psi Chi Journal of Psychological Research*, 21(3), 138-151.
- Irwin, D., Lass, N. J., & Pannbacker, M. H. (2014). *Clinical research methods in speech-language pathology and audiology*. Plural Publishing.
- Iverach, L., Jones, M., Lowe, R., O'Brian, S., Menzies, R. G., Packman, A., & Onslow, M. (2018). Comparison of adults who stutter with and without social anxiety disorder. *Journal of Fluency Disorders*, 56, 55–68. <https://doi.org/10.1016/j.jfludis.2018.03.001>
- Kerr, C., Nixon, A., & Wild, D. (2010). Assessing and demonstrating data saturation in qualitative inquiry supporting patient-reported outcomes research. *Expert Review of Pharmacoeconomics & Outcomes Research*, 10(3), 269-281. <https://doi.org/10.1586/erp.10.30>
- Kittilstved, T. (2014). Education and changing the perceptions of stuttering. *Proceedings of the National Conference on Undergraduate Research (NCUR)*, Lexington. <https://doi.org/0.13140/2.1.2961.3763>
- 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(4), 275–305. <https://doi.org/10.1016/j.jfludis.2004.10.001>
- Leedy, P. D., Ormrod, J. E., & Johnson, L. R. (2021). *Practical research: Planning and design* (12th ed). Pearson.
- Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The All Ireland Journal of Teaching and Learning in Higher Education*, 9(3), 3351-33514. <http://ojs.aishe.org/index.php/aishe-j/article/view/335>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Maree, K. (Ed.). (2016). *First steps in research* (2nd ed.). Van Schaik.

- McGill, M., Siegel, J., Nguyen, D., & Rodriguez, S. (2018). Self-report of self-disclosure statements for stuttering. *Journal of Fluency Disorders*, 58, 22–34. <https://doi.org/10.1016/j.jfludis.2018.09.004>
- Medina, A., Almeida, N., Amarante, K., Martinez, N., & Prezzemolo, M. (2020). Adults who stutter and their motivation for attending stuttering support groups: A pilot study. *Perspectives of The ASHA Special Interest Groups*, 5(1), 142-154. https://doi.org/10.1044/2019_persp-19-00049
- Molini-Avejonas, D., Rondon-Melo, S., de La Higuera Amato, C., & Samelli, A. (2015). A systematic review of the use of telehealth in speech, language and hearing sciences. *Journal of telemedicine and telecare*, 21(7), 367-376.
- Plexico, L. W., Erath, S., Shores, H., & Burrus, E. (2019). Self-acceptance, resilience, coping and satisfaction of life in people who stutter. *Journal of Fluency Disorders*, 59, 52–63. <https://doi.org/10.1016/j.jfludis.2018.10.004>
- Polit, D.F. and Beck, C.T. (2017) *Nursing research: generating and assessing evidence for nursing practice* (10th ed.), Wolters Kluwer Health. <https://doi.org/10.1016/j.iccn.2015.01.005>
- Ratner, N., & Tetnowski, J. (2014). *Current issues in stuttering research and practice*. Psychology Press.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84. <https://doi.org/10.1002/nur.20362>
- Schou, L., Høstrup, H., Lyngsø, E.E., Larsen, S., & Poulsen, I. (2011). Validation of a new assessment tool for qualitative articles. *Journal of Nursing Scholarship*, 68(9), 2086-2094
- Sheehan, C. (2018). *Acceptance in stuttering therapy: A clinician perspective* [Master's thesis, Appalachian State University].
- Sønsterud, H., Feragen, K., Kirmess, M., Halvorsen, M., & Ward, D. (2020). What do people search for in stuttering therapy: Personal goal-setting as a gold standard? *Journal of Communication Disorders*, 85, 105944. <https://doi.org/10.1016/j.jcomdis.2019.105944>
- Speakeasy. (n.d.). *SpeakEasy: Run by people who stutter for people who stutter*. <http://www.speakeasy.org.za/>.
- Swartz, E., Irani, F., & Gabel, R. (2014). Coping with stuttering. *Perspectives on Fluency and Fluency Disorders*, 24(2), 58–68. <https://doi.org/10.1044/ffd24.2.58>

- Taylor, S. E. (2011). *Social support: A review. The Oxford handbook of health psychology*. Oxford University Press.
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig & W. Stainton Rogers (Eds), *The SAGE handbook of qualitative research in psychology*. SAGE Publications Ltd.
<https://dx.doi.org/10.4135/9781526405555.n2>
- Thoits, P. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior*, 52(2), 145-161.
<https://doi.org/10.1177/0022146510395592>
- Tichenor, S. E., & Yaruss, J. S. (2018). A phenomenological analysis of the experience of stuttering. *American Journal of Speech–Language Pathology*, 27(3S), 1180–1194. https://doi.org/10.1044/2018_AJSLPODC11-17-0192
- Tichenor, S. E., & Yaruss, J. S. (2019). Group experiences and individual differences in stuttering. *Journal of Speech, Language, and Hearing Research*, 62(12), 4335–4350. https://doi.org/10.1044/2019_JSLHR-19-00138
- Trichon, M. (2007). Getting the maximum benefits from support groups: Perspectives of members and group leaders. *Perspectives on Fluency and Fluency Disorders*, 17(1), 10–13. <https://doi.org/10.1044/ffd17.1.10>
- Trichon, M. C. (2010). *Self-help conferences for people who stutter: an interpretive phenomenological analysis* (dissertation).
- Trichon, M., & Tetnowski, J. (2011). Self-help conferences for people who stutter: A qualitative investigation. *Journal of Fluency Disorders*, 36(4), 290-295.
<https://doi.org/10.1016/j.jfludis.2011.06.001>
- Vedprakash, K. (1999). *The role and function of the KwaZulu Natal speakeasy support group* (dissertation). publisher not identified.
- Weigel, M. (2013). *Adolescents who stutter: Perception of effective therapy techniques* [Master's thesis, Duquesne University]. <https://dsc.duq.edu/etd/1348>
- WHO. (2001). International Classification of Functioning, Disability and Health. World Health Organization.
- World Health Organization (WHO). (2010). Community-based rehabilitation: CBR guidelines. Empowerment component. WHO Press. World Health Organization.
https://apps.who.int/iris/bitstream/handle/10665/44405/9789241548052_empower_eng.pdf?sequence=5

Yaruss, J., & Quesal, R. (2004), Stuttering and the internal classification of functioning, disability, and health (ICF): An update. *Journal of Communication Disorders*, 37, 35–52

Appendices

Appendix A: Telephonic semi-structured interview schedule

Section 1: Biographic and demographic information

Question	Expansion of question	Additional clarifying and prompting questions
1. What is your current age in years?	None.	How old are you now? In what year were you born?
2. Out of the following options, which describes your gender identity? a. Female b. Male c. Other d. I would rather not say	None.	None.
3. How would you describe your race?	None.	What is your ethnicity?

Section 2: Fluency history and behaviours

Question	Expansion of question	Additional clarifying and prompting questions
4. Around what age did you start to stutter?	None.	How long have you known you have had a stutter? Do you remember when you first started stuttering? Have any members of your family told you how old you were when they realized you had a stutter?

<p>5. Did you realise by yourself that you stuttered or was it something someone told you?</p>	<p>(If told by someone) Do you remember who told you that you stuttered?</p>	<p>None.</p>
<p>6. What was your initial reaction to learning that you had a stutter?</p>	<p>None.</p>	<p>What is your first memory in terms of your stutter? Do you remember how you felt that day?</p>
<p>7. How do you feel now about your stutter?</p>	<p>None.</p>	<p>Have your feelings changed regarding how you feel about your stutter changed since your initial reaction to learning you stuttered? (If yes) Can you describe these feelings? (if no) Why do you think that you feel the same way about your stutter? Is your stutter something that is on your mind all the time?</p>
<p>8. In terms of your speech, how severe do you consider your stuttering? Please choose one of the following options. a. Mild b. Moderate c. Severe d. Other (ask to elaborate)</p>	<p>Can you give me an explanation of why you chose that severity rating?</p>	<p>None.</p>
<p>9. How does your stutter affect you in your everyday life?</p>	<p>None.</p>	<p>Can you describe what a regular day looks like for you? Are there any aspects of this regular day that you just described impacted by your stutter? Are there any activities or things you feel that you cannot do because of your stutter? Do you feel nervous when you have to participate in everyday activities?</p>

<p>10. On the scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following stuttering behaviours in terms of how often you experience them when speaking to others in a typical day. I can provide you with an example if requested.</p> <ol style="list-style-type: none"> Repetitions of sounds in words (Example if needed - “Do you have a p-p-p-pencil?”) Repetitions of syllables in words (Example if needed - “Do you have a pen- pen- pen- pencil?”) Repetitions of single syllable words (Example if needed - “I-I-I need a pencil.”) Whole word repetitions (Example if needed - “Do you you you you have a pencil?”) Prolongations of sounds (Example if needed - “I nnnnnneed a pencil”) Blocks (uncontrollable stoppage of air or voice) (Example if needed - “I...need a...pencil”) 	<p>None.</p>	<p>Can you describe how some of your stuttering moments look when speaking to others in a typical day?</p> <p>How often do you experience moments like these in a typical day?</p>
<p>11. On the scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following behaviours in terms of what you do during a stuttering moment and/or before you stutter.</p> <ol style="list-style-type: none"> Blink more often Break eye contact with the person you are talking to Use filler words (e.g. “umm”, “uh”, “you know”, “so”) Use body movements (e.g., hand movements or feet tapping) Feel tension in your muscles 	<p>None.</p>	<p>Are there any particular behaviours that you find yourself doing during a stuttering moment and/or before you stutter?</p> <p>Did you realise you did these behaviours on your own or did someone else point them out to you?</p> <p>Do you do these behaviours unconsciously or do you actively use them?</p>

<p>12. On the scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following behaviours in terms of what you do to avoid stuttering.</p> <p>a. Change the words or sounds you were going to say because you think you might stutter on them</p> <p>b. Avoid situations or activities that involve talking to people</p> <p>c. Avoid seeing or socialising with people</p>	None.	<p>Do you try to avoid stuttering or are you open about stuttering?</p> <p>Are there any particular words or sounds you always stutter on?</p> <p>Do you actively try to avoid using these words or sounds when talking to others?</p>
<p>13. On the scale of “never”, “rarely”, “sometimes”, “most of the time” or “all of the time”, please rate the following emotions and feelings in terms of how you feel about the way you speak.</p> <p>a. Nervous</p> <p>b. Afraid</p> <p>c. Anxious</p> <p>d. Angry</p> <p>e. Frustrated</p> <p>f. Upset</p> <p>g. Embarrassed</p>	None.	<p>How do you feel when you are talking and your speech is relatively fluent?</p> <p>How do you feel before you start to speak?</p> <p>How do you feel during a stuttering moment?</p> <p>How do you feel after you have experienced a stuttering moment?</p>

Section 3: Speech-language therapy treatment

Question	Expansion of question	Additional clarifying and prompting questions
<p>14. Have you ever received individual speech-language therapy for your stutter?</p>	<p>Are you currently receiving speech-language therapy or did you receive speech-language therapy in the past?</p>	<p>Have you ever seen a healthcare professional about your stutter?</p> <p>Do you remember who?</p> <p>Can you describe what the healthcare professional did to help with your stuttering?</p>

<p>15. (If yes to question 14) (If seen in the past) How old were you when you saw a speech-language therapist? (If currently seeing) How long ago did you start attending speech-language therapy?</p>	None.	<p>Were you very young when you started seeing a speech-language therapist?</p> <p>Did see a speech-language therapist because you wanted to or did someone else encourage you to go?</p>
<p>16. (If yes to question 14) How long did you receive this individual speech-language therapy?</p>	None.	<p>How old were you when you first started individual speech-language therapy?</p> <p>How old were you when you stopped going to individual speech-language therapy?</p> <p>Do you remember what sort of activities the speech-language therapist did with you?</p> <p>Did you attend this therapy alone or was an adult always with you?</p>

Section 4: Support groups

Question	Expansion of question	Additional clarifying and prompting questions
<p>17. How did you first hear about SpeakEasy?</p>	None.	<p>Did you first hear about SpeakEasy from someone else? Who?</p> <p>Did you find out about SpeakEasy through your own research?</p>
<p>18. Do you attend SpeakEasy meetings regularly?</p>	<p>(If no) Is this by choice or have other factors prevented you from attending? Can you explain some of these factors to me?</p>	None.

<p>19. Do any of your friends, family, significant other etc., attend the meetings with you?</p>	<p>(If yes) Who usually attends the meetings with you?</p> <p>(If no) Would you like anyone else to attend the meetings with you? Can you explain your reasoning behind your answer?</p>	<p>Do your friends, family, significant other etc., know you attend SpeakEasy?</p> <p>Have you invited any of them to attend a meeting with you?</p>
<p>20. What made you decide to go to your first SpeakEasy support group meeting?</p>	<p>None.</p>	<p>What were you hoping would happen at your first Speakeasy meeting?</p>
<p>21. Were there any factors that caused you to hesitate about attending your first SpeakEasy meeting?</p>	<p>None.</p>	<p>When you first found out about SpeakEasy, did you immediately want to attend or were you a bit hesitant? What were some of the things making you hesitate?</p> <p>Were you nervous about attending your first SpeakEasy meetings? What was making you nervous?</p>
<p>22. What are your main reasons for attending this SpeakEasy support group?</p>	<p>None.</p>	<p>What are some of the things that make you keep coming back to Speakeasy?</p> <p>Do you hope that SpeakEasy will help you cope with your stuttering?</p> <p>Are you hoping to meet other people who stutter?</p> <p>Do you hope that attending SpeakEasy might make you change your perspective about your stutter?</p> <p>Do you hope SpeakEasy will help you understand your stutter better or learn more about it?</p>
<p>23. What do you enjoy most about SpeakEasy?</p>	<p>None.</p>	<p>What about SpeakEasy makes you excited to attend?</p>

		What do you look most forward to when you attend the meetings?
24. Is there anything that you do not like or would change about SpeakEasy?	None.	Do you like that most meetings are run and coordinated by a speech-language therapist? Would you prefer the meetings to be run by a member of the group who is a person who stutters? Do you feel that the activities and topics spoken about during the meetings are interesting and appropriate? Do you find that meetings once a month are enough?
25. Do you feel that SpeakEasy has influenced your perception of your stutter?	(If yes) Can you tell me how has it influenced your perception? (If no) Why do you feel as though it has not changed your perception?	Do you view your stutter differently now compared to when you first started attending SpeakEasy?
26. Would you say that attending a stuttering support group helps your emotional well-being?	(If yes) In what ways has it helped your emotional well-being? (If no) Why do you feel as though it has not helped your emotional well-being?	Do you usually feel better after attending a meeting? Can you describe the emotions your stutter used to cause compared to the emotions it causes now? Are these feelings as severe as they used to be?
27. Has attending a stuttering support group helped you cope with your stutter?	(If yes) Can you explain to me how the group has helped you cope better with your stutter?	Have you learnt important skills from other members of the groups in terms of how to cope with your stutter?

	(If no) Can you explain to me why it has not helped you cope with your stutter?	
28. Would you recommend this or any other support group to other people who stutter?	None.	(If yes) What are some things you may say to another person who stutters to encourage them to join the group?
29. Have you been able to form relationships with other group members?	(If no) Would you like to form relationships with other group members? (If yes) How would you describe these relationships? Do you view them as friendships or perhaps as mentorships?	Do you communicate with any of the SpeakEasy members outside of the support group sessions?
30. What did you think SpeakEasy was going to be like or be about before you attended your first meeting?	None.	None.
31. What do you want and need from your support group?	None.	None.
32. Have you tried any other support groups besides SpeakEasy?	(If yes) Would you mind telling me the name of the other support group or groups you have tried? (If yes) Do you still attend these support groups?	None.
33. (If yes to question 32) What are some of the differences between the groups you have tried?	None.	What has been the main focus of each group? Who runs or manages each group?

		How often does each group meet? How many members are part of each group?
34. Have you tried any other forms of self-help such as social media platforms, books, podcasts etc?	(If yes) Can you specify which other forms of self-help you have tried?	None.

Appendix B: Ethical approval letter from Research Ethics Committee, Faculty of Humanities, University of Pretoria



Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotheo



23 June 2021

Dear Miss NE Bloye

Project Title: Why do people who stutter attend stuttering support groups?
Researcher: Miss NE Bloye
Supervisor(s): Miss CJ Eslick
Ms SS Abdoola
Department: Speech Language Path and Aud
Reference number: 17069892 (HUM025/0521)
Degree: Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 23 June 2021. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

Research Ethics Committee Members: Prof I Pikirayi (Deputy Dean); Prof KL Harris; Mr A Bizo; Dr A-M de Beer; Dr A dos Santos; Ms KT Govinder; Andrew; Dr P Gutura; Dr E Johnson; Prof D Maree; Mr A Mohamed; Dr I Noomé; Dr C Puttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

Appendix C: Information letter and informed consent document



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Department of Speech-Language Pathology and Audiology



Information and Informed Consent Document

1 July 2021

Dear prospective research participant

You are invited to participate in a research study titled *“Why do people who stutter attend stuttering support groups?”* This research study is part of a Master’s degree in Speech-Language Pathology at the University of Pretoria. This information letter can help you to decide if you would like to participate. Before you agree to participate, it is important that you fully understand what is involved. If you have any questions, please do not hesitate to ask the researcher, Miss Nicola Bloye.

The nature and purpose of the study:

This study aims to understand why people who stutter (PWS) attend stuttering support groups. The purpose is to expand research within the field of stuttering to ensure that PWS receive the best possible treatment and services from speech-language therapists (SLTs). By conducting this study, the researcher hopes to generate new information regarding what is important to PWS who attend stuttering support groups, in order to encourage SLTs to potentially start new support groups or expand and structure existing support groups so that they meet the needs of PWS.

Explanation of procedures and what will be expected from research participants:

Please note that due to the COVID-19 pandemic, all communication and data collection for this study will be done electronically and telephonically. You will therefore need to have access to an email address and a mobile phone or telephone. You must also have attended at least three SpeakEasy meetings in order to participate in this study. Your attendance of these three meetings does not have to be consecutive. In addition, if you have a history of any communication difficulties, such as those resulting from a stroke or brain injury and/or hearing difficulties, you will unfortunately not be able to participate.

Should you be willing to participate in this research study, you will be requested to sign the informed consent section of this document and email it to the researcher. The researchers contact details can be found on page two of this document. Once the researcher receives your signed informed consent, you will be contacted by the researcher via your preferred means of contact to arrange a date and time for a telephonic interview. Questions asking about your stuttering history, your stuttering experiences, and your perspectives regarding stuttering support groups, specifically SpeakEasy, will be included in the interview. The interview will take approximately 45-60 minutes. All participants will receive a code to ensure that the responses given during the telephonic interview can be processed while maintaining confidentiality. You are welcome to ask the researcher any questions at any point during the telephonic

interview. You are also welcome to contact the researcher via email should you have any questions before or after participating in the telephonic interview. Your interview will be recorded and transcribed for analysis.

Once comprehensive results have been generated, you will be emailed a simple report that summarises the findings and conclusions of the study. This report is purely for interests sake.

Please note that should you wish to, you may discontinue with the study at any time. Your withdrawal will not affect your attendance and participation in the SpeakEasy support group.

Risk and discomforts involved:

There are no foreseeable physical discomforts or risks involved in this study. If you do experience any discomfort, please inform the researcher. The study will, however, take up some of your time when you participate in the telephonic interview, approximately 45-60 minutes.

Possible benefits of this study:

By determining why the members of SpeakEasy attend stuttering support groups, it will provide the SLTs of South Africa with a better understanding of their clients and what they value in terms of stuttering support groups. With this information, existing stuttering support groups can be adjusted and structured to better meet the needs of the members who attend, and new support groups can be formed based on evidence-based information. The results yielded from this particular study will not only provide evidence for SLTs that can be shared with clients considering attending support groups, but will also ensure that PWS who attend stuttering support groups are regularly doing so because they are attending a group best suited to them. The results from this study will ensure that PWS continue to further their personal goals beyond traditional stuttering therapy settings.

Ethical approval:

This study has been submitted for ethical approval to the Research Ethics Committee of the Faculty of Humanities as well as the Speech-Language Pathology and Audiology Departmental Ethics and Research Committee at the University of Pretoria.

Information:

If you have any questions concerning this study, please contact the researcher: Nicola Bloye (nicola.bloye@gmail.com) or the research supervisors: Ms Abdoola (shabnam.abdoola@up.ac.za) and Ms Eslick (casey.eslick@up.ac.za).

Confidentiality:

No identifying information will be required during the telephonic interview. Instead, you will be assigned a numerical code that will be used to represent your information during data analysis (e.g., P1, P2). The only identifying information you will be requested to provide is your contact details on the informed consent document and these will only be used to contact you to arrange a time and date for the interview.

In accordance with the University policy, all data collected will be securely stored and archived on the Department of Speech-Language Pathology and Audiology's data repository for 15 years.

Compensation:

You will not be paid to take part in this study. There are no costs involved for you to participate. The researcher will phone you for the telephonic interview and therefore, you will not have to cover the cost of airtime.

If you are willing to participate in this study, please sign the informed consent document and email it back to the researcher (nicola.bloye@gmail.com). Should you require any further information or have any questions, please do not hesitate to contact the researcher.

Kind regards,



Miss Nicola Bloye

BA. Speech-Language Pathology
Primary researcher



Ms Shabnam Abdoola

MA. Speech-Language Pathology & Audiology
Research Supervisor



Ms Casey Eslick

MA. Speech-Language Pathology
Research Co-supervisor



Prof. Jeannie van der Linde

MA. Speech-Language Pathology
Head of Department Speech-Language Pathology & Audiology

Informed consent

I confirm that the researcher requesting my consent to take part in this study titled “*Why do people who stutter attend stuttering support groups?*” has informed me about the nature and process, any risks and discomforts as well as the benefits of the study. I have also received, read and understood the written information about the study stated in the information sections of this document (pages 1-3).

I have had the opportunity to ask questions and I am willing to participate in this study. I confirm that I have the necessary resources to participate including access to an email address and a mobile phone or telephone. In addition, I confirm that I have attended at least three SpeakEasy meetings and I understand that my attendance of these three meetings does not have to be consecutive. I am aware that no identifying information will be included in the reporting of results. I am aware that the contact details I provide below will only be used by the researcher to contact me to arrange a time and date for a telephonic interview and by signing below, I give permission for the researcher to contact me. I also consent to having my interview recorded by the researcher. I consent to the information I provide being used for future research. I understand that I will not be penalised in any way should I wish to discontinue with the study and my withdrawal will not affect my participation in the SpeakEasy support group. I am participating willingly. I also have a signed copy of this informed consent agreement.

Participant's email address: _____

Preferred means of contact for arrangement of telephonic interview (e.g., email, SMS, WhatsApp, phone call etc.): _____

Relevant details for preferred means of contact above: _____

Participant's name (please print)

Date

Participant's signature

Date

Researcher's name (please print)

Date

Researcher's signature

Date

Name of person who witnessed the informed
Consent (please print)

Date

Signature of witness

Date

Appendix D: Permission letters from SpeakEasy coordinators



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

Department of Speech-Language Pathology and Audiology



Date: 16 April 2021

Permission Letter

Based on my review of the proposed research by Miss Nicola Bloye, who is supervised by Miss Shabnam Abdoola and Miss Casey Eslick entitled “*Why do people who stutter attend stuttering support groups?*”, I, (Full name) _____ **Ms Shabnam Abdoola** give permission for the researcher to use members of my stuttering support group, (Group name) **SpeakEasy** held at (Venue) **University of Pretoria** in (Suburb/City) **Pretoria**, Gauteng, South Africa, as research participants and am willing to distribute this study's information letter and informed consent document to my members and invite them to participate. As part of this study, I authorize the researcher to contact the members of my stuttering support group once they sign the informed consent document and email it back to the researcher. I am aware that subsequent to signing the informed consent document, the members will be requested to participate in a telephonic interview. I have been informed that members' participation is voluntary and at their own discretion. Members will not be penalised in any way should they wish to discontinue with the study and their withdrawal will not affect their attendance or participation in the SpeakEasy support group.

I understand that my responsibilities include distributing the information letter and informed consent document to the members of my stuttering support groups and inviting them to participate in this research study.

This authorization covers the time period of 2021 and 2022.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from my stuttering support group.

Sincerely,



Full name: **Ms Shabnam Abdoola**

Email address: **shabnam.abdoola@up.ac.za**

Position in SpeakEasy: **SpeakEasy Coordinator (Pretoria)**

DINA LILIAN
SPEECH THERAPIST
PRACTICE NUMBER: 014 8814

Date: 6 June 2021

Permission Letter

Based on my review of the proposed research by Miss Nicola Bloye, who is supervised by Ms Shabnam Abdoola and Ms Casey Eslick entitled "Why do people who stutter attend stuttering support groups? I, (Full name) D. LILIAN, give permission for the researcher to use members of my stuttering support group, (Group name) SpeakEasy held at (Venue) Johannesburg, Norwood in (Suburb/City) Johannesburg, Gauteng, South Africa, as research participants and am willing to distribute this study's information letter and informed consent document to my members and invite them to participate. As part of this study, I authorize the researcher to contact the members of my stuttering support group once they sign the informed consent document and email it back to the researcher. I am aware that subsequent to signing the informed consent document, the members will be requested to participate in a telephonic interview. I have been informed that members' participation is voluntary and at their own discretion. Members will not be penalised in any way should they wish to discontinue with the study and their withdrawal will not affect their attendance or participation in the SpeakEasy support group.

I understand that my responsibilities include distributing the information letter and informed consent document to the members of my stuttering support groups and inviting them to participate in this research study.

This authorization covers the time period of 2021 and 2022.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from my stuttering support group.

Sincerely,



Full name: D. LILIAN
Email address: dina.lilian@gmail.com
Position in SpeakEasy: Chair person



Appendix E: Referral letter for counselling



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Department of Speech-Language Pathology and Audiology



Date: _____

Referral Letter for Counselling

Dear _____,

Thank you for taking the time to participate in the research study titled "Why do people who stutter attend stuttering support groups?" You expressed the need to consult with a qualified counsellor who can help you further discuss your feelings and experiences related to your stutter. Please find a list of possible counsellors situated in Pretoria and Johannesburg. Please note that the counsellors included in this list are only recommendations and you are welcome to consult any other counsellor or psychologist of your choice. The counsellors below can be contacted in your own capacity.

Pretoria		
Counsellor	Contact details	Description
LifeLine Pretoria	Telephone counselling service: 012 804 3619 or 0861 322 322 Face-to-face counselling (by appointment): 012 804 1853	LifeLine provides a confidential crisis intervention service. Counsellors who are skilled in the art of listening provide this service and are committed to giving emotional support either telephonically, online or in face-to-face sessions at no cost. (https://lifelinepta.org.za/)
Vita Nova Counselling Centre	Tel: 071 297 9992	Counselling is conducted by the Humanitas Counselling Students. Most of these students have degrees Psychology or Social Work, and have recently completed their theoretical counselling training with the Vita Nova Counselling Centre. These students are available for free of charge face-to-face counselling or online counselling via Zoom. (https://www.vitanova.co.za/)
Johannesburg		
Counsellor	Contact details	Description
LifeLine Johannesburg	To book for an individual WhatsApp call, please visit the website (https://www.cognitofirms.com/LifeLineJohannesburg/WebsiteFaceToFaceIntakeRequest) or call the counselling manager on 076 218 4264 or WhatsApp message LifeLine on 065 989 923 and they will ask for more details to confirm for a WhatsApp call appointment. In their personal capacity/community, a client is also welcome to reach LifeLine for counselling support on the Lifeline South Africa/Johannesburg 24/7 telephone counselling lines, 011 728 1347 or 0861 322 322, if they would like to speak to one of the counsellors immediately. For any counselling related enquiries, please feel at liberty to contact LifeLine on the details below or to speak to Reabetsoe Noge, Act. Counselling and EWS manager at reabetsoe@lifelinejhb.org.za or 076 218 4264 or 011 728 1331 (office line).	LifeLine Johannesburg currently offers telephonic or online counselling (via WhatsApp video) services at no cost for up to 4 to 6 sessions. Face-to-face counselling has been postponed until further notice to respect lockdown regulation. LifeLine Johannesburg aims to counsel people and help them better handle stress and improve their emotional health. If clients present with challenges outside of LifeLine's counselling scope, they will refer the client to the relevant organisation/practitioner that can assist the client further. (https://www.lifelinejhb.org.za/index.ashx)

Kind regards,



Miss Nicola Bloye
BA. Speech-Language Pathology
Primary researcher



Ms Shabnam Abdoola
MA. Speech-Language Pathology & Audiology
Research Supervisor



Ms Casey Eslick
MA. Speech-Language Pathology
Research Co-supervisor

Appendix F: Referral letter for speech-language therapy services



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Department of Speech-Language Pathology and Audiology



Date: _____

Referral Letter for Speech-Language Therapy

Dear _____,

Thank you for taking the time to participate in the research study titled "Why do people who stutter attend stuttering support groups?" You expressed interest in attending speech-language therapy for your stutter. Please find a list of possible speech-language therapists situated in Pretoria and Johannesburg. Please note that these speech-language therapists do charge for their services. Additionally, please note that the speech-language therapists included in this list are only recommendations and you are welcome to consult any speech-language therapist of your choice. The speech-language therapists below have all granted their permission to be contacted and you may contact them within your personal capacity should you feel the need to.

Pretoria	
Speech-language therapist	Contact details
Fluency Clinic (University of Pretoria's Department of Speech-Language Pathology and Audiology)	Ms Mokaba Matsei (Appointments and queries) Email: mokaba.matsei@up.ac.za Tel: 012 420 5327 Ms Shabnam Aboodla (Head of the Fluency Clinic) Email: shabnam.abdoola@up.ac.za
Sigma Speech and Hearing (Centurion)	Tel: 081 576 6656 Email: sigmasph@gmail.com

Johannesburg	
Speech-language therapist	Contact details
Dina Lilian (The Norwood Therapy Centre)	Tel: 082 820 6225
University Speech and Hearing Clinic (University of Witwatersrand)	Mr Gift Khumalo (Clinic Manager) Email: gift.khumalo@wits.ac.za Ms Nomvuselelo Nompondwana (Clinic Secretary) Email: Nomvuselelo.nompondwana@wits.ac.za Tel: 011 717 4567

Kind regards,



Miss Nicola Bloye
BA. Speech-Language Pathology
Primary researcher



Ms Shabnam Abdoola
MA. Speech-Language Pathology & Audiology
Research Supervisor



Ms Casey Eslick
MA. Speech-Language Pathology
Research Co-supervisor

Appendix G: Referral permission letters from speech-language therapists (Pretoria and Johannesburg)



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomo

Department of Speech-Language Pathology and Audiology



7 June 2021

To whom it may concern

I, Ms Shabnam Abdoola, hereby grant Miss Nicola Bloye permission to refer any research participants who participate in her study titled “Why do people who stutter attend stuttering support groups?”, for speech-language therapy to the fluency clinic at the University of Pretoria’s Department of Speech-Language Pathology and Audiology. I give her permission to share my contact details with the research participants and for the participants to then contact me within their personal capacity.

Kind regards,



Ms Shabnam Abdoola

Room 3-4, Department of Speech-Language Pathology and Audiology, University of Pretoria

Private Bag X20, Hatfield 0028, South Africa

Tel: +27 (0)12 420 6485

Email: shabnam.abdoola@up.ac.za



Sigma Speech and Hearing

Phone: 081 576 6656

E-mail: sigmasph@gmail.com

Address: Eldo Office Park, (1257 Willem Botha Street, Wierdapark, Centurion)

9 June 2021

Dear Ms Bloye

Thank you for your email.

This letter serves to confirm that we grant you permission to refer any research participants, as Speech-language therapy or Audiology clients, to our practice. We wish you well with your research, and hope to create a long-lasting working relationship with you.

Warm regards

A handwritten signature in black ink that reads "Fatima Mohamed".

Fatima Mohamed

Kind Regards



081 576 6656

Eldo Office Park, (1257 Willem Botha Street, Wierdapark, Centurion)

Email address: sigmasph@gmail.com

Website: www.sigmasph.co.za



8 June 2021

Ms Nicola Bloye
Department of Speech Pathology and Audiology
University of Pretoria

Dear Ms Bloye

I have received your email regarding your Masters project and I would be very happy for you to refer any clients to the Wits Speech and Hearing Clinic. Presently we offer a combination of traditional face-to-face interventions and teletherapy interventions, depending on the client's needs and the country's level of lockdown. We do charge fees for services rendered but these are nominal and may be negotiated where clients are not able to pay the full fees.

Should you wish to refer any clients, please contact the clinic manager, Mr Gift Khumalo on gift.khumalo@wits.ac.za or the clinic secretary, Ms Nomvuselelo Nompondwana on Nomvuselelo.nompondwana@wits.ac.za or 011 717 4567.

Should you require any further information from me, please do not hesitate to contact me on joanne.neille@wits.ac.za.

Kind regards

A handwritten signature in black ink, appearing to read 'Neille', enclosed in a thin black rectangular border.

Joanne Neille, PhD
Head of Discipline: Speech-Language Pathology

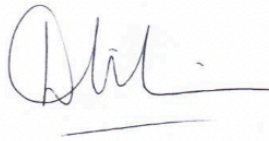
DINA LILIAN
SPEECH THERAPIST
PRACTICE NUMBER: 014 8814

8 June 2021

To whom it may concern

I, Ms Dina Lilian, hereby grant Miss Nicola Bloye permission to refer any research participants who participate in her study titled "*Why do people who stutter attend stuttering support groups?*", to my practice at Norwood Therapy Centre for speech-language therapy. I give her permission to share my contact details with the research participants and for the participants to then contact me within their personal capacity.

Kind regards,



Ms Dina Lilian

Email: dina.lilian@gmail.com

Tel: 082 820 6225

Practice number: 014 8814

Appendix H: Explanations and rationale for the telephonic semi-structured interview schedule

Section 1: Biographic and demographic information
<p>The research study's telephonic semi-structured interview (Appendix A) included three closed-ended demographic questions. The American Psychological Association ([APA], 2010) states that demographic questions help describe the research sample. These questions were formulated using Hughes et al. (2016) guidelines to ensure they were sensitive and inclusive.</p>
Section 2: Fluency history and behaviours
<p>The telephonic semi-structured interview (Appendix A) included questions about stuttering history, severity, stuttering behaviours, feelings, and attitudes. It is vital to ask these questions because while PWS have the same diagnosis, it doesn't necessarily describe their unique experiences (Weigel, 2013). Thus, the answers in this section helped the researcher gain a holistic understanding of the research participants. Dillman et al. (2014) recommend varying question formats within semi-structured interviews to improve measurement and ensure useful data is collected. This section therefore used open-ended questions, a closed-ended question, and closed-ended questions with ordinal scales. To avoid confusion, participants were given a visual of the rating scale (Appendix H) before the telephone semi-structured interview. The open-ended questions allowed participants to express themselves more freely without being constrained by predetermined answers (Christensen et al., 2015).</p>
Section 3: Speech-language therapy treatment
<p>The third section briefly asked the participants about their SLT treatment history for interests' sake. Research has found that the outcomes of traditional SLT can be enhanced by having clients who stutter participate in support groups (Trichon, 2010). PWS who regularly attend support groups have also been found to be able to achieve better carryover of the techniques and strategies taught in traditional SLT (Trichon & Tetnowski, 2011).</p>
Section 4: Stuttering support groups
<p>Section 4 included questions that were intended to directly answer the research question for this research study. The questions were all open-ended in nature. The goals of these questions were to help SLTs form a better understanding of what can encourage PWS to attend SSGs, actively participate in them and ways to improve the effectiveness of SSGs for the participants who attend.</p>

Appendix I: Rating scale

Rating Scale

Dear research participant

Thank you for taking the time to participate in the research study titled “*Why do people who stutter attend stuttering support groups?*” Below is a rating scale that you can refer to when answering specific questions during your telephonic interview with the researcher. The researcher will guide you on when and how to use this scale during the interview. Please do not hesitate to ask the researcher if you require further explanation or clarification.

Never	Rarely	Sometimes	Most of the time	All of the time
-------	--------	-----------	------------------	-----------------

Kind regards,



Miss Nicola Bloye
BA. Speech-Language Pathology
Primary researcher



Ms Shabnam Abdoola
MA. Speech-Language Pathology & Audiology
Research Supervisor



Ms Casey Eslick
MA. Speech-Language Pathology
Research Co-supervisor

Appendix J: Quotes for themes

Theme	Subtheme	Quotes
Altered perceptions	Increased acceptance of stutter	"...stuttering... is not the biggest thing in our lives... it's one part of who we are. It's something that shouldn't get the complete focus of our energies." [P1]
		"...it [SSG] provides you with a place to work on that acceptance of your speech..." [P3]
		"...it [SSG] helped me a lot... to be able to accept...myself..." [P4]
		"...it's [SSG] also helped me see that it's not the end of the world." [P6]
		"I was able to, together with the one-on-one therapy, I was able to accept and embrace the fact that I stutter." [P8]
		"I realized that my situation is not the end of the world. It could have been a lot worse." [P9]
		"...it's [SSG] taught me to accept the way I am." [P10]
		"...it [SSG] has helped me to really accept that I have a speech problem... and even normalise [stuttering]..." [P11]
	Improved confidence	"...boosts my self-esteem, to be confident." [P4]
		"...it [SSG] made me more confident speaking to... some people. I'm usually battling with speaking with certain people with their position or status in life... but it [SSG] did somehow make me more open..." [P7]
		"In my family, going to the shops, I would get someone else to speak for me because I wouldn't want to speak. At work, I would get a colleague to ask the boss for something...now I'm the person that does all speaking to everybody else." [P8]
		"I think again with the confidence, to step out and do things that I wouldn't normally do. Be the first person to speak, that was never me." [P8]
		"...it [SSG] gives me more self-control and self-confidence." [P10]
		"And [SSG] also boosts my confidence and I'm free..." [P12]

Increased sense of community	No subthemes	"... [the] support group really helps [me]...to not feel alone..." [P1]
		"... [the SSG] kind of opened my eyes, that people like me are in the same situation like me..." [P2]
		"...they [SSGs] just help you to not feel as isolated...to not feel as if it's just you and every day you're going up against your speech and having a tough time on your own..." [P3]
		"I think it helped me a lot...I'm not alone." [P4]
		"That's why my fluency increased, because I saw it as it is what it is... I'm not the only one in the world who stutters." [P8]
		... it [SSG] helped me... to see that you're not the only one..." P9]
		"...you know that we're not alone and there are people out there willing to give you support..." [P13]
Support group reciprocity	Learning from others	"I found that...oftentimes the best way to learn [is] from others opinions because you can draw from that." [P1]
		"... just gaining that insight, and also giving my insights to them. That conversation is what I like the most." [P2]
		"I...want to learn more and discuss more things." [P4]
		"I just want to attend these things [SSG meetings]... to learn from others, what they did to overcome their problems... It is... good for people who suffer from the same problems to just learn from each other." [P5]
		"So I definitely think it helped me... to learn a bit from them [other PWS] as well." [P9]
		"I'm learning, you know, each time we have those meetings, there's always a takeaway point..." [P12]
		"I... get to learn on how other ways of improving my stuttering" [P13]
	Encouragement and empowerment	"...when I come out of a [SSG] meeting, I always feel inspired... because I've just come from a platform where people have been honest, really, I mean people have stripped themselves, to bare, to expose themselves as much as they did to, to explain the core feelings which they actually experiencing..." [P1]
		"It's encouraging. You feel as if there's like people who are trying to help. You're not fighting the battle on your own..." [P3]

		<p>“It [SSG] definitely does help you to feel a bit more positive and optimistic about your speech.” [P3]</p> <p>“...it [SSG] does give me a bit of hope because, for example, at the very first [SSG meeting], there was a person who struggled to speak way more than what I ever did, and he did overcome it, um, so it was quite inspiring for me to see...” [P5]</p> <p>“...after you speak, then somebody would like say something or, “well done”, or “that was good”, so it's very encouraging...” [P6]</p> <p>“...when you walk away from there, you feel a little bit empowered and it's going to be okay, the team encourages you...” [P6]</p> <p>“The things that they [other PWS] were saying, it motivates me...” [P10]</p>
<p>Support group environment, participants and topics</p>	<p>Environment</p>	<p>“I've got this off my chest and at least someone's heard me. I've been heard.” [P1]</p> <p>“...they're [other PWS] not going to judge, or things like that. It's a place to speak openly about things like that.” [P2]</p> <p>“The atmosphere of the meeting...really plays a big role, it's not a serious conversation, it's...an open heart-to-heart conversation...” [P2]</p> <p>“... [the SSG]...has been an important safe space where you can express your emotions and... [discuss] the emotional aspects of disfluent moments...that really helps a lot” [P2]</p> <p>“ [The SSG] to me is a support environment...” [P3]</p> <p>“I feel more relaxed...” [P4]</p> <p>“What I enjoy about [the SSG]... is... we don't judge.” [P4]</p> <p>“Nobody laughs at you ... it's a safe place.” [P6]</p> <p>“It's an open environment.” [P7]</p> <p>“It [SSG] was the one platform [where] you can speak, and no one gives a rat's ass.” [P8]</p> <p>“... feel as [though] we are home.” [P10]</p>

		"I always feel as if I'm different and so when I'm at [the SSG], I'm at home and... I feel like I belong." [P12].
		"Sometimes the time is not convenient as such." [P4]
		"...maybe like two options [of dates for SSG meetings] per month that people can choose one of the two, that would be good." [P5]
		"I wish that maybe... we could have more sessions..." [P13]
	Value of SLTs as facilitators	"...that's why it's [SSG] so valuable as well to have that... collaboration between like, the people who experience it every day and then the people who are actually educated on it..." [P3]
		"It's encouraging. You feel as if there's like people who are trying to help." [P3]
		"I think they the professional, and, um, so I mean we each have a turn to speak, so it's not but, I think, I think because they are the professional, they would be able to guide the conversation and to coordinate it with that professionalism, and also, you know, align, ensure that we are aligning to the agenda, but also because they've got the knowledge that's different to us that's living with it. So, I understand myself, but they would understand everybody." [P6]
		"So there were times when I was the only participant in the group that was a stutterer and it felt like all of the attention was on me and almost like an interrogation... I think, so when the students ask questions and I answer them, like if all of the students or some of the students could also answer the questions, to like give their thoughts or their insights, it feels more like a speech therapy group and unlike a speech therapy interrogation or something like that." [P2]
	Meeting topics	"...[the SSG] has been an important safe space where you can express your emotions and... the emotional aspects of disfluent moments and sharing that, talking about it, that really helps a lot..." [P2]
		"...it [SSG] needs to be more to do with like, the things going on in the world of disfluency and like speaking about new... research ideas, or new techniques..." [P3]
		"...I prefer it to be centred around stuttering. " [P6]
		"They [SSG facilitators] should focus on activities that are more stuttering related." [P7]
		"...it [SSG] was educational but it was supportive at the same time" [P3]

		“...what did help me was really just unpacking all the emotions attached to stuttering.” [P8]
--	--	---

Appendix K: Proof of article submission to the South African Journal of Communication Disorders

30/11/2022, 14:54

Gmail - SAJCD Submission 958 - Confirmation and acknowledgement of receipt



Nicola Bloye <nicola.bloye@gmail.com>

SAJCD Submission 958 - Confirmation and acknowledgement of receipt

1 message

aosis@sajcd.org.za <aosis@sajcd.org.za>
Reply-To: AOSIS Publishing <submissions@sajcd.org.za>
To: Miss Nicola Erin Bloye <nicola.bloye@gmail.com>

Wed, Nov 30, 2022 at 2:54 PM

Ref. No.: 958
Manuscript title: Why do people who stutter attend stuttering support groups?
Journal: South African Journal of Communication Disorders

Dear Miss Bloye

Your submission has been received by the journal and will now be processed in accordance with published timelines.

Processing time guidelines are available under the journal's 'About' section, however, please note that each submission is assessed on its individual merit and in certain circumstances processing times may differ.

You can check the status of your submission in three ways:
- Journal Website: login to your account at <https://sajcd.org.za/index.php/sajcd/author/submission/958>.
- Publisher Enquiry Service: telephone numbers are +27(0)219752602 and/or 0861000381.
- Publisher FAQ and Email Service: visit the Publisher FAQ and Email service at <https://publishingsupport.aosis.co.za/index.php>

You will receive additional emails from the journal as your submission passes through the phases of the editorial process.

Kind regards,
AOSIS Publishing
South African Journal of Communication Disorders

South African Journal of Communication Disorders | <https://sajcd.org.za>
| ISSN: 0379-8046 (PRINT) | ISSN: 2225-4765 (ONLINE)

If you require immediate assistance, please contact AOSIS Publishing |
Tel: +27 21 975 2602 | Support email: publishing@aosis.co.za |
Business hours are weekdays between 8:00am-16:30pm

Interested in more Health and Veterinary Sciences research, visit:
• African Journal of Disability [<https://ajod.org>] | • African Journal of Laboratory Medicine [<https://ajlmonline.org>] | • African Journal of Primary Health Care & Family Medicine [<https://phcfm.org>] | • African Vision and Eye Health [<https://avehjournal.org>] | • African Journal of Psychological Assessment [<https://ajopa.org>] | • Curationis [<https://curationis.org.za>] | • SA Journal of Radiology [<https://sajr.org.za>] | • South African Journal of Communication Disorders [<https://sajcd.org.za>] | • South African Journal of Physiotherapy [<https://sajp.co.za>] | • South African Journal of Psychiatry [<https://sajp.org.za>] | • Southern African Journal of HIV Medicine [<https://sajhivmed.org.za>] | • SA Journal of Oncology [<https://sajo.org.za>] | • Journal of the South African Veterinary Association [<https://jsava.co.za>] | • Southern African Journal of Infectious Diseases [<https://sajid.co.za>] | • Onderstepoort Journal of Veterinary Research [<https://ojvr.org>] | • South African Family Practice [<https://safpj.co.za>] | • Health SA Gesondheid

<https://mail.google.com/mail/u/0/?ik=7d7317cebe&view=pt&search=all&permthid=thread-f%3A1750925672032859157%7Cmsg-f%3A1750925672032859157...> 1/2

30/11/2022, 14:54

Gmail - SAJCD Submission 958 - Confirmation and acknowledgement of receipt

[<https://hsag.co.za>]

Confidentiality: The information contained in and attached to this email is confidential and for use of the intended recipient. This email adheres to the email disclaimer described on <https://aosis.co.za>

<https://mail.google.com/mail/u/0/?ik=7d7317cebe&view=pt&search=all&permthid=thread-f%3A1750925672032859157%7Cmsg-f%3A1750925672032859157...> 2/2